A FRAMEWORK TO EXPAND PUBLIC HEALTH SERVICES TO HIV EXPOSED AND HIV POSITIVE CHILDREN

MARIANNE REID

A FRAMEWORK TO EXPAND PUBLIC HEALTH SERVICES TO HIV EXPOSED AND HIV POSITIVE CHILDREN

by

MARIANNE REID

Submitted in fulfilment of the requirements for the degree
Doctor Societatis Scientiae in Nursing
In the Faculty of Health Sciences, School of Nursing at the University of the Free State

PROMOTOR: Prof. Y. Botma

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CERTIFICATE

To Whom It May Concern

This is to certify that the dissertation by Marianne Reid has been edited by me Ms Ronny Snyman

Address: P.O.Box 17592
Bainsvlei
9338

Tel: 051-4511091

Cell: 0834440884

E-mail: cutman@yebo.co.za

Qualification: HPOD, Cape Town and Bloemfontein

Date: July 2009

DECLARATION

I declare that the research report hereby submitted as compliance with the requirements for the degree Doctor Societatis Scientiae in Nursing to the University of the Free State is my own independent work and has not previously been submitted by me to another university. I further cede copyright of this research report in favour of the University of the Free State.

FINANCIAL CONTRIBUTION

This study forms part of the following research project: *"Compiling best practices for a paediatric ART program and developing strategies for expanding paediatric ART enrolment in the Free State"*. The researcher hereby acknowledges the financial contribution of the National Research Foundation towards this project. Without this assistance the research would not have been possible.

DEDICATION

This work is dedicated to my Heavenly Father who guided me in a practical way and allowed our relationship to grow much deeper, reminding me in a loving way that I am what I am, through Him.

ACKNOWLEDGEMENTS

I wish to express my sincere gratitude to:

⇒ My husband, Johnny Reid whose love carried me, and my children Leslie and Nicole who supported me in a more mature way than expected.

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⇒ My study supervisor, Prof. Yvonne Botma, for instilling faith and confidence and offering her friendship

“There can be no keener revelation of a society’s soul than the way in which it treats its children”

Nelson Mandela

OPSOMMING

Die doelstelling van die studie was om ‘n raamwerk te ontwikkel ten einde publieke gesondheidsorgdienste uit te brei wat aan MIV blootgestelde en MIV positiewe kinders in die Vrystaat gelewer word. Doelwitte is gestel om die doelstelling te bereik, naamlik om strategieë te identifiseer ten einde gesondheidsorgdienste vir dié kinders uit te brei en om dan ‘n raamwerk te ontwikkel wat gesondheidsorgdienste vir hulle in die Vrystaatse publieke gesondheidsorgsektor sal uitbrei.

Die studie bestaan uit verskeie komponente, wat as fases voorgestel word. Die navorser was verantwoordelik vir twee komponente, naamlik Fase 1b en Fase 2. Die fases skakel met elk van die genoemde doelwitte. ‘n Kollega, wat navorsing as Meester student verrig, het Fase 1a van die studie voltooi, naamlik ‘n beskrywing van gesondheidsorgdienste wat aan MIV blootgestelde en MIV positiewe kinders in die Vrystaatse publieke gesondheidsorgsektor gelewer word. Die navorser was nou betrokke met Fase 1a, aangesien sy as mede-studieleier opgetree het.

Gesondheidbeleidsnavorsing is gebruik, wat ‘n tipe gesondheidsisteem navorsing is, ten einde hoër vlakke van gesondheid in te lig aangaande beleidskeuses. Gesondheidbestuur, as belanghebbendes, was derhalwe aktief deel van die ontwikkeling van die raamwerk. Een voorbeeld van hul betrokkenheid was die identifisering van strategieë ten einde gesondheidsorgdienste aan MIV blootgestelde en MIV positiewe kinders uit te brei. Die Nominale Groep Tegniek is gebruik om die strategieë te identifiseer.

‘n Konsep raamwerk is ontwikkel volgens die teoretiese beginsels wat in die *“Theory-of-Change Logic”* model voorgestel word. Die empiriese grondslag is gebaseer op getrianguleerde data wat verkry is van literatuur bevindings, Fase 1a en Fase 1b van die studie. ‘n Werkswinkel wat met belanghebbendes gehou is, het die geleentheid geskep om die raamwerk te finaliseer. Tydens die werkswinkel het belanghebbendes die geleentheid gekry om die geidentifiseerde problem te valideer, naamlik dat

gefragmenteerde sorg aan MIV blootgestelde en MIV positiewe kinders gebied word, as gevolg van ‘n oor-vertikalisering van programme. Verder is die gewensde resultate, moontlike faktore wat ‘n invloed op die resultate kan hê, asook strategieë wat gevolg kan word om gesondheidsorgdienste aan genoemde kinders uit te brei gevalideer. Aangesien gesondheidsbeleidsnavorsing slegs beleidskeuses inlig, is die mate waarin die raamwerk wel beleid sal inlig in die hande van die Vrystaat se Department van Gesondheid.

SUMMARY

The aim of this study was to develop a framework to expand public health care services to HIV exposed and HIV positive children in the Free State. The objectives set in order to meet the aim were to identify strategies to expand health care services to these children and to then develop a framework to expand health care services to them within the Free State public health sector.

The study consisted of various component projects, depicted as phases. The researcher conducted two components, Phase 1b and Phase 2 which links to the fore mentioned objectives of the study. A colleague, conducting research as Master student, conducted Phase 1a of the study, describing health care services rendered to HIV exposed and HIV positive children in the Free State public health sector. The researcher was intimately involved in Phase 1a, as she was acting as co-study leader.

Health policy research was used, which is a type of health systems research, in an effort to inform higher levels of health on policy choices. Health managers were therefore active stakeholders in the development of the framework. The identification of strategies to expand health care services to HIV exposed and HIV positive children were one such activity where stakeholders assisted in the development of the framework. The Nominal Group Technique was used to identify mentioned strategies.

A draft framework was developed using the Theory-of-Change Logic model as theoretical underpinning of the framework, with the empirical foundation being based on triangulated data obtained from literature findings, Phase1a and Phase 1b of the study. During a workshop with stakeholders, the framework was finalized, providing stakeholders the opportunity to validate the identified problem, namely that of fragmented care being delivered to HIV exposed and HIV positive children, due to over-verticalisation of programs. The validation of the framework was completed by

confirming the desired results, possible influential factors that could impact on the results, as well as strategies that could be followed to expand health care services to fore mentioned children. Since health policy research only informs policy choices, the extent to which the framework will actually inform policy is in the hands of the Free State Department of Health.

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
BCG	Bacille Calmette - Guerin
CHW	Community health workers
DHS	District Health System
DHIS	District Health Information System
DNA PCR	Deoxyribonucleic Acid Polymerase Chain Reaction
DoH	Department of Health
DOTS	Directly Observed Therapy - Short course
ELISA	Enzyme – linked Immunosorbent Assay
EPI	Expanded Programme on Immunization
HAART	Highly Active ART
IMCI	Integrated Management of Childhood Illnesses
INH	Isoniazid
ELISA	Enzyme – linked Immunosorbent Assay
EPI	Expanded Programme on Immunisation
FS	Free State province
HCW	Health care worker
HIV	Human Immunodeficiency Virus
ICAM	Interactive Distance Communication and Management System
IMCI	Integrated Management of Childhood Illness
JLIC	Joint Learning Initiative on Children and HIV and AIDS
NGO	Non - Governmental organisation
NGT	Nominal Group Technique
NNRTI	Non - nucleoside Reverse Transcriptase Inhibitors
NRTI	Nucleoside Reverse Transcriptase Inhibitors
NSP	National Strategic Plan
PCP	Pneumocystis jiroveci pneumonia
PHC	Primary Health Care

PI	Protease Inhibitors
PMTCT	Prevention of Mother-to-Child Transmission of HIV
SA	South Africa
TASO	The AIDS Support Organisation
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNICEF	United Nations Children's Fund
VCT	Voluntary counselling and Testing
WHO	World Health Organisation

GLOSSARY

AIDS orphan: The South African Children's Bill identifies an orphan as a child who has no surviving parent caring for him or her (South Africa, 2005).

Antiretroviral Therapy (children): The FS follows the national guideline of using the following groups of drugs in a combination of three groups as antiretroviral therapy: Nucleoside reverse transcriptase inhibitors, Non-nucleoside reverse transcriptase inhibitors and Protease inhibitors (South Africa, 2005a: 76).

Antiretroviral Therapy qualification criteria (children): Children must meet clinical and social criteria before being accepted for treatment. The clinical criteria include a confirmation of diagnosis of HIV infection, more than two hospitalizations in one year or being hospitalized for more than four weeks for HIV related illness or the child being classified as either World Health Organisation Stage 3 / 4 or a CD4% of less than 20% in under 18 months or less than 15% if over 18 months. The social criteria include the presence of at least one caregiver who is able to supervise the child for administering medication and disclosure to another adult in the same house is encouraged (South Africa, 2005a: 81).

Community Health Care Centre: A community health care centre provides a 24 hour comprehensive health care service, which includes emergency care and normal deliveries. Nursing personnel have the support of medical doctors who assist in handling client referrals from primary health care clinics and hospitals (South Africa, 2001a: 29).

Comprehensive care: This type of care is rendered when health is promoted, disease prevented and existing conditions curatively managed and rehabilitated (Dreyer, Hattingh & Lock, 2002:36). In this study comprehensive care refers to the various components of care that is encompassed in all HIV related health programmes rendered to children. Preferably as many components as possible

should be available to the child at one facility or should be provided by a single health care worker.

District Health System: According to Tarimo (in Pillay, McCoy & Asia, 2001: online) a district health system is a "*more or less self-contained segment of the national health system. It comprises first and foremost a well-defined population living within a clearly delineated administrative and geographic area. It includes all the relevant health care activities in the area, whether governmental or otherwise*".

Fragmented care: When fragmented care is delivered people are looked after in an unconnected manner (Anderson, Crozier, Gilmour, Grandison, McKeown, Stibbs & Summers, 2006:118, 335). In this study fragmented care is used in relation to the various health programmes presented by the FS DoH in an effort to address the needs of HIV exposed and HIV positive children.

Framework: A framework reflects the conceptual underpinnings of a study in that its logical structure of meaning guides the development of the study and enables the researcher to link findings to the body of knowledge (Polit & Beck, 2006:501; and Burns & Grove, 2009:701).

Functional integration: Functional integration occurs when services seek out opportunities for integration through improved cross referral systems, better communication and greater flexibility, thus leading to better service delivery (Van Rensburg, 2004:144; and Pleaner, 2007:10). This study refers specifically to functional integration of health programmes rendering care to HIV exposed and HIV positive children.

Health care worker: For the purpose of this study, a health care worker refers to a professional nurse registered with the South African Nursing Council, as well as a doctor registered with the Health Professional Council of SA, rendering health care to HIV exposed and HIV positive children within the public health sector in the FS.

Health directorate: In this study a health directorate refers to a directorate resorting under the Strategic Health Programmes Chief directorate of the FS DoH. A health directorate may be further constituted of sub-directorates as well as divisions.

Health programme: Health programmes in this study includes the various programmes forming part of different health directorates, of which each renders a section of paediatric HIV related services.

HIV exposed child: A child is deemed to be exposed to HIV when the mother of the child is HIV positive and the child has been exposed to possible mother-to-child transmission (South Africa, 2005a: 8).

HIV positive child: A child is HIV positive when tested positive with the ELISA test, if the child is over the age of eighteen months. A child is also HIV positive when tested positive with the PCR technique, if the child is aged six weeks and older (South Africa, 2005a: 14-15).

Integrated care: Integrated care refers to care being rendered by integrating two or more health programmes (Heunis & Schneider, 2006:263).

Paediatric: Paediatric refers to children from the age of 0-14 years (Dorrington, Johnson, Bradshaw & Daniel, 2006:8).

Primary Health Care approach: The primary health care approach was defined in the Declaration of Alma Ata. Basic health care is delivered through this approach by providing promotive, preventative, curative and rehabilitative services (International Conference on Primary Health Care, 1978; World Health Organization, 1988:15; and Lewis, Eskeland & Traa-Valerezo, 2004:303).

Primary Health Care clinic: Primary health care clinics provide preventative and curative health care services on a daily basis. The service is mostly nurse-driven, with clients being referred to community health care centres for more specialised help.(South Africa, 2001a: 18)

Paediatric HIV related services: In this study paediatric HIV related services include any service rendered through a health programme to HIV exposed and HIV positive children.

Prophylactic HIV treatment (children): Infants born to HIV positive mothers who received optimal PMTCT receive a single dose Neverapine within 72 hours after birth and Zidovudine for seven days. Infants born to HIV positive mothers who received suboptimal PMTCT should also receive a single dose Neverapine within 72 hours after birth and Zidovudine for 28 days (South Africa, 2008:44).

Public sector: The public sector refers to the section of a country's economy that consists of state-owned industries and services. In the case of this study of health services (Anderson *et al.*, 2006:684).

Strategies: Strategies are specific, measurable, obtainable set of plans carefully developed with involvement by an institution's stakeholders (Strategic Human Resource Management, 2000: online).

Vertical health programmes: A vertical health programme follows a selective primary health care approach in that it targets a specific health problem or issue (Travis, Bennett, Haines, Pang, Bhutta, Hyder, Pielemeier, Mills & Evans, 2004:364; and Van Rensburg, 2004:413).

INDEX

LISTS OF FIGURES

LISTS OF TABLES

LIST OF ADDENDUMS

CHAPTER 1

Overview of the study

1.1 INTRODUCTION

The number of children living with Human Immuno deficiency Virus (HIV) per year has globally increased eight-fold since 1990. An estimated 2 million children were living with HIV in 2007, 90% of them in sub-Saharan Africa. These overwhelming statistics do not stop here. 370 000 Children were newly infected with HIV in 2007, representing 17% of all new HIV infections globally, with 270 000 children being believed to have died from Acquired Immune Deficiency Syndrome (AIDS) in that year (World Health Organisation, UNAIDS & UNICEF, 2008:80). South Africa (SA) is one of the countries hardest hit by the pandemic.

SA's under five mortality rate rose from 65 per 1 000 live births in 1990, to 75 per 1 000 live births in 2006 (Giese, 2009:15). In the Free State (FS) province in SA, the AIDS mortality rate for that period was 91 per 1 000 births (Dorrington, Johnson, Bradshaw & Daniel, 2006:44). Children do not only die themselves of AIDS, but are also left orphaned by this disease. AIDS alone contributed to 1.2 million children being orphaned in SA, with 69 000 AIDS orphans residing in the FS (Dorrington *et al.*, 2006:44). Beyond the facts and figures stated few direct HIV surveillance data is available for children (Richter, 2008:3; UNAIDS, 2008:37).

Reasons for the appalling statistics are that children who have been maternally exposed to the HIV and those who became infected with the virus due to this exposure have been failed by the health system. It is a world wide phenomenon that progress in preventing, diagnosing and treating HIV disease in children is still lagging far behind (World Health Organisation, UNAIDS & UNICEF, 2007a: 9). In an effort to understand why this phenomenon occurs, one has to take cognizance of the fact that the overwhelming majority of children who are HIV-positive are infected through mother-to-child transmission. Transmission can occur during pregnancy, birth or

breastfeeding. Vertical transmission from mother to child is avoidable. By supplying antiretroviral drugs to the mother a reduction in risk of between 15% and 45% to the infant occurs (Van Dyk, 2008:41; World Health Organisation *et al.*, 2008:80).

Though the effectiveness of these drugs is proven, interventions to prevent mother-to-child transmission (PMTCT) are not reaching enough mothers or infants who need them (Richter, 2008:1). While 75% of HIV positive women in SA have access to PMTCT services, the uptake remains low at only 30% (UNAIDS, 2009: 5). Testing infants for HIV and providing prophylactic and antiretroviral treatment (ART) are examples of interventions aimed at children. However, only 8% of infants in low-and middle-income countries were tested for HIV within two months of their birth. With fewer than 4% of two-month olds exposed through maternal HIV receiving prophylactic Cotrimoxazole. Globally, only 10% of HIV positive infants received ART in 2007 (Richter, 2008:1; World Health Organisation *et al.*, 2008:90).

SA has the largest AIDS treatment programme in the world. Of the estimated 80,000 children in need of ART, approximately 29% are currently receiving treatment (UNAIDS, 2009:4). In the FS, 1 400 children under the age of fourteen years were receiving ART by mid-2006. A further 2,000 children were in Stage 4, and therefore qualifying to be on treatment, but were not on ART. Adding to these numbers, 16,000 children in this age group were in the pre-AIDS phase and would therefore in the near future be in need of ART (Dorrington *et al.*, 2006:43).

Trials worldwide have shown that ART is effective in suppressing HIV replication and reversing immunodeficiency in children. This could result in a reduction in paediatric hospital admissions and a decrease in HIV and AIDS related morbidity and mortality (Reddi, Leeper, Grobler, Geddes, France, Dorse, Vlok, Mntambo, Thomas, Nixon, Holst, Karim, Rollins, Coovadia & J., 2007: online). The decrease is significant, with a mortality rate of HIV positive children under the age of two years, who go without ART treatment, being around 50%. Two thirds of HIV infected children under the age of two years, die before reaching 12 months of age (Marazzi, Guidotti, Liotta & Palombi, 2005:483, 486). ART can further significantly improve childhood development outcomes of children who receive treatment (Rochat, Mitchell & Richter, 2008:5). This treatment to HIV positive children meeting qualification criteria

and the care needed by HIV exposed children is delivered within the context of a specific health care environment.

In SA the public health sector follows a primary health care (PHC) approach within a district health system (DHS). This approach is well-established in various policies on national and provincial level, aiming to provide comprehensive care and treatment for people living with HIV and AIDS. The provincial Department of Health (DoH) in the FS implemented the PMTCT Guidelines in June 2002. The aim of this document was to orientate midwives and attending medical staff on how to manage HIV positive women who enter the PMTCT programme in the FS (South Africa, n.d.-b: 1). In November 2003 the SA government's national HIV roll-out was launched with the *"Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa".* The plan made provision for ART within the public sector to infected adults and children, who met the qualification criteria (Shung-King & Zampoli, 2004:6, 12). The national DoH followed this policy up with the launching of the *"HIV & AIDS and STI Strategic Plan for South Africa 2007-2011"* in April 2007. Apart from also aiming to provide comprehensive care, this document further aspired to strengthen the national health system (South Africa, 2007a: 54).

1.2 PROBLEM STATEMENT

In spite of the SA government's response by approving various policies in attempting to address the HIV and AIDS epidemic, major challenges in the expansion of public health services to HIV exposed and HIV positive children in the country and provinces such as the FS exist. A key challenge that has been identified is that although the *"Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment",* clearly endorsed the integration of services as a core principle, a predominantly vertical ART-specific, roll-out programme was implemented in the FS (South Africa, 2003b: 8; Heunis & Schneider, 2006:257). This has led to a situation where the best interest of the child is not being served, as an integrated and comprehensive approach is not followed (Shung-King & Zampoli, 2004:21, 38). Children further receive fragmented care rendered by health care workers (HCW) working within an array of linear health programmes, with each

programme focusing on a specific aspect of health care. Flowing from these vertical health programmes is the absence of an effective network for HIV service delivery. The network refers to the routes followed by HCW when referring HIV exposed or HIV positive children in need of health care, intra- and inter-departmental collaboration and co-operation, specifically focusing on co-ordination between the national DoH and the provincial DoH (South Africa, 2004:15; Michaels, Elay, Ndlovu & Rutenberg, 2006:3). It further includes liaison with other sectors, such as non-governmental organisations in order to ensure a comprehensive care and support network (Shung-King & Zampoli, 2004:24).

Another major challenge is that a human resource and training need exists amongst HCW who render a service to HIV affected children (South Africa, 2004:3-4). Health care facilities at all levels in SA are understaffed and unable to cope with the large number of patients requiring HIV and AIDS care (Shung-King & Zampoli, 2004:38; South Africa, 2004:4). SA is especially experiencing a shortage of trained and skilled nurses and doctors in paediatric HIV care and ART (Shung-King & Zampoli, 2004:38; Michaels *et al.*, 2006:3). This challenge needs to be addressed in order to meet the Millennium Development Goal of halting the spread of AIDS and rolling back HIV infections by 2015. SA has set its own target in the *"National Strategic Plan"* namely to "*reduce the impact of HIV and AIDS on individuals, families, communities and society by expanding access to appropriate, care and support to 80% of all HIV positive people and their families by 2011*" (South Africa, 2007a: 10; UNAIDS, 2008:9).

Developing a framework to expand public health services to HIV exposed and HIV positive children in the FS will work towards supporting these international and national AIDS strategies. The expansion of paediatric HIV and AIDS care in SA and the FS has been hampered due to the various challenges so far identified. This study will contribute towards streamlining the expansion of paediatric HIV and AIDS care in the public health sector in the FS. The inclusion of the provincial DoH as partner in the development of the framework will ensure that their expert advice is encapsulated in the framework and that they buy into the framework from the very beginning.

1.3 AIMS AND OBJECTIVES

The aim of this study is to develop a framework to expand public health services to HIV exposed and HIV positive children in the FS. The objectives of the study within the context of the FS public health sector are to:

- Identify strategies to expand health care services to HIV exposed and HIV positive children; and to
- Develop a framework to expand health services to HIV exposed and HIV positive children.

1.4 POSITION OF STUDY WITHIN PROJECT FUNDED BY NATIONAL RESEARCH FOUNDATION

This study forms part of a project funded by the National Research Foundation of SA. The aim of the project is to develop a framework to expand public health services to HIV exposed and HIV positive children in the FS province in SA. The study consists of various component projects, depicted as phases within the project. Figure 1.1 depicts these phases as they unfold. The researcher will conduct two components, Phase 1b and Phase 2 of the study (identifiable with a grey coloration on the graph). A colleague, conducting research as Master student, will conduct Phase 1a of the study, with the researcher acting as co-study leader of this particular research.

Phase 1a of the study consists of a description of health care services rendered to HIV exposed and HIV positive children in the FS public health sector. Data obtained from Phase1a will be integrated in literature references conducted by the researcher in Phases 1b and 2. In order to describe health care services the research colleague will hold structured interviews with professional nurses rendering care to HIV exposed and HIV positive children.

During Phase 1b the researcher will, with the assistance of stakeholders, identify strategies to expand health care services to the fore mentioned group of children. The strategies will be formulated during a nominal group discussion that will be held with stakeholders involved in some form of care to these children.

Phase 2 will create the opportunity to develop a framework that aims to expand public health services in the FS to these children. Data culminating from Phase 1a and Phase 1b of the study, as well as input from stakeholders will be intertwined in the framework.

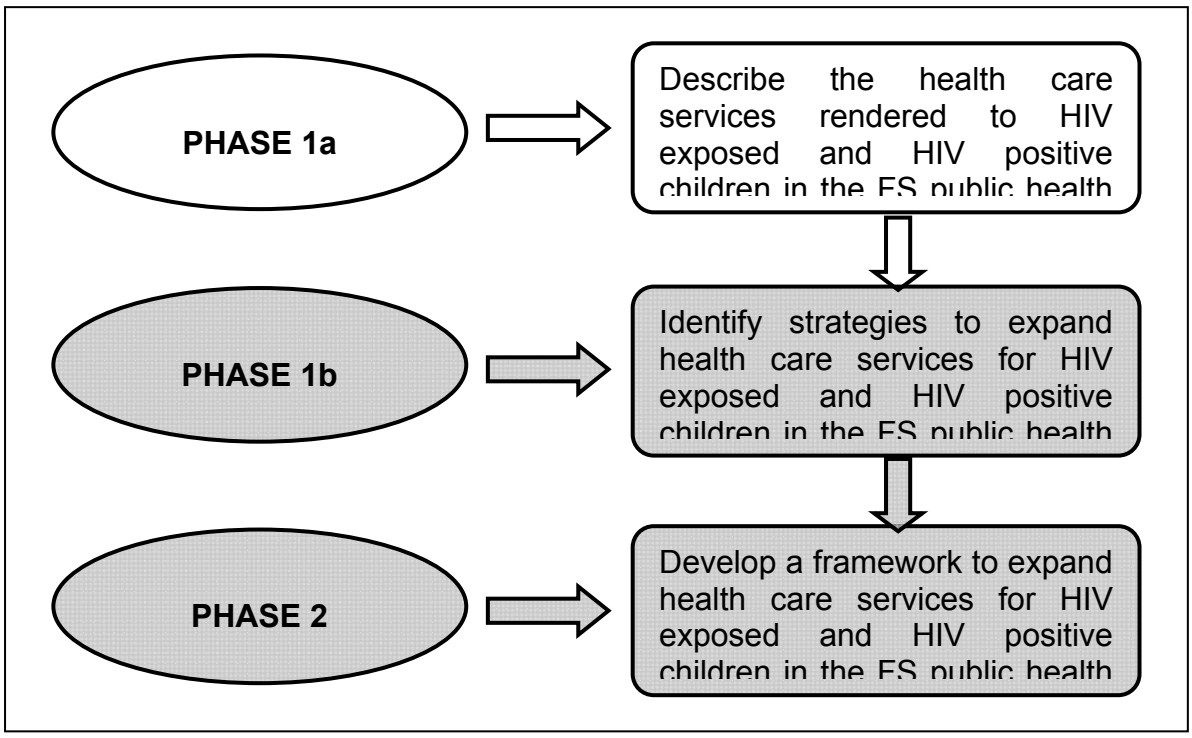

FIGURE 1.1: Position of study within National Research Foundation Project

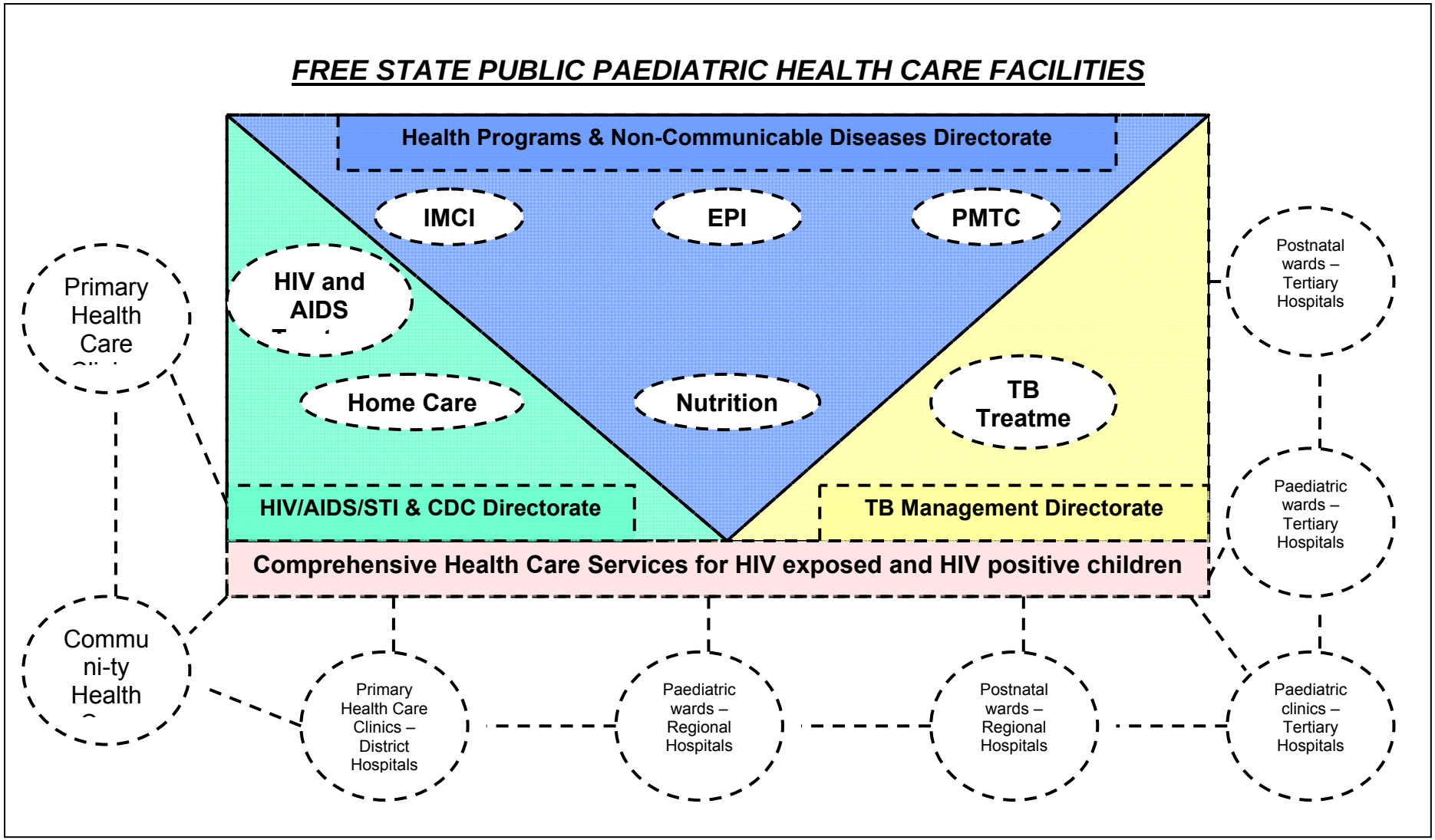

FIGURE 1.2: **Conceptual framework of the study**

1.5 CONCEPTUAL FRAMEWORK

Figure 1.2 depicts the conceptual framework of this study. A framework is envisaged where functional integration of health programmes occurs across health directorates and across health programmes within a directorate. This would lead to comprehensive health care being rendered to all HIV exposed and HIV positive children. It is further envisioned that paediatric health care facilities within the FS DoH would form a support network within a well established referral system. These facilities would not only cross refer children, but would also render as comprehensive a service as possible at the facility by integrating health programmes indicated for a specific child.

1.6 CONCEPTUAL AND OPERATIONAL DEFINITIONS

A conceptual definition provides the abstract or theoretical meaning of the concept being studied and is established through concept analysis, concept derivation, or concept synthesis (Polit & Beck, 2006:497; Burns & Grove, 2009:693). An operational definition on the other hand is a description of how variables or concepts will be measured or manipulated in a study (Polit & Beck, 2006: 505; Burns & Grove, 2009:712). The concepts in this study are presented in alphabetical order linking the description of how the concepts will be measured to each conceptual definition.

Comprehensive care: This type of care is rendered when health is promoted, disease prevented and existing conditions curatively managed and rehabilitated (Dreyer, Hattingh & Lock, 2002:36). In this study comprehensive care refers to the various components of care that is encompassed in all HIV related health programmes rendered to children. Preferably as many components as possible should be available to the child at one facility or should be provided by a single health care worker.

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Framework: A framework reflects the conceptual underpinnings of a study in that its logical structure of meaning guides the development of the study and enables the researcher to link findings to the body of knowledge (Polit & Beck, 2006: 501; Burns & Grove, 2009:701).

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Primary Health Care approach: The primary health care approach was defined in the Declaration of Alma Ata. Basic health care is delivered through this approach by providing promotive, preventative, curative and rehabilitative services (International Conference on Primary Health Care, 1978; World Health Organization, 1988:15; and Lewis, Eskeland & Traa-Valerezo, 2004:303).

Vertical health programmes: A vertical health programme follows a selective primary health care approach in that it targets a specific health problem or issue (Travis, Bennett, Haines, Pang, Bhutta, Hyder, Pielemeier, Mills & Evans, 2004:364; Van Rensburg, 2004:413).

1.7 RESEARCH DESIGN

A research design is a blueprint for the conduct of a study that maximizes control over factors that could interfere with the desired outcomes of the study (Burns & Grove, 2009:696). It is also seen as a logical arrangement from which future researchers can select a design suitable for their specific research goals (Uys & Basson, 2005:37; Brink, 2006:82). The researcher will use health system research to accomplish research goals.

This type of research will be appropriate, as the study will focus on the development of a framework to expand public health services to HIV exposed and HIV positive children in the FS. Health system research is used when a researcher is concerned with enhancing the health of people and communities. It allows the researcher to offer policy options to health managers, assisting them to make decisions on health related problems they are facing. The health managers will be involved in the whole process, making them an active stakeholder in the development of the framework (Barron, Buthelezi, Edwards, Makhanya & Palmer, 1997:4-5; Varkevisser, Pathmanathan & Brownlee, 2003:16).

1.7.1 Phase 1b

During Phase 1b of the study the researcher, in collaboration with the relevant stakeholders, will aim to identify strategies to expand health care services to HIV exposed and HIV positive children in the FS.

1.7.1.1 Unit of analysis

A unit of analysis is the basic unit or focus of analysis, thus referring to the *"what"* and *"whom"* being studied. Most typically the units of analysis are individuals, but it could also be groups or organizations (De Vos, Strydom, Fouche & Delport, 2005:104; Uys & Basson, 2005:87; Polit & Beck, 2006:512; and Babbie, 2007:94).

1.7.1.1.1 Population

A population includes the entire set of individuals, objects or events that have some common characteristic and therefore meet the sample criteria for inclusion in a study (Polit & Beck, 2006:506; Burns & Grove, 2009:714). In this study, the population will exist of representatives of three directorates within the Strategic Health Programmes Chief Directorate of the FS DoH, as well as representatives of important stakeholders outside this specific Chief Directorate, who are also involved in rendering care to HIV positive children.

The reason for targeting managers from specific health directorates, is that it is within these directorates that services to HIV exposed and HIV positive children is rendered. Representatives of the FS DoH will be managers of various programmes within the identified directorates and their representation will be constituted in the following way:

- HIV and AIDS/STI & Communicable Diseases Control Directorate (4) – One representative each from the:
    - Directorate;
    - Comprehensive HIV & AIDS Management Sub-Directorate;
    - Partnership Sub-Directorate; and
    - Communicable Diseases Control Sub-Directorate
- TB Management Directorate (4) – One representative each from the:
    - Directorate;
    - Advocacy and Social Mobilization and Training Sub-Directorate;
    - Technical and clinical Support Sub-Directorate; and
    - Clinical Advisory Services Sub-Directorate
- Health Programmes & Non-Communicable Disease Directorate (3) – One representative each from the:
    - Directorate;
    - Nutrition & Child Health Sub-Directorate; and
    - Reproductive Health Sub-Directorate.

An additional four representatives from important stakeholders who are also involved in rendering care to these children will form part of the population. These identified stakeholders will consist of a medical officer, researchers doing related research and a representative of a private sector paediatric HIV service. The population for this study therefore will consist of fifteen representatives, eleven from the Strategic Health Programmes Chief Directorate and an additional four from stakeholders outside the mentioned directorate.

1.7.1.1.2 Sampling

A sample refers to a subset of the population that is selected for a study, whereas sampling refers to the process whereby the sample is drawn from the population (Burns & Grove, 2005:750; De Vos *et al.*, 2005:194; Uys & Basson, 2005:87; and Polit & Beck, 2006:509). Due to the small population, no sampling will be conducted in this study.

1.7.1.2 Research technique

The Nominal Group Technique (NGT) will be used to identify strategies to expand health care services to HIV exposed and HIV positive children in the FS. This interview technique will allow structured group work to take place, whilst obtaining multiple inputs from participants (which are the stakeholders already identified). During the NGT participants will work in the presence of each other, but write ideas independently rather than stating them verbally. In this way this idea generating strategy acts as a consensus-planning tool that helps prioritize issues according to a prescribed sequence of problem solving steps (Delbecq, Van de Ven & Gustafson, 1975:33; Sample, 1984: online; University of Vermont, 1996: online; Center for Rural Studies, 1998: online; Ihuseman, Lahif & Hatfield, 2000: online; Macphail, 2001:162; Taylor-Powell, 2002: online; and Potter, Gordon & Hamer, 2004:126). The researcher will act as facilitator and assist in identifying and ranking issues identified by the group (Delbecq *et al.*, 1975:8; Debold, 1996: online).

1.7.1.3 Explorative interview

The function of an explorative interview is to create the opportunity for the researcher to have a small scale exercise of the data collection process to follow (Thomas in Potter *et al.*, 2004:127). Since the identified population is the only participant who can also take part in such an interview, an explorative interview is not planned. In order to still meet the requirement of pre-testing the question the be used during the NGT, the question will be put to colleagues to clarify their understanding of the

question (Bezruchka, 1998: online; De Vos *et al.*, 2005:331). Recommendations from them regarding the question will be implemented.

1.7.1.4 Data collection process

In preparation for the nominal group discussion, a suitable venue will be arranged that would be large enough to accommodate participants at individual tables placed in a U-shape. A flip chart and laptop and screen will be placed at the open end of the U and necessary stationery would be provided (Delbecq *et al.*, 1975: 41; Dunham, 1998: online; and Taylor-Powell, 2002: online).

The nominal group discussion itself will follow four steps. After an opening statement by the facilitator (in this case the researcher), the nominal question will be put to participants. They will then generate ideas in silence, where after the second step of the discussion will follow, namely the verbalizing of their ideas in a round-robin fashion (Delbecq *et al.*, 1975: 67; Sample, 1984: online; and Taylor-Powell, 2002: online). Thirdly a discussion of ideas generated will create the opportunity to clarify any possible misconceptions. Lastly participants will get the opportunity to prioritize ideas from the pool of ideas generated by all participants (Delbecq *et al.*, 1975:8). During these mentioned data collection steps, participants would be recording their ideas as well as the priority ranking they ascribe to an idea. Simultaneously the group's ideas and eventual priority ranking of ideas will be reflected on the flipchart and laptop with screen, enabling all participants to keep track of the process (Delbecq *et al.*, 1975:68; Sample, 1984: online).

1.7.1.5 Data analysis

Data analysis refers to the systematic organization and synthesis of research data, which allows the researcher to reduce, organize and give meaning to data (Polit & Beck, 2006:498; Burns & Grove, 2009:695). Even though the NGT can be seen as a mixed method approach, using qualitative and quantitative methods in the analysis and reporting of results, the emphasis in this study will mainly fall on the analysis of the qualitative data provided by participants (Potter *et al.*, 2004:128). The researcher

will adapt the guideline Van Breda (2005:4-11) propose to analyze multiple NGT data, to analyze a single NGT data-as was the case in this study. During the collection of data a stepwise process was followed and the analysis of data will do likewise. Data will be captured in a specific format on a spreadsheet, which will then assist the researcher in ordering the five statements participants deemed to be most important. The researcher will then be in a position to identify categories and themes from the data. The rigorous process of content analyses will further be confirmed by a scheduled peer review session of colleagues who are skilled in NGT and who have not been involved in the research process. Before the researcher will be able to report on data, a meticulous calculation would reveal the final ranking specific themes within categories would receive. Again the calculations will be confirmed by a colleague who is an expert in NGT and the calculation of ranks.

1.7.1.6 Measures to ensure trustworthiness of results

Trustworthiness of results refers to the degree of confidence qualitative researchers have in their data. The data will be assessed using the following criteria: *credibility*, *dependability*, *confirmability* and *transferability* (Polit & Beck, 2006:511; Speziale & Carpenter, 2007:49). Each of criteria will be applied to the NGT used in Phase 1b of the study.

After Phase 1b has been completed, Phase 2 of the study will commence.

1.7.2 Phase 2

During Phase 2 the researcher will follow a staggered approach to develop a framework to expand health care services to HIV exposed and HIV positive children in the FS. The approach to framework development and the development of the framework itself will be guided by literature findings on framework development. Data that will be gathered during Phase 1 and further literature findings will be triangulated, in order to be incorporated into a draft framework. As part of the health policy research to be used in the study the framework will be validated by stakeholders during a workshop. These stakeholders will consist of a senior

managerial representative of the same three directorates that will also take part in the NGT (Phase 1b), namely;

- HIV and AIDS/STI & CDC directorate (1);
- TB Management directorate (1) and
- Health Programmes & Non-Communicable Disease Directorate (1)

Other stakeholder representatives, who are also involved with the care of these children and who will also take part in the nominal group discussion during Phase 1b will be:

- Medical practitioner (1);
- Researcher in field of paediatric HIV care (2); and
- Professional nurse in private paediatric HIV practice (1)

The validation of the framework will form part of the process to pursue the methodological integrity of the framework.

1.7.2.1 Methodological integrity

The touchstones of methodological integrity forming part of the development of the framework will be the *credibility* of the framework, various types of *validity* tested by questions forming part of the validation workshop just discussed, *transferability* of the framework to the health setting and a range of *triangulations* that will strengthen the development of the framework. Each of these criteria will be applied to the framework and discussed in detail.

The ethical considerations the researcher will take into account will be applied to Phase 1b as well as Phase 2 of the study.

1.7.2.2 Ethical considerations

Ethics is a system of moral values that is concerned with the degree to which research procedures adhere to professional, legal and social obligations to the study participants (Polit & Beck, 2004:717). The study will be guided by the three primary ethical principles on which standards of ethical conduct in research should be based, as was expressed in the Belmont report. The principles of *beneficence, respect for human dignity* and *justice w*ill be briefly discussed, followed by procedures the researcher will adopt to comply with each of these principles (Burns & Grove, 2005:735; Polit & Beck, 2006:87).

Beneficence necessitates the researcher to minimize harm and maximize possible benefits participants can derive from a study. In this fundamental ethical principle doing good should therefore always override doing harm, with any harm being excluded as far as possible (Burns & Grove, 2005:728; Polit & Beck, 2006:87). Beneficence incorporates participants' right to protection from harm and discomfort and the right to protection from exploitation. The researcher will be sensitive to protect participants from harm or discomfort, whether in a physical or emotional manner (Burns & Grove, 2005:190; De Vos *et al.*, 2005:58; Polit & Beck, 2006:85; and Babbie, 2007:63). This sensitivity would transpire whilst the researcher facilitates the discussion and by clearly outlining the researcher's expectations of participants prior to them partaking in the study. Participants' right to protection from exploitation implies that they may never be placed at a disadvantage (Polit & Beck, 2006:88). This right will be upheld by participants receiving the assurance verbally and in writing (via consent form), prior to their participation in the study.

Respect for human dignity is supported in research when participants' right to full disclosure, right to self-determination and right to informed consent is adhered to. In this discussion anonymity and confidentiality will be linked to the right of privacy, which is intertwined with the right to informed consent. The right to full disclosure implies that the researcher has comprehensively explained the nature of the study to participants, conveyed the participants right to refuse participation, clarified the researcher's role, as well as discussed the likely risks and benefits participants

would incur (Polit & Beck, 2006:89). The researcher will use the consent form (Addendum B) to disclose mentioned information to participants. Closely linked to participants' right to full disclosure is the right to self-determination. By obtaining permission prior to research and acknowledging participants' right to full disclosure, the researcher will ensure that participants' right to self-determination will be adhered to. Informed consent on the other hand, can only occur when the right to full disclosure is acknowledged. By completing the informed consent form, autonomy of participants and recognition of them as self-governing persons with decision-making capacities will be given (Polit & Beck, 2006:85; Speziale & Carpenter, 2007: 6). Permission to conduct the research will also be obtained. The study will be submitted to the Ethics Committee of the Faculty of Health Sciences of the University of the FS (Addendum A) for approval. Acknowledging the right to privacy can not take place without simultaneously acknowledging the participants right to privacy. A participant's right to privacy implies that he/she determines their own conditions under which private information may be shared or withheld (Burns & Grove, 2005:747; De Vos *et al.*, 2005:61; and Berg, 2007:79). The right to privacy is protected by striving towards anonymity and confidentiality (Polit & Beck, 2006:95). Anonymity occurs when the researcher cannot link individual participants with data obtained. This is however not always possible in qualitative research (De Vos *et al.*, 2005:62; Uys & Basson, 2005:98; Polit & Beck, 2006:495, 497; Babbie, 2007:64; and Berg, 2007:79). Neither the NGT as an interview technique, or the workshop during Phase 2, will allow the researcher to ensure anonymity of participants. Confidentiality on the other hand, does not refer to personal data, but rather to the handling of information in a confidential manner. All attempts should be made by the researcher to remove any element that may indicate the identity of a participant (Burns & Grove, 2005:188; De Vos *et al.*, 2005:61; and Berg, 2007:79). The manner, in which data will be obtained when conducting the nominal group, will enable the researcher to depersonalize data and so enhance confidentiality. The last principle to be discussed is that of justice.

Justice goes hand in hand with participants being treated fairly (Burns & Grove, 2009:706). The right to fair treatment entails that participants should be treated fairly. This fairness is based on the way study participants are selected and whether they receive remuneration or not (Burns & Grove, 2005:189; Polit & Beck, 2006:90). Participants will be selected based on research requirements, namely them representing a specific programme within a directorate or sub-directorate or a group caring for HIV exposed and HIV positive children. The researcher will clarify that participants would not be receiving any remuneration prior to the group discussion.

The possible value of the study needs to be looked at, having reflected on ethical considerations that will be taken into account.

1.8 VALUE OF THE STUDY

The development of a framework to expand public health services to HIV exposed and HIV positive children will be of value to the following role players in the FS:

- FS DoH;
- Public sector HCWs involved in paediatric HIV services and
- Community members affected by HIV exposed and HIV positive children.

The FS DoH will receive a scientifically formulated framework that will guide them as how to go about in expanding services to the children mentioned in this study. This would assist them in implementing the *"Comprehensive HIV and AIDS Care and Treatment Plan"* for South Africa. Public sector HCW involved in paediatric HIV services will be sensitized towards fragmented care delivered to these children and hopefully respond positively towards proposed strategies to rectify the situation. Community members affected by HIV exposed and HIV positive children will be able to benefit from integrated and comprehensive service delivery, once the FS DoH take their participation in the development of the framework a step further by implementing the framework as well as evaluating the implementation thereof.

The limitations of the study need to be acknowledged.

1.9 LIMITATIONS OF THE STUDY

The conceptual framework of the study allows for programmes traditionally presented within a primary health care environment to form the basis of health care delivered to HIV exposed and HIV positive children. Health care presented within a hospital environment has not been unpacked and hospital settings are only seen as a service delivery point. Although Phase 1a described the implementation of the these programmes in the hospitals, further research is indicated to explore health care presented to the children in mention within the hospital environment. Due to the contextualized nature of the framework, the content of the framework will also not be able to be transferred to other health care systems. Another possible limitation is that policy and other relevant documents to this study originating from the DoH are not readily accessible which could limit the richness of data reflected in the study.

1.10 STUDY OUTLINE

The rest of the study will address the following aspects:

- Chapter 2 will consist of a literature review addressing the background of the South African health care system and various models of health care. A discussion of the various directorates in the DoH that present paediatric HIV related services follows. The impact of a selective primary health care approach and integration of primary health care programmes on paediatric HIV services are explored. Specific further attention is given to the public health referral system and available paediatric HIV related training to professional nurses.

- Chapter 3 will clarify the plan and structure of Phase 1b of the study. This phase will identify strategies to expand health care services for HIV exposed and HIV positive children in the FS public health sector. The methodology of this phase will be discussed, where after a discussion of research findings will follow. Specific recommendations regarding these findings will also be addressed. The chapter will draw to a close with a discussion of possible limitations of this phase of the study.

- Chapter 4 will discuss Phase 2 of the study. This phase will explain how preceding chapters contributed towards the development of a framework to expand health care services to HIV exposed and HIV positive children in the FS public health sector. The theoretical underpinning and empirical foundation of the framework will be discussed which will lead the reader through a staggered approach in the development of the framework. The study will be concluded with the validation of the framework and highlighting the strengths and limitations of the framework.

CHAPTER 2

Literature review

"*A focus on children is long overdue. Children have been visible in the photo opportunities and headlines, but almost invisible in the response to HIV*"
(Richter,2008:3)

2.1 INTRODUCTION

Strategies are urgently needed to expand public sector paediatric HIV services. Based on the current South African birth cohort of approximately 1 million, between 83,000 and 90,000 HIV paediatric infections of the current total of 104,963 could have been prevented (Michaels *et al.*, 2006:52). Apart from the paediatric infections that could have been prevented, it is estimated that 230,000 children are infected with HIV and AIDS in SA (Reddi *et al.*, 2007: online; World Health Organisation *et al.*, 2007a: 59). Statistics suggest further that 50 000 of this group qualify for ART, while only 7 000 have been initiated on the national ART roll-out programme (Reddi *et al.*, 2007: online). It was estimated that a further 2 000 children would have been in need of ART in the FS during 2008 (Uebel, 2008: personal communication). Exactly how many of these children would eventually benefit from ART in the FS is difficult to say.

Trials worldwide have shown that ART is effective in suppressing HIV replication and reversing immunodeficiency in children. This could result in a reduction in paediatric hospital admissions and a decrease in HIV and AIDS related morbidity and mortality (Reddi *et al.*, 2007: online). The decrease is significant, with a mortality rate of HIV positive children under the age of two years, who go without ART treatment, being around 50%. Two-thirds of HIV infected children under the age of two years, die before reaching 12 months of age (Marazzi, Germano, Liotta, Buonomo, Guidotti & Palombi, 2006:483,486). In spite of the above-only 43% of HIV infected children

being admitted with lower respiratory tract infections to a referral centre in Cape Town, were at that stage receiving pneumocystis jiroveci pneumonia (PCP) prophylaxis (Jeena, McNally, Stobie, Coovadia, Adhikari & Petros, 2005:227). This implies that standardized prophylaxis guidelines for HIV infected children are not implemented and children are therefore not benefiting from these interventions.

HIV infected children who do not receive treatment and who do not die before their first birthday, will experience rapid progression to severe symptomatic disease and death. This is especially true in resource-limited settings. A study conducted in Africa, where seven peri-natal trials were conducted enrolling 3500 children in the study, findings suggested that 35% of the infected children had died by one year of age and 53% had died by two years of age (Committee on Pediatric AIDS and Section on International Health, 2007:838). The same situation is found in rural SA. In a study conducted in KwaZulu-Natal, SA, it was found that AIDS is now a leading cause of death in children under the age of 15 years (Garrib, Jaffar, Knight, Bradshaw & Bennish, 2006:1847). HIV is also the cause of the mortality rate of South African children under five increasing at an annual rate of 1.6% (Michaels & Elay, 2007:135). The FS is also a predominantly rural area with a perinatal mortality rate of 24 per 1,000 births recorded in December 2006 (Stephen & Patrick, 2006) The other side of the coin being that paediatric HIV disease has been almost eradicated in high-income countries, where mother-to-child transmission has been lowered to less than 2% and 80% of the children now live beyond the age of 6 years. This scenario being possible due to readily available prevention and treatment services (World Health Organisation *et al.*, 2007a: 17). This is unfortunately not the case in SA.

Action has to be taken urgently to expand paediatric HIV, rather than waiting for some ideal situation to arise (World Health Organisation & UNAIDS, 2004:16). The urgent need for strategies addressing expansion of public sector paediatric HIV services are enhanced by the need to attend to lost opportunities in treating HIV exposed and HIV infected children. Large numbers of critically ill HIV infected children are seen in public health sector services in developing countries. These children's outcome was poor before ART became available (Cowburn, Hatherill, Eley, Nuttal, Hussey, Reynolds, Waggie, Vivian & Argent, 2006:9). Diagnosing and

establishing these children on ART would better the long-term outcome of the children. Despite increased knowledge on HIV and AIDS in SA and wider therapeutic opportunities to children, many children being exposed to HIV and those with HIV infection are not being recognized, despite their entry into the healthcare system (Bowley, Rogers, Meyers & Pitcher, 2007:431).

In order to address this identified need of the children this study will develop a framework to expand public health services to HIV exposed and HIV positive children in the FS. The framework will support the National Strategic Plan (NSP), adopted by the South African National AIDS Council, as the document expressing the national commitment and approach to HIV and AIDS and Sexually Transmitted Infections (STI). The NSP is the manner in which the South African government fulfills its obligation to ensure universal access to ART treatment as stipulated under the *"International Guidelines in HIV and AIDS and Human Rights"* and to fill the void of inadequate medical care for children identified by the Children's Charter of South Africa (South Africa, 1992; World Health Organisation & UNAIDS, 2004:10; and South Africa, 2007a). One of the primary aims of the NSP being, the expansion of access to appropriate treatment care and support of all HIV positive people and their families. The special needs of children are highlighted in the plan with early determination of HIV status of children and the rendering of a comprehensive package of services to these children. The NSP provides a broad framework, but specific operational plans are to be developed by each sector (South Africa, 2007a: 10, 12, 53, 150). Any plans within the health sector have to consider the health care system that is in place.

2.2 BACKGROUND TO THE SOUTH AFRICAN HEALTH CARE SYSTEM

Health care systems are a complicated matter, as no single uniform scheme exists whereby these systems can be classified. Due to the fact that the systems are never isolated entities, but always part of a wider societal context, they are never static and are highly changeable (van Rensburg, 2004:10). Although many different health care

systems exist, all systems aim to promote the well-being of individuals, families and communities (Roemer, 1991:31).

The SA health care system has evolved from different origins, namely Western medicine and various African cultures with their traditional tribal medicines. These two health systems have developed alongside each other, with Western medicine having the official status (Dennill, King and Swanepoel, 1999:34). According to Roemer's (2001:367) fourfold typology of national health care systems, SA' s health care system is typified as developing and transitional on economic level and entrepreneurial and permissive in their health system policy. Cockerham (2001) on the other hand, classifies SA' s health care system as a free-market medicine system. Such systems are characterized by finance and health care delivery being available privately, as well as in the public sector. Irrespective of the classification of SA' s health care system, this system, as has been the case with other health care systems, has been influenced by international and national events.

The Declaration of Alma Ata (International Conference on Primary Health Care, 1978) redirected health care systems worldwide and in SA towards primary health care (PHC). Further reforms were spelled out in the Reconstruction and Development Programme adopted by the newly elected South African government in 1994 (African National Congress, 1994). Annual National Health Plans have since aimed to improve the health status of the nation by focusing on access, equity, efficiency, quality and sustainability of these services. All health care rendered in SA must further comply with the Constitution of the RSA, where the Bill of Rights enshrines the rights of all citizens. The Patient's Rights Charter is further being used by the DoH as a common standard for achieving the realization of this right (South Africa, 1996; The Constitution Act, 1996:6; and South Africa: online). This legal framework has been set with PHC as backdrop.

2.2.1 Primary health care approach within a district health system

The Declaration of Alma Ata clearly stated PHC to be the approach to be followed in any comprehensive national health system. It was at Alma Ata the concept PHC was clarified. It stated that "*primary health care is essential care based on practical, scientifically sound and socially acceptable methods and technology, made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and the community with the national health system, bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care service*" (International Conference on Primary Health Care, 1978; World Health Organization, 1988:15).

This approach of care is accepted to successfully deliver basic health care in developing countries, since it is used to address the main health problems in a community by providing promotive, preventive, curative and rehabilitative services (International Conference on Primary Health Care, 1978; Lewis *et al.*, 2004:303). In SA, PHC also presents an integrated package of essential primary health care services available to the entire population, therefore being the cornerstone of health services in SA (South Africa, 2000:3). PHC consists of eight basic elements namely:

- education about prevailing health problems and methods of preventing or controlling them;
- the promotion of food supply and proper nutrition;
- an adequate supply of safe water and basic sanitation;
- maternal and child health care, including family planning and care of high risk groups;
- immunization against the major infectious diseases;
- prevention and control of locally endemic diseases;
- appropriate treatment of common diseases and injuries; and

- the provision of essential drugs (International Conference on Primary Health Care, 1978).

In order to put these elements into practice, two key approaches are identified within the PHC context, namely a selective and a comprehensive PHC approach. The selective PHC approach targets specific health problems or diseases, addressed by vertical programmes, where-as the comprehensive PHC approach also includes the social context and the conditions under which people live (Travis *et al.*, 2004:364; Van Rensburg, 2004:413). Mosley (in Dennill *et al.*, 1999:17) introduced a third approach that emphasized a problem-orientation in preference to the disease-orientated approach of the selective PHC approach. Mosley's referral to *"categorical programmes"* provides for a series of tasks or strategies that are focused and manageable. With this approach PHC can be directed towards diseases such as HIV and AIDS as well as more general problems such as poor health access or a high infant mortality rate. A comprehensive approach would thus be followed requiring both an intersectoral approach and community involvement.

The terminology *"vertical"* and *"selective"* are used interchangeably since selective PHC has been associated with vertical programmes. The FS implemented a selective PHC approach with the establishment of a predominantly vertical, ART specific roll-out programme. Specific ART staffing, rooms, administrative and reporting procedures that operated differently from the larger facility were created (Heunis & Schneider, 2006:257). In 2008, 26 clinics had been accredited to serve as [1]treatment sites and a further 12 sites as combination sites, where treatment and assessment of clients were handled. The FS DoH is following a process where it is envisaged, that over a period of time, all primary health care clinics would be in the position to be accredited as treatment sites for ART (Van Turha, 2008: personal communication).

The terms *"integrated"* and *"comprehensive"* are often also used interchangeably. This being so since increased comprehensiveness of services, necessitates an increased need for integration. The World Health Organisation (WHO) clearly states

[1] T*reatment sites are* doctor driven. Children's ART is initiated by the doctor at the treatment site

the purpose of integration to be able "*to tackle the need for complementarily of different independent services and administrative structures, so as to achieve common goals*" (World Health Organisation, 2005:108).

Different meanings have been allocated to the concept integration. Firstly an integrated PHC as an overall approach to all health sectors emphasize intersectoral collaboration and community participation and development. Here the health system is seen as an integrated whole, collaborating with different levels through the district health system (DHS). Secondly, integrated PHC packages refer to the incorporation of key PHC programmes. Thirdly, reference to integrated PHC programmes refers to the integration of two or more programmes that were previously separated (Heunis & Schneider, 2006:263). It is however, important to note that integration does not necessarily imply *"one-stop"* services as proposed in the Alma Ata declaration, or that a selective PHC approach can not be delivered in an integrated PHC package (Heunis & Schneider, 2006:264).

This study will refer to integration in the context of specific paediatric HIV related PHC programmes combining with one another on a functional level. Functional integration occurs when services seeks out opportunities for integration through improved cross referral systems, better communication and greater flexibility (Pleaner, 2007:10). Functional integration decreases fragmentation and duplication, thus enhancing integrated service provision (Pillay in Heunis & Schneider, 2006:266).

The pronounced shift towards PHC already mentioned, lead to an added emphasis of PHC within a DHS. In 1986, the WHO's Global Programme Committee defined a DHS as follows: *"A DHS based on PHC is a more or less self-contained segment of the national health system. It comprises first and foremost a well-defined population, living within a clearly delineated administrative and geographic area, whether urban or rural. It includes all institutions and individuals providing health care in the district, whether governmental, private or traditional. A DHS therefore consists of a large variety of interrelated elements that contribute to health, schools, work places and communities. It includes self-care and all health workers and facilities up to and including the hospital at first referral level and appropriate laboratory, other*

diagnostic and logistic support services" (World Health Organisation cited in Gray, Govender, Gengiah & Singh, 2005:45).

The DHS's aim is to include all the PHC resources and institutions available to a specific area, thus facilitating an integrated, intersectoral and collaborative approach to service delivery (McCoy, Buch & Palmer, 2000:10; McCoy, 2006:8). The WHO's view that the DHS is to be seen as the vehicle to ensure integrated health care delivery is reflected in the White Paper on the Transformation of the Health System in SA. This document declares that service delivery must be both integrated and comprehensive. Fragmentation should also be overcome and access to services improved (South Africa, 1997:14, 28). The National Health Act, no 61 of 2003, allocated further authority and functions to specific services within the district health care system. These services consist of community health care services, district health care services; provincial and national health care services (South Africa, 2003a: 38). In the presence of these guidelines, one however, still find poorly developed chronic disease care systems and a lack of integrated approaches to HIV and AIDS care and prevention at district level (McCoy, 2006:26). One further has to take note of the model of health care followed within a specific health care system.

2.3 MODELS OF HEALTH CARE

Models of Health Care within a Health Care System follow the Health Traditions Model, also known as the *Holistic Health Model*, or Allopathic Model, also referred to as the *Biomedical Model* of care. The Holistic Health Model aims to understand, assess and analyze the beliefs and practices of the individual, family and community. The protection, maintenance and restoration of their physical, mental and spiritual health are of utmost importance in this health model (Spector, 2002:197-198). The Biomedical Model sees health and illness in the biological context because the nature and causes of health and disease are traced to a specific etiology. Treatment is organ-specific and technical in nature (Van Rensburg, 2004:509).

Although one can distinguish between these models of care, in sub-Saharan Africa the models must be adapted to address major challenges experienced by this area, like scarce financial and human resources and an inadequate health care infrastructure. Data depicting the experiences and client outcomes in different models of care are however, not readily available (Ferradini, Jeannin, Pinoges, Izopet, Odhiambo, Mankhambo, Karungi, Szumilin, Balandine, Fedida, Carrieri, Spire, Ford, Tassie & Brasher, 2006:1335). The situation in SA does not differ from the rest of the continent as differing geographical and structural challenges, as well as management and human resource capacity in various provinces in SA, makes a *"one size fits all"* model of paediatric care and treatment very difficult (Michaels *et al.*, 2006:51).

The Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for SA included ART (South Africa, 2003b: 4). This plan proposed one service point per district, but was not specific as to the exact service model that was to be followed. Provinces opted for different choices. Gauteng province utilized their large academic hospitals to rapidly enrol thousands of clients into ART via their hospital outpatient clinics. The FS decided to make use of a nurse and clinic-based ART with district hospitals playing a specific role at particular junctures in the care process (Pienaar, Myer, Cleary, Coetzee, Michaels, Cloete, Schneider & Boulle, 2006b: 3). The vast majority of clients however, consisted of adults.

Models of health care used within the paediatric HIV services in the public health sector in SA, tend towards the Biomedical Model. Health care team members from the CHIVA-KZN project rendering care to HIV affected individuals in KwaZulu-Natal, found that health care staff need to focus less on a medical-centred approach and more on a multidisciplinary one (Cross & arriner, 2006:24). This group is not alone in their thought pattern, as other health planners also believe that health should be seen as a multifaceted and multidimensional process, where the well-being of the total person should be viewed in the context of the environment the person lives in (Van Rensburg, 2004:508).

Following mainly the Biomedical Model, various programmes forming part of different health directorates, render a segment of paediatric HIV services. Integration of a specific combination of health programmes, are sometimes in literature referred to as *"specific models of care".* In the light of available models of care just discussed, this would then be a misnomer. A discussion of the various paediatric HIV services presented by the FS DoH follows.

2.4 VARIOUS DIRECTORATES IN THE DoH PRESENTING PAEDIATRIC HIV RELATED SERVICES

This study only investigates paediatric HIV related services rendered within the public health system of the FS DoH. In this study paediatric HIV related services refer to preventative, curative and rehabilitative services presented to HIV exposed and HIV positive children. Services rendered to these children within the public health sector are regulated by spheres of governance on national, provincial and district level. Since the study focuses on the FS, the provincial structure will be used as departure point investigating paediatric HIV related services. Figure 2.1 depicts an adaption of the Strategic Health Programme Chief Directorate of the FS DoH. Directorates, sub-directorates and divisions indicated in blue, present paediatric HIV related services.

The HIV and AIDS/STI and Communicable Diseases Control (CDC) Directorate comprises of three sub-directorates, namely the Comprehensive HIV and AIDS Management, Partnership and Communicable Diseases Control sub-directorates. It is however, the *HIV and AIDS Treatment Division*, forming part of the Comprehensive HIV and AIDS Management sub-directorate, and the *Step Down and Home Based Division*, resorting under the Partnership sub-directorate, who are amongst public health services presenting paediatric HIV related services (South Africa, 2007).

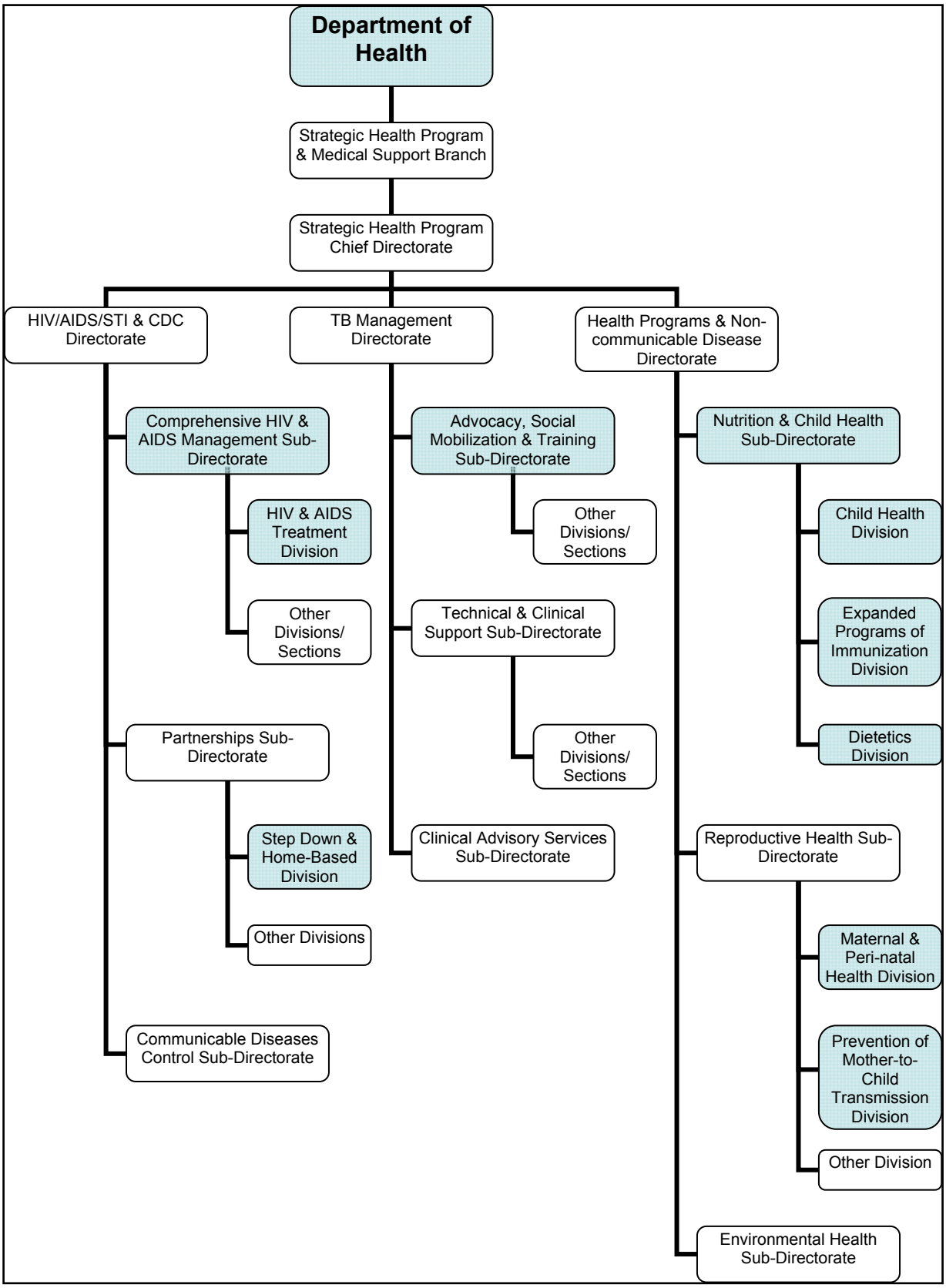

FIGURE. 2.1: Adapted FS DoH organogram depicting the Strategic Health Programme Chief Directorate (South Africa, 2007)

The TB Management Directorate comprises of three sub-directorates, namely the Advocacy, Social Mobilization and Training; Technical and Clinical support and Clinical Advisory Services sub-directorates (South Africa, 2007). These sub-directorates assist the TB (Tuberculosis) co-coordinators at district level to implement national and provincial TB policies and guidelines (Van der Merwe, 2008: personal communication). Al three sub-directorates are involved in rendering paediatric HIV related services.

The Health Programmes and Non-Communicable Diseases Directorate comprises of six sub-directorates, namely the Nutrition and Child Health, Reproductive Health, Environmental Health, Disabilities and Rehabilitation, Personal Health Care and Chronic Diseases and Palliative Care sub-directorates. Paediatric HIV related services are rendered by all three divisions of the Nutrition and Child Health sub-directorate. These divisions include the *Child Health, Expanded Programme of Immunization and Dietetics* divisions. The divisions resorting under the Reproductive health sub-directorate that renders paediatric HIV related services are the *Maternal and Perinatal Health* and *Prevention of Mother to Child Transmission* divisions. The other sub-directorates do not directly render any services to HIV exposed and HIV infected children (South Africa, 2007).

2.4.1 HIV and AIDS/STI and Communicable Diseases Control Directorate

Figure 2.2 depicts an adapted organogram of the HIV and AIDS/STI and Communicable Diseases Control directorate.

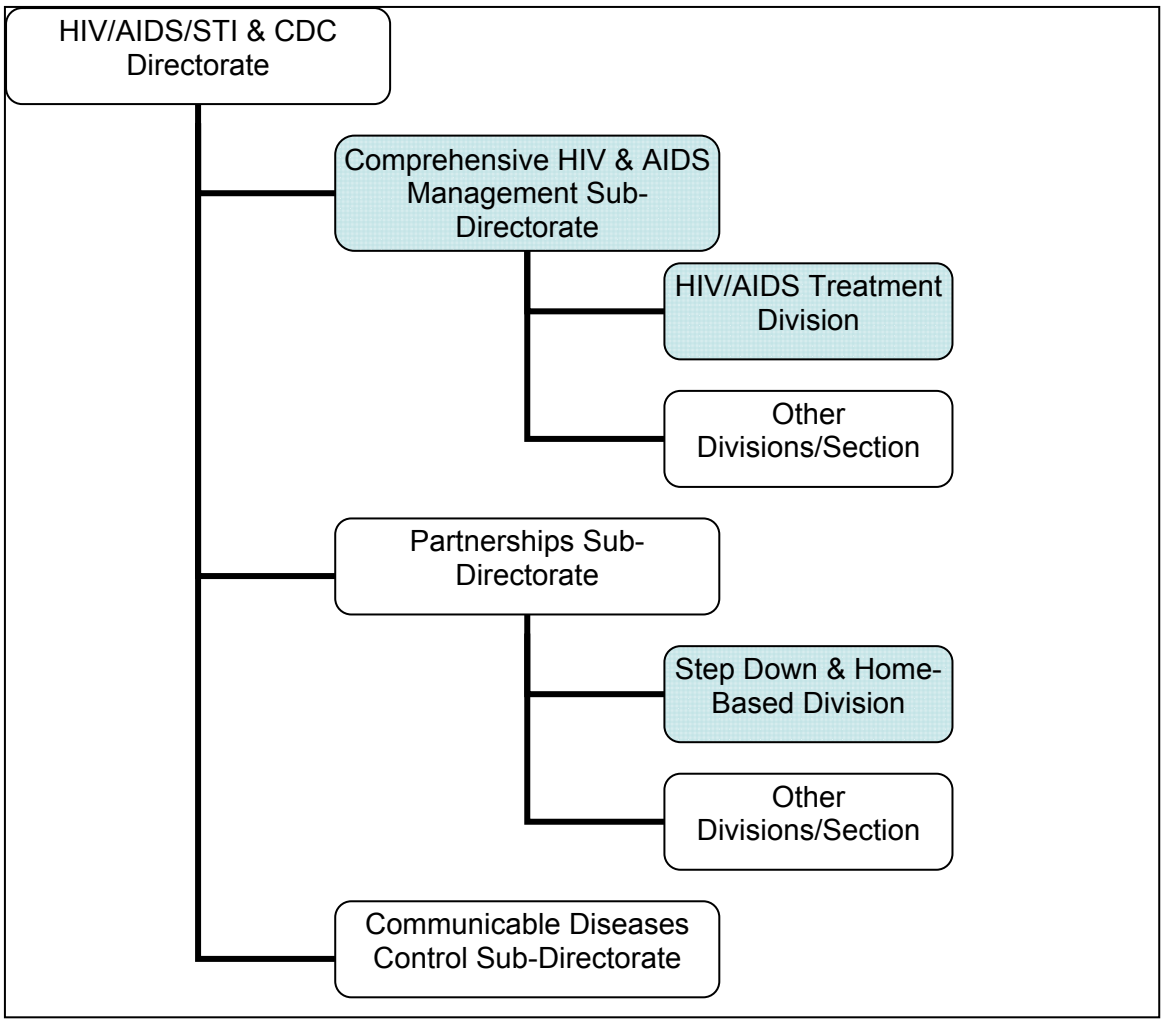

FIGURE 2.2: Adapted FS DoH organogram depicting the HIV and AIDS/STI and Communicable Diseases Control Directorate (South Africa, 2007)

A discussion follows of paediatric HIV related services rendered by divisions within the HIV and AIDS/STI and Communicable Diseases Control directorate. The division rendering a service to paediatric HIV clients in the Comprehensive HIV and AIDS Management sub-directorate is the *HIV and AIDS Treatment division*.

2.4.1.1 HIV and AIDS Treatment Division

The division renders a comprehensive range of services including the identification of possible HIV cases, HIV testing with pre- and post-test counselling, the treatment of associated infections, referral of appropriate cases, HIV disease education and promotion of universal precautions to prevent HIV infection (South Africa, 2000:36).

Within this division children at high risk are identified, tested and referred to a medical doctor at a treatment[2] site, from where those meeting ART qualification criteria are placed on ART. Follow-up of children is the done at clinic level by the professional nurse at the ART[3] assessment site (Van Turha, 2008: personal communication).

When one examines why above mentioned services plays an important role in paediatric HIV related services one finds that identifying possible HIV infected children, in need of ART, already pose a challenge. Although services for voluntary testing and counselling are widely available in the South African public health sector, only 30% of the population has made use of this testing opportunity (World Health Organisation *et al.*, 2007a: 60). Seen in the light of testing and counselling by health care providers emerging as a key strategy for expanding access to HIV prevention, treatment and care services, identification of children in need of ART is of utmost importance (World Health Organisation *et al.*, 2007a: 49). Identification of these children are however, complicated, since most children in resource limited settings acquire HIV from their mothers during birth and breastfeeding. These children's exposures to their HIV positive mother's antibodies, lead to antibody tests not being able to be used until the children are 15 to 18 months old. In the mentioned settings viral tests that can be used during this period, are not readily available. The South African HIV paediatric testing guideline will be looked at shortly (World Health Organisation, 2002:59; Stevens, Sherman, Cotton, Gernholtz & Webber, 2006:27; and Van Dyk, 2008:89).

Treatment rendered is vital as ART is the most effective intervention for improving the outcome of paediatric HIV infection (Eley & Nuttal, 2007:2). By the end of September 2006, children represented only 10% of the total number of clients in SA who received ART (World Health Organisation *et al.*, 2007a: 76). The national and FS provincial target for children being on ART has been set at 15% (Dlamini, 2008: personal communication).

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2 The *treatment site* is doctor driven. Children's ART is initiated by the doctor at the treatment site. Those who have been stabilized on treatment are referred back to the assessment site for further follow-up

3 *Assessment sites* are primarily nurse driven and assess adults and children for eligibility for ART and provide follow-up care

It was estimated that by the end of 2006, SA only mastered a 33% ART coverage for all adults and children in need of ART (World Health Organisation *et al.*, 2007a: 67). Getting children enrolled on ART is challenging due to the fact that paediatric treatment tends to be available at tertiary hospitals only, with limited expertise in treating children at public health facilities. Due to the anticipated escalation in ART initiations in SA, the current drive is towards ART being delivered by nurses within a PHC setting (Population Council & Health Systems Trust, 2006:8; Meintjies, Wilson & Venter, 2007:544). The issuing of adult ART has evolved a step further than what is the current case with children. Professional nurses in twelve FS clinics are already initiating ART to adult clients and repeating scripts for stable adult clients (Uebel & Polinyane, 2008). However, treatment is not the only important aspect to take note of when caring for HIV exposed and HIV positive children.

Referral of appropriate cases is essential as a referral system acts as a support system for health services, assisting the services to be more effective, efficient and equitable to the public (Siddiqi, Kielmann, Khan, Ali, Ghaffar, Sheikh & Mumtaz, 2001:197). Disease education is further important, as the mother or caregiver should be taught to identify potential common HIV related features, the need for Co-trimoxazole prophylaxis and the need of follow-up visitation to the health centre (South Africa, 2005a: 20). Knowing the importance of services rendered by the HIV and AIDS Treatment division, leads one to ask how these services are rendered within the South African public health sector? Fig 2.3 depicts the HIV testing guidelines for children in SA that is followed by the division.

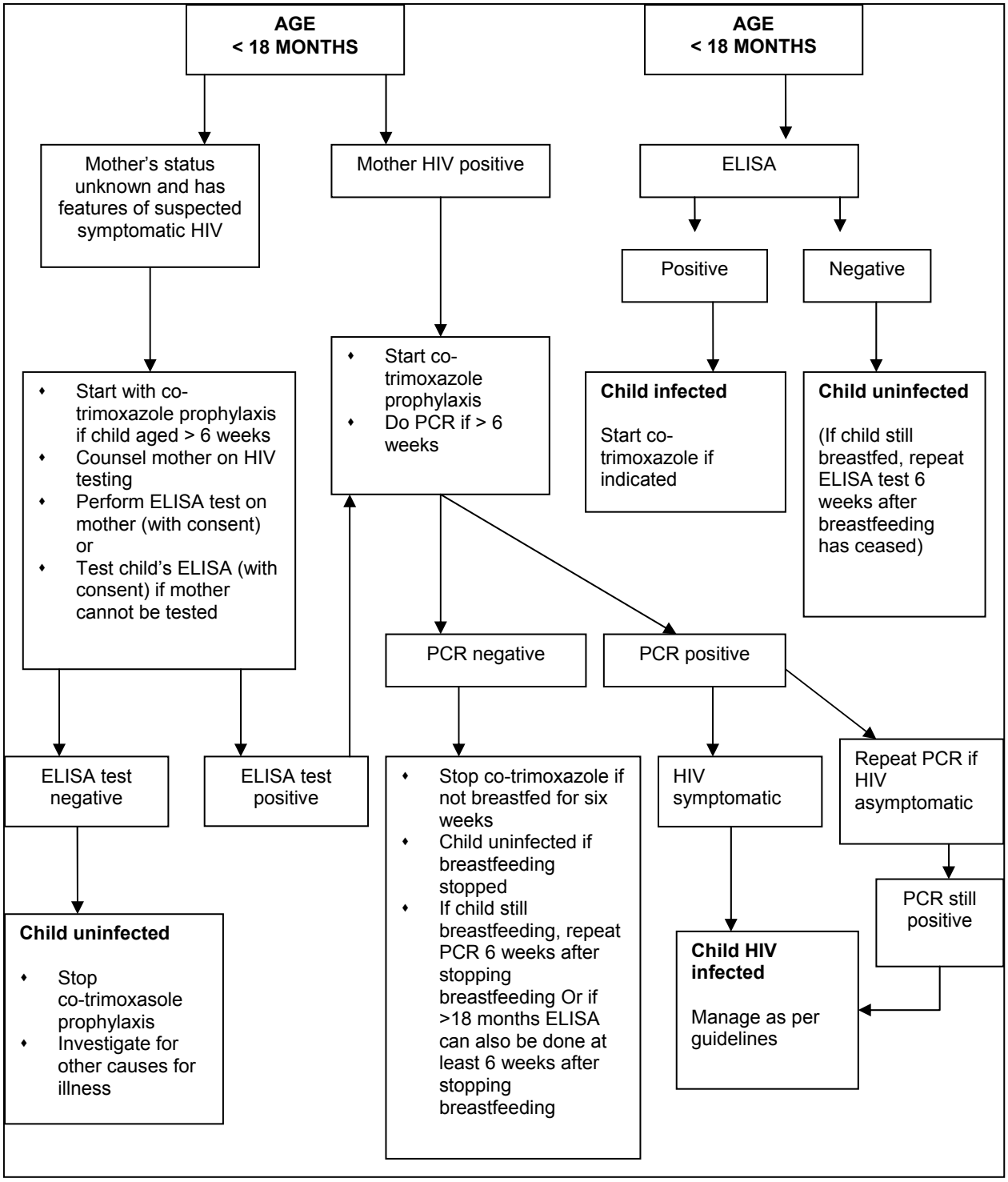

FIGURE 2.3: HIV testing guidelines for children in SA (South Africa, 2005a)

The national guidelines for the management of HIV infected children assist health care workers (HCW) in the identification and management of HIV exposed children and those who are HIV positive (South Africa, 2005a). A child born to an HIV positive mother is deemed to be HIV exposed. Due to the influence of maternal antibodies, such a child should not be labelled HIV positive based on a HIV ELISA (antibody-test), under 18 months of age (South Africa, 2004:26; Van Dyk, 2008:89). This being the reason HIV infection in children is currently diagnosed by using DNA PCR test (viral test) at six weeks of age. The use of dried blood spot technology in diagnosing children with the DNA PCR test, expanded the access to treatment for children (World Health Organisation *et al.*, 2007a: 45). Dried blood spots were introduced in 2007 in the FS, with 90% of PHC clinics implementing this technique currently (Mangoejane, 2008: personal communication). Testing for HIV is only conducted after pre-test counselling has been provided to the parents or legal guardians of the child and after informed consent has been obtained from either of these parties (South Africa, 2004:26; South Africa, 2005a: 42). The HIV status of the child is necessary in order to decide on further treatment.

Identified HIV positive children are clinically staged according to the Guidelines for the Management of HIV infected Children. These guidelines correspond with the WHO Clinical Staging Guidelines (World Health Organisation, 2002:100; South Africa, 2005a: 42).

The stages have been divided into:

- Stage 1: Asymptomatic
- Stage 2: Mild symptoms
- Stage 3: Moderate severity
- Stage 4: Severe

Although this clinical staging is not solely performed by professional nurses in the FS's public health sector, clinical staging is used by all HCW to determine the prognosis, to strengthen the clinical diagnosis when laboratory testing is unavailable or delayed and to guide the management and consideration for ART (South Africa, 2005a: 19).

Before a child can be accepted for ART, children have to adhere to set clinical as well as social criteria. Clinically the diagnosis of HIV needs to be confirmed. The confirmed diagnosis should then further be coupled with one of the following criteria: either recurrent (more than two) hospital admissions or prolonged (longer than four weeks) for HIV related illness or been staged as Stage 4 or a CD4 percentage <20% if under 18 months or <15% if over 18 months. In order to improve adherence the social criteria is that at least one identifiable caregiver will be able to supervise the administration of medication, and that disclosure to another adult living in the house has taken place (South Africa, 2005a: 14).

Should a child be accepted for ART, also referred to as highly active ART (HAART), the treatment would consist of a combination regimen of three groups of antiretroviral drugs. These groups are nucleoside reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs) and protease inhibitors (PI). A combination of these drugs, for example 2 NRTIs with either an NNRTI or a PI is used to reduce the viral load to undetectable levels when treating ART naïve children (South Africa, 2005a: 76). Apart from receiving ART, the recommendation of the WHO that Co-trimoxazole be given to children diagnosed as HIV positive, as well as children born to HIV infected mothers, is also followed in SA (South Africa, 2005a: 14; World Health Organisation *et al.*, 2007a: 17).

The division rendering a service to paediatric HIV clients in the Partnership sub-directorate, is the *Step Down and Home Based Division*.

2.4.1.2 Step Down and Home Based Division

Step down facilities consist of designated wards within identified hospitals in the FS, caring for mostly adult clients who are ready to be discharged, but who lack sufficient care within their home environment (Mohapi, 2008: personal communication). This division uses informal caregivers to render health services in the home. The home based care services rendered can be classified into preventive, promotive,

therapeutic, rehabilitative, long-term maintenance and palliative care categories (South Africa, 2001a: 1).

In order to clarify the concept of an informal caregiver, one has to know that as from 2004 the term community health worker (CHW) has been introduced as an umbrella concept for all community/lay workers in the health sector, including informal caregivers. This term has however not become institutionalized in the health system (Schneider, Hlope & Van Rensburg, 2008a: 1, 8). This study will however, refer to workers rendering home based care within the HIV/AIDS programme as a CHW. CHW 's in the FS's HIV and AIDS programme are mainly involved with adults, assisting with drug readiness training, voluntary counselling for HIV, adherence support and defaulter tracing. Children affected/effected by HIV and AIDS will occasionally receive the same type of assistance, but are not actively searched for (South Africa, 2002:5; Bekker, Myer, Orrel, Lawn & Wood, 2006:316; and Mohapi, 2008: personal communication).

Should one look at why above mentioned services play important roles in paediatric HIV related services one finds that since health does not occur in isolation, various sectors need to work together. CHW can assist in identifying needs of the community (Magnussen, Ehiri & Jolly, 2004:172). Simplified treatment guidelines have enabled community members by means of *"task sharing/shifting"* to become involved in the treatment and continuity of care of people living with HIV and AIDS. They are often the only source of help for these people (World Health Organisation & UNAIDS, 2004:20; Campbell, Nair, Maimane & Sibaya, 2005:25; Bekker *et al.*, 2006:319; and Hlope, 2006:197). The NSP endorses the principle of strengthening the health care system through close co-operation with groups rendering home based care. The National PMTCT Policy and Guideline also emphasizes the value of close co-operation with such groups (South Africa, 2007a: 60; South Africa, 2008:73).

CHW 's role needs to be further explored, in that they could become more active in drug readiness training and voluntary HIV counselling (Steyn, Van Rensburg & Engelbrecht, 2006:128; Mohapi, 2008: personal communication). The role of well trained CHW are crucial as they can conduct home visits to monitor and support HIV positive clients and caregivers, especially those struggling with administering

treatment (Campbell *et al.*, 2005:26; Hlope, 2006:191; Marazzi *et al.*, 2006:488; Pienaar *et al.*, 2006b: 7; and Reddi *et al.*, 2007). Adherence support and defaulter tracing therefore plays an important role within the HIV and AIDS programme.

Knowing the value of services rendered by the Step Down and Home Based division, leads one to ask how these services are rendered within the public health sector? CHW in the FS reflect the aims of this specific group as portrayed by the National Guideline on Home-Based Care & Community Based Care. Although health facilities rendering ART, has a few dedicated ART CHW (only five in 16 PHC facilities in the FS in 2006), more generalist CHW render services in the FS. In the same period an average of 200 CHW rendered services in the mentioned clinics. FS CHW also receive a stipend of R1000/month and are not employed by government. These workers are expected to undergo accredited training, forms part of a Non-Governmental Organisation (NGO) and resides in the communities they work in. They usually only work for a few hours a week and voluntarism is encouraged (South Africa, 2001a; Schneider *et al.*, 2008a: 4,5). Policy makers should however take note of challenges created, as these CHW remain *"outside"* the employment structures of the health system, with a non-uniform selection criteria followed and different training courses presented amongst different NGO‘s (Michaels & Elay, 2007:139).

The FS DoH governs NGO‘s rendering home based care through its Free State NGO Policy, 2004 and Free State Policy on Voluntary Work, 2002 (South Africa, 2002; Hlope, 2006:198-199). The Free State NGO Policy outlines the relationship between the DoH and NGO’s, as well as procedures to be followed when services are rendered. The Free State Policy on Voluntary work addresses aspects such as scope of practice, paying of stipends and administrative routes to be followed by CHW. In practice the policy is not fully implemented and urgent strategies need to be developed to ensure effective policy implementation (Hlope, 2006:199). A FS study concluded that CHW experienced problems in relation to training, resources, stipends, support, supervision and management. The role of the CHW was also not clear to workers themselves or to PHC nurses working side by side with them. Gaps in policy implementation have therefore to be addressed (Hlope, 2006:191; Population Council & Health Systems Trust, 2006:11; and Schneider *et al.*, 2008a: 2). In spite of fore mentioned possible constraints CHW are assisting in drug

readiness training, voluntary counselling for HIV and adherence support (Daviaud & Chopra, 2007:49).

The TB Management directorate renders a service to paediatric HIV clients

2.4.2 TB Management Directorate

Figure 2.4 depicts an adapted organogram of the TB Management directorate.

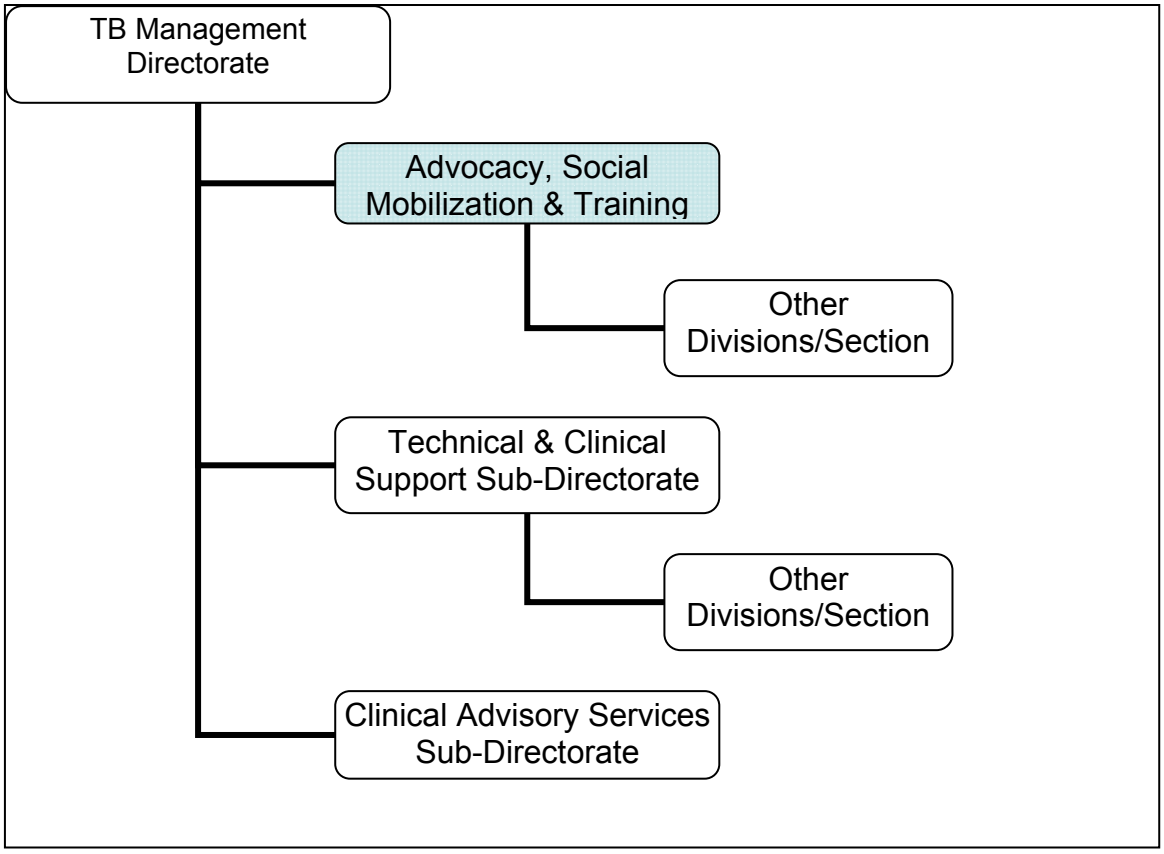

FIGURE 2.4: Adapted FS DoH organogram depicting the TB Management Directorate

Since all three sub-directorates of the TB Management directorate are involved in rendering paediatric HIV related services, a discussion of what the directorate does for these children follows. Within this directorate HCW diagnoses TB on clinical suspicion, according to national protocols. The protocols provide guidelines for the management of adults and children. The PHC clinics provide information, education and counselling to affected communities and screen families of clients with TB. Voluntary HIV testing, TB treatment, follow-up of clients using the DOTS strategy and completion of the TB register also forms part of TB related services rendered (South Africa, 2000:43).

When one scrutinizes why above mentioned services plays an important role in paediatric HIV related services one finds that HCW need to have a high index of suspicion for HIV infection, as HIV infected children have an eight times increased risk of developing TB. Thirty percent of children who come into contact with an infectious case of TB will become infected with TB, but will not necessarily develop symptoms. It is further estimated that about 10% of children infected with TB will develop symptoms and progress to TB disease. The progression from infection to TB disease also occurs more frequently and rapidly in HIV positive children (South Africa, 2005a: 42; Chintu, 2007: online; and South Africa, 2007b: 55, 65). As can be derived from above mentioned information diagnosing TB in children is and has always been difficult, and HIV co-infection complicates the matter further (South Africa, 2005a: 42; Chintu, 2007: online; and Eley & Nuttal, 2007:6).

National protocols followed by the TB Management directorate are important to ensure optimal treatment for HIV positive children co-infected with TB (South Africa, 2005a; South Africa, 2007b). HCW also need to understand the critical role the DOTS strategy (Directly Observed Therapy-Short course) plays in reaching treatment targets set by the National TB Control Programme (South Africa, 2007b: 11).

Recognizing the importance of services rendered by the TB Management directorate, leads one to ask how these services are rendered within the South African public health sector. The tuberculin skin test is used to diagnose TB in children. The interpretation of this test is however, influenced by the high prevalence

of HIV, wide coverage of Bacille Calmette-Guerin (BCG) and malnutrition, making the test less useful (Chintu, 2007: online). In SA BCG is given soon after birth. Asymptomatic HIV infected babies also receive BCG, with it only being withheld in a child with symptomatic HIV infection, as it may lead to disseminated BCG disease (South Africa, 2005b: 16; South Africa, 2007b: 55).

Children under five years of age in SA, who were in close contact with an infectious case of TB and who are asymptomatic for TB, should receive a course of Isoniazid (INH) prophylaxis to prevent the development of TB disease. Unfortunately the likelihood of TB infection in these children is high and a skin test is not required before commencing INH prophylaxis. Should the index case be an HIV positive parent, it is important to also check the HIV status of the child and to offer HIV testing (South Africa, 2007b: 56). Children who are further classified with severe pneumonia, severe malnutrition, chronic/persistent diarrhoea and TB must also be tested for HIV infection. Siblings of children diagnosed as HIV infected should be tested as well (South Africa, 2005a: 16). A baby born to a mother with TB, needs special follow-up support. If the mother was diagnosed with TB in the last two months of her pregnancy, the infant would be at a greater risk for developing severe disease. This baby should not receive BCG at birth, but would require either full TB treatment if TB is diagnosed or prophylaxis with INH if asymptomatic (South Africa, 2007b: 56, 57).

Children are treated using the same principles as adults and the DOTS Expansion and Enhancement Strategy is applicable to all clients with TB, including children (South Africa, 2007b: 62). The DOTS strategy is used to address problems occurring due to the combination of ART and TB drugs. This combination leads to children experiencing a pill burden, causing adherence and compliance problems (Chintu, 2007: online).

The next directorate rendering services to paediatric HIV clients is the Health Programmes and Non-Communicable Diseases Directorate.

2.4.3 Health Programmes and Non-Communicable Diseases Directorate

The Health Programmes and Non-Communicable Diseases Directorate have two sub-directorates that render paediatric HIV related services. Services presented to HIV exposed and HIV infected children within the *Nutrition and Child Health sub-directorate* will first be discussed, where after services rendered to these children within the *Reproductive Health sub-directorate* will be discussed.

2.4.3.1 Nutrition and Child Health Sub-Directorate

Figure 2.5 depicts an adapted FS DoH organogram depicting the Nutrition and Child Health sub-directorate.

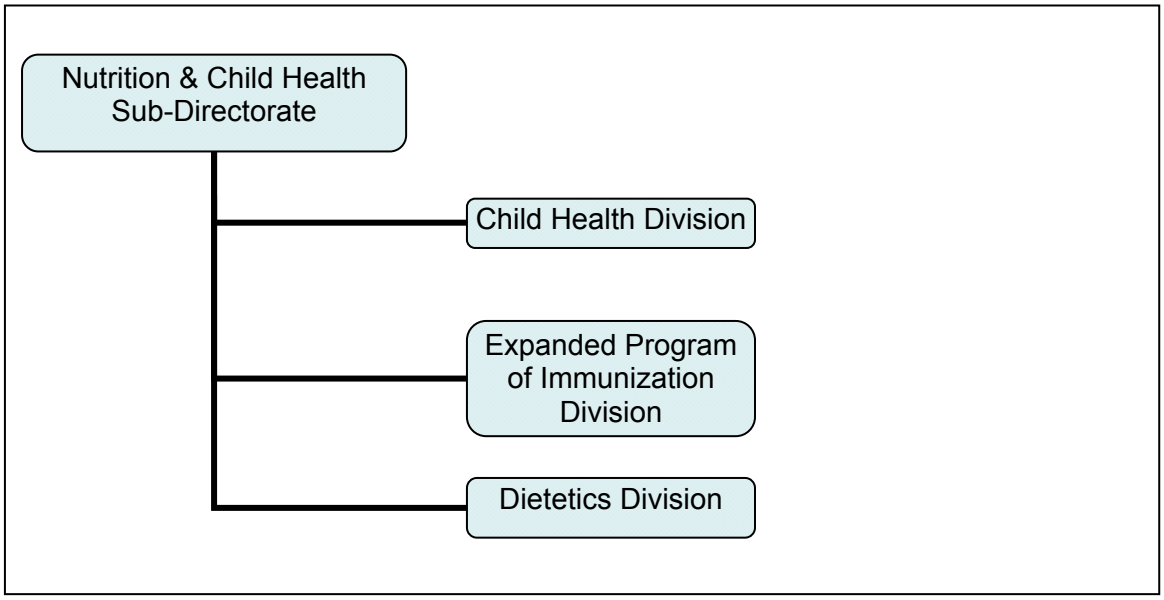

FIGURE 2.5: Adapted FS DoH organogram depicting the Nutrition and Child Health Sub-Directorate

The divisions rendering services to paediatric HIV clients in the Nutrition and Child Health sub-directorate are the Child Health, Expanded Programme on Immunization and Dietetics divisions. It is through these divisions the DoH assists the WHO in obtaining the fourth millennium development goal, namely to reduce child mortality. In order to reduce the under-five mortality rate by two thirds, between 1990 and

2015, the WHO promotes three main strategies namely Integrated Management of Childhood Illnesses (IMCI), Expanded Programme on Immunization (EPI) and infant and young feeding (World Health Organisation, n.d.: online). These strategies are encompassed in the Child Health, Expanded Programme on Immunization and Dietetics, divisions.

2.4.3.1.1 Child Health Division

Common childhood infections are the most frequent cause of illness in HIV infected children. These children are managed according to the well established IMCI protocols. The protocols being referred to in this study is the IMCI Case Management and Comprehensive IMCI (South Africa, 2005a: 5). IMCI is a strategy developed by the WHO (World Health Organisation) and UNICEF (United Nations Children's Fund) in the mid to 1990's as a response to the high mortality rate of children under five. According to this strategy an integrated approach to common childhood illnesses is followed. IMCI Case Management provides guidance in the assessment, classification and treatment of acute respiratory infections, diarrhoeal disease, measles, malaria, malnutrition and other infections. Possible HIV identification is also conducted on each child. IMCI includes both preventive and curative elements that are implemented by families and communities as well as health facilities (Loenig in Kibel, Saloojee & Westwood, 2007:196; World Health Organisation, 2008a: online). In 2000 the WHO started research to include an HIV component to the IMCI guidelines, referred to as the Comprehensive IMCI. The final HIV component added assessment, classification and treatment for common HIV related skin and mouth conditions, anti retroviral dosages, ART side effects and drug dosages for opportunistic infections to the IMCI Case Management protocol (Qazi & Muhe, 2006:11).

The significance of IMCI is that it facilitates decentralized implementation and that it is integrated within existing health systems. The simplified operational guidelines enable HCW on different levels of care to deliver HIV prevention, care and ART, as well as to use standardized referral criteria (Gilks, Crowley, Ekpini, Gove, Perriens, Souteyrand, Sutherland, Vitoria, Guerma & De Cock, 2006:505).

The IMCI strategy has been rolled out in all provinces in SA, with 97% of health care facilities implementing IMCI in the Free State (Masakala, 2008: personal communication). Children with symptomatic HIV infection can be identified effectively by HCW through the use of an algorithm (Horwood, Liebeschuetz, Blaauw, Cassol & Qazi, 2003:858). After extensive research conducted in KwaZulu-Natal, IMCI produced such an algorithm to identify HIV infection. On primary level a child eligible for ART can now be identified, the child's parents referred for further investigation, the child itself managed at the clinic until ART eligibility becomes apparent and care given to the child and family on ART, following down-referral from the ART initiating centre (Loenig in Kibel *et al.*, 2007:199). Professional nurses are therefore not initiating ART, but monitor children during follow-up visits to the clinic.

Table 2.1 depicts the mentioned algorithm, excluding the proposed guideline for treatment for each classification.

TABLE 2.1 IMCI algorithm for HIV (South Africa, 2008a: 7)

SIGNS	CLASSIFY
• Positive HIV test in child or • Child on ART	• Confirmed HIV infection
• Negative HIV test and • Child still breastfeeding or stopped breast-feeding less than 6 weeks ago	• Possible HIV infection
• Negative HIV test and • Child no longer breastfeeding (stopped at least six weeks ago)	• HIV Negative
• 3 or more features of HIV infection	• Suspected symptomatic HIV infection
• Mother HIV positive	• HIV exposed
• Less than 3 features	• HIV infection unlikely

According to the above mentioned algorithm, children who have been tested for HIV infection are classified for HIV infection as Confirmed HIV infection, Possible HIV infection or HIV negative. If no HIV test result is available, IMCI trained nurses' classify for symptoms of HIV infection should one or more of the following conditions

be present namely pneumonia, persistent diarrhoea, ear discharge, low weight for age, multiple enlarged lymph glands, oral thrush or parotid enlargement (South Africa, 2008a: 7). Within the IMCI strategy the immunization status of the child should be checked. Immunisation services are managed by the Expanded Programme on Immunisation (EPI) division.

2.4.3.1.2 Expanded Programme on Immunisation Division

The Expanded Programme on Immunisation (EPI) is a global programme for the control of childhood diseases that are vaccine preventable by immunization. Through the programme the national eradication of poliomyelitis and neonatal tetanus is envisaged. The goal is also to reduce the morbidity and mortality of a number of other immunisable diseases namely: measles, polio, diphtheria, pertussis, tetanus, TB, hepatitis B and haemophilus influenza type b infection (South Africa, 2005b: 6, 14; World Health Organisation, 2007c: 15).

The EPI is an essential component of a comprehensive PHC service, underlining why this service plays an important role in paediatric HIV related services. EPI-SA follows a policy of *"Everyday is an Immunisation Day".* Therefore no-one should be turned away because he/she did not attend the scheduled immunization day (South Africa, 2005b: 18, 23).

HCW responsible for immunization of children are guided by the *"Immunisation that works: The vaccinators manual",* ensuring that the EPI is uniformly implemented (South Africa, 2005b: 6). Immunization services are delivered as part of integrated mother-and-child health care intervention, with HIV and AIDS care supposedly forming part of this integrated package of care (World Health Organisation, 2007c: 24).

Immunisation of HIV infected children may pose some challenges. The bodies' inadequate immune response to vaccines may cause a theoretical risk of some live vaccines, causing progressive infection. HIV infected children should however, receive all childhood vaccines, at EPI recommended intervals. Polio, BCG and

measles should therefore be included in these children's immunization schedules. It has been found that children who are well controlled on ART, respond well to vaccines (Madhi, Saloojee, Schoub in Kibel *et al.*, 2007:131-132; and World Health Organisation, 2007c: 49).

Children in SA receive BCG vaccine at birth (South Africa, 2005b). The efficacy of BCG vaccination however, varies from 0% to 80% in people living in different geographical areas. Despite high BCG coverage, BCG only render protection against TB meningitis, bone TB and military TB. Severe disseminated TB still occurs in immunized children, especially those who are HIV infected. The role of current BCG vaccination should therefore be critically reviewed in the light of the HIV epidemic (Chintu, 2007: online).

The dietetics division plays an important role in care rendered to HIV exposed and HIV infected children. It is impossible to confront HIV infection without nutritional interventions (Marazzi *et al.*, 2006:484).

2.4.3.1.3 Dietetics Division

This division strives towards improving the nutritional status of South Africans, taking into consideration that nutrition is multi-sectoral and complex and can only be improved through a mix of direct and indirect nutrition interventions. These interventions are implemented at various points of service delivery (South Africa, 2000:78; South Africa, 2001b: 67).

Nutritional services plays an important role in paediatric HIV related services as nutritional deficiencies occur commonly in HIV exposed and HIV infected children due to decreased intake, impaired absorption and increased nutrient requirements (South Africa, 2005a: 26). Malnutrition contributes to morbidity and mortality in these children. Therefore nutritional assessment and intervention (such as food supplementation), should form part of comprehensive care of children (Van Kooten Niekerk, Knies, Howard, Rabie, Zeier, Van Rensburg, Frans, Schaaf, Fatti, Little & Cotton, 2005:9; Eley & Nuttal, 2007:5). It is even possible that a combination of

better nutrition and access to ART can turn a HIV and AIDS clinic into a well-child clinic (Roux, 2004:5) .

As part of the Integrated Nutrition Programme, the Protein Energy Malnutrition Scheme provides food supplementation for children whose weight has been monitored and found to be below the 3rd percentile on the Road-to-Health Chart. Caregivers are also informed about IMCI feeding recommendations and referred to available support agencies. All of the above mentioned actions are to take place at clinics rendering PHC. Additional food supplementation is available at ART service points to children and their caregivers who are HIV positive and malnourished or at risk of malnutrition (South Africa, 2005a: 31; Spencer, Harman & Botha, 2008:35).

HIV infected women need to be counselled during pregnancy about infant feeding choices. She has to make a choice between exclusive breastfeeding, exclusive formula feeding or mixed feeding (alternating breast milk and formula feed) (South Africa, 2005a: 26). Mothers who choose to formula feed their children, receive free formula for the first 6 months of their child's life, with those who exclusively breastfeed and receive the free formula for 6 months after weaning (Spencer *et al.*, 2008:47). The mother should make an informed choice, after having received guidance from HCW regarding several aspects that could influence her decision. Depending on the pattern and duration of breastfeeding, children born to HIV infected mothers run an additional 5 to 16% risk of infection after birth. Excluding breastfeeding as a possible choice due to this reason alone would be ill advised. Breast milk provides the infant with all the required nutrients, renders protection against common infections and stabilizes the intestinal mucosa (preventing transmission of HIV). Adding any other substances to breast milk is deemed as mixed feeding. Research has proven mixed feeding to be the worst infant feeding option, since the introduction of multiple foreign *"antigens"* including bacteria compromise the integrity of the infant's gastrointestinal tract, enhancing the risk of HIV infection (Spencer *et al.*, 2008:43-44).

The WHO has strongly advised that although exclusive formula feeding poses no risk of HIV transmission, this feeding choice should only be made by a care giver meeting the AFASS criteria. This criterion refers to formula feeding being acceptable,

feasible, affordable, sustainable and safe up to the age of six months of age. When all these conditions cannot be met, exclusive breast feeding up to six months is recommended. Inappropriate selection of formula milk could lead to poor child health outcomes, particularly referring to HIV free survival (South Africa, 2005a: 27; Doherty, Chopra & Jackson, 2006:117; and Spencer *et al.*, 2008:43). A study in Kwa-Zulu Natal analyzing bottles of formula milk found that 63% were contaminated with e.coli bacteria, which can cause fatal diarrhoea, with a further 28% of the bottles having been filled with diluted formula feed. This despite all the mothers having had at least 12 years of schooling and having fridges in which to keep pre-mixed formula feed. It thus emphasizes the importance for mothers to make a well informed decision regarding choice of infant feeding (Kahn, 2007: online).

The reproductive health sub-directorate renders reproductive services to women. These services also encompass services to HIV exposed children.

2.4.3.2 Reproductive Health Sub-Directorate

Figure 2.6 depicts an adapted FS DoH organogram depicting the Reproductive Health Sub-Directorate.

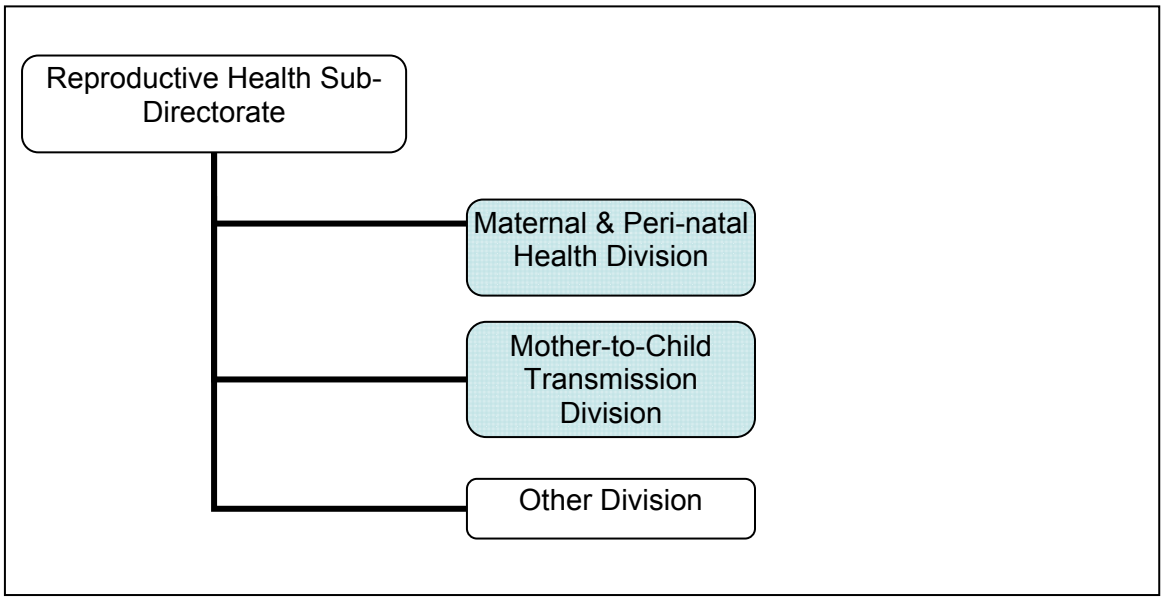

FIGURE 2.6: Adapted FS DoH organogram depicting the Reproductive Health Sub-Directorate

Two divisions within the Reproductive Health sub-directorate renders paediatric HIV related services. The Maternal and Perinatal Health Division aims to render reproductive services for HIV positive and HIV negative women in an integrated comprehensive manner encompassing preventative, promotive, curative and rehabilitative aspects of care. The focus of this care being on antenatal care, delivery, postnatal and family planning care (South Africa, 2000:15). It is however, the Prevention of Mother to Child Transmission (PMTCT) Division, that is of importance to this study, since special attention is given to HIV exposed children (Mangoejane, 2008: personal communication).

2.4.3.2.1 Prevention of Mother-to-Child Transmission Division

The PMTCT package currently consists of primary HIV prevention programmes for women of child-bearing age, routine offer of voluntary HIV counselling and testing to pregnant women, safe infant feeding counselling and support, safe obstetric practices, Nevirapine and Zidovudine to the mother and infant, as well as the provision of infant formula to women choosing this route and who are in a position to do it safely, in a acceptable, feasible, affordable and sustainable manner (South Africa, 2008:18,23).

PMTCT plays an important role in paediatric HIV related services, for the reason that primary prevention of HIV infection among women of childbearing age is the most effective and sustainable intervention for PMTCT. Antenatal Care services act as entry point to all PMTCT activities (South Africa, 2008:71). As most HIV infection in children is vertically acquired, the prevention of HIV infection in women (through PMTCT), remains the main preventative measure against HIV infection in children. The size of the paediatric HIV epidemic is also reduced and it is the most cost effective way of managing paediatric HIV (Rabie, Marais & Cotton, 2006:13; Chintu, 2007: online; and Michaels & Elay, 2007:135).

Unfortunately, in spite of the widespread implementation of the PMTCT programme in SA, HIV related admission rates were found to be similar to those found in a

survey conducted in 1996 – before the implementation of PMTCT programme (Schneider, Moore & Dlamini, 2006:110). The effect of the limited impact of the PMTCT programme, was also found in Kwa-Zulu Natal. A study conducted in Kwa-Zulu Natal concluded that the impact of HIV among children could be substantially reduced if there was an effective national PMTCT programme (Sengwana & Veenstra, 2006:115). It is therefore understandable that people like professor Nigel Rollins, head of the Department of Paediatrics and Child Health at the University of Kwa-Zulu Natal, SA, warns that *"PMTCT fatigue"* had set in, leading to many children getting needlessly infected. In a study conducted at eleven different immunization clinics around Kwa-Zulu Natal, 7% of the infants were already infected by the time they reached the clinic. The picture however gets worse in that more children get further infected through mixed breast feeding. If one takes into consideration that more than 90% of HIV infected pregnant women attend antenatal clinics and could therefore be reached with preventative intervention (Thom, 2007: online).

The value of PMTCT within paediatric HIV related services is further emphasized by the routine offering of voluntary HIV counselling and testing to pregnant women. According to Rollins (cited in Thom, 2007: online) between 40 to 80% of women attending at antenatal clinics accept voluntary counselling and testing while only 10 to 60% of HIV infected women get Neverapine and less than half of their babies get tested (Thom, 2007: online). A joint study conducted by the WHO, UNAIDS and UNICEF confirmed the low ART uptake amongst HIV infected pregnant women in SA (World Health Organisation *et al.*, 2007a: 59). The situation is further complicated by findings from another South African study establishing that one-third of infants attending public PMTCT services; do not return for follow-up and more than 70% are lost to follow-up by 4 months of age. If this situation is not rectified, children will first present for medical care when they develop symptoms of HIV disease or they will die undiagnosed in their communities (Sherman, Jones, Coovadia, Urban & Bolton, 2004:289). Although children with advanced HIV disease responds favourably to ART, the death rate amongst these children is also higher than in HIV positive children being placed on ART at an earlier stage of their infection. Therefore, every effort should be made to identify and treat HIV positive children as soon as possible. Children on ART should also be closely monitored and supported (Reddi *et al.*, 2007).

The National PMTCT programme was implemented in 2002, with the South African government approving the provision of ART in the public sector in November 2003. PMTCT services are offered in all public hospitals and in more than 90% of PHC centres, making it the largest PMTCT programme in Africa (South Africa, 2008:13; Eley, 2006:21). These programmes have been implemented in public health settings at designated pilot sites and then nationally, by order of a July 2002 Constitutional Court judgment. Initially the DoH was ordered to make Neveripine universally available for all HIV infected pregnant women, with the rest of the current interventions being phased in (Sherman *et al.*, 2004:289). According to the 2008 version of the DoH's PMTCT Policy, the Free State is also in the process of phasing in the administration of dual therapy consisting of Neverapine and Zidovudine to both HIV positive mother and her exposed baby. This programme is in accordance with international guidelines to minimize the risk of HIV transmission from mother to child (Rabie *et al.*, 2006:34; Committee on Pediatric AIDS and Section on International Health, 2007; and South Africa, 2008:19).

The various directorates and sub-directorates within the DoH rendering HIV related services have now been discussed. The impact these different directorates and sub-directorates have on paediatric HIV service delivery will now be explored.

2.5 THE IMPACT OF A SELECTIVE PHC APPROACH AND INTEGRATION OF PHC PROGRAMMES ON PAEDIATRIC HIV SERVICE DELIVERY

As has been explained in 2.2.1 the FS implemented a selective PHC approach, therefore targeting specific health problems within vertical programmes. Although different meanings have been allocated to the concept integration, it was highlighted that this study will refer to functional integration between PHC programmes rendering paediatric HIV related services in the public health sector. Although NGO's and the private sector can play an important roll in the roll-out of the HIV programme, it is the public sector that can reach the large number of people requiring treatment in an equitable manner, simultaneously providing wider support and services for a

more comprehensive HIV programme (Chopra, 2005:3). In the face of this responsibility, one would expect national programmes to integrate HIV and AIDS prevention, care and treatment for women and children, including PMTCT services, into antenatal, maternal, neonate and child health services. This is however, not the case (World Health Organisation *et al.*, 2007a: 47). Before exploring the integration of PHC programmes, we would first look at the impact a selective PHC approach has on paediatric HIV related services.

2.5.1 Selective PHC approach

The main benefit of a selective PHC approach, such as found with paediatric HIV, is that short-term goals can be reached by targeting manageable dimensions of a health system. This approach is often followed within weak health systems (Heunis & Schneider, 2006:264). HCW working exclusively in one programme is also seen to be more focused and knowledgeable in the specific field, especially since not all HCW have the inclination or time to consult literature in order to keep themselves updated (Heunis & Schneider, 2006:274).

Following a selective PHC approach does however, pose many disadvantages. According to Travis in Heunis and Schneider (2006:264), vertical programmes pose a serious risk to health systems in that the following four *"d's"* occur: duplication, distortion, disruption and distraction. These risks are confirmed, since vertical programmes are centred in urban hospitals and health care facilities, with little or no participation of communities, leading to limited opportunities for change. Only one disease is fought at a time and efforts are not incorporated into a higher baseline of health status. The poor communication among vertical programmes, lead to redundancy, overlap and waste (Magnussen *et al.*, 2004:170-171). One further finds that inequities between health programmes increase when extra resources are made available for the HIV programme. An already under-resourced health care system is thus further taxed (Chopra, 2005:4; McCoy, 2005:18). Another way in which imbalances are created is the pressure exerted on salaries. In order to attract workers, well-funded programmes that are implemented through HIV and AIDS NGO's, often pay higher salaries than is available in the public sector. As a result

two tiers of salaried workers emerge, often within the same institution (World Health Organization, 2006a: 21). The various national programmes driving their individual programme objectives, place further heavy demands on health managers and service providers on district health level. These parallel demands include reading documents, filling forms, writing reports, attending meetings and rendering specific services or making field visits. Reporting requirements alone can occupy 10% to 20% of a district health manager's time (World Health Organization, 2006a: 21). Verticalisation within the PHC approach however necessitates an increased need for integration.

2.5.2 Integration of PHC programmes

Integration of programmes holds specific benefits to all relevant role players. This type of approach are seen to be more democratic and politically correct (Heunis & Schneider, 2006:274). Even though an integrated approach provides less certain outcomes and continues over longer time frames, the health system benefits from the more holistic approach followed (Heunis & Schneider, 2006:264). A FS study confirmed the need for rendering integrated care especially in more rural areas due to the practicality of this approach in these under-resourced areas, thus strengthening the health system (Heunis & Schneider, 2006:275). Programmes aimed at integrating skills among providers of primary care for children are taking place at district and primary care level. The WHO's IMCI and the HIV adaption to this strategy, provides a fresh approach to scaling up HIV prevention, care and treatment, as well as TB care and co-management of TB/HIV and AIDS clients (World Health Organization, 2006a: 23). An integrated programme would imply that HCW need to be multi-skilled and therefore also trained in paediatric HIV services (Pruitt & Epping-Jordan, 2005:638; Heunis & Schneider, 2006:275). The programme would be more accessible, since clients would be attended to at all levels of health care. Having trained staff available, will lead to a decline in morbidity and age-related mortality from HIV infection, as well as enhancing the quality of life (South Africa, 2005a: 76).

Integrating programmes could potentially have its down side as well. In a study conducted in the FS, health managers and HCW were concerned that integration of the comprehensive HIV and AIDS care and treatment would place a too heavy a burden on HCW already struggling to cope with PHC responsibilities, leading to burnout and discontent (Heunis & Schneider, 2006:274; Steyn *et al.*, 2006:128).

Having explored the impact of a selective PHC approach and integration of PHC programmes on paediatric HIV service delivery, it is necessary to discuss the public health referral system in order to get the necessary background on how these various programmes fit into the referral system.

2.6 PUBLIC HEALTH REFERRAL SYSTEM

An efficiently functioning referral system is essential to ensure an operational district-based PHC system. Such a referral system consists of three levels of care namely primary, secondary and tertiary care. It is however, of utmost importance that users enter the health care system at the lowest level and least complicated service facility, only to progress to higher levels of care if needed. Further on, it is vital that referral needs to be seen as a two-way process of communication, with the retention of clients in a referral institution being as brief as possible (Siddiqi *et al.*, 2001:197; Van Rensburg, 2004:149, 150). In this way an effective public health care referral system will lead to alteration in the pattern of diseases presented at hospitals and health centres, with more complex conditions being treated at higher levels and simpler conditions at lower levels of care (Siddiqi *et al.*, 2001:197). The above mentioned referral system has to comply with standards set.

2.6.1 Standards for a functional public health referral system

According to the set of core standards prescribed by the DoH (South Africa, 2000:12-13), the following standards regarding referral should be in place:

- a clear system for referrals and feedback on referrals;
- all clients should be referred to the next level of care when needs fall beyond the scope of clinic staff competence;

- clients with a need for additional health or social services should be referred as appropriate;
- every clinic should be able to arrange transport for an emergency within one hour;
- referrals within and outside the clinic are recorded appropriately in the registers; and
- merits of referrals are assessed and discussed as part of continuing education of the referring health professional to improve outcomes of referrals.

Looking at the expected system for referrals and feedback on referrals, one finds that a commitment has been made in the White Paper for the Transformation of the Health System in South Africa, to ensure that all persons infected/affected by HIV and AIDS have access to a continuum of appropriate care and support. It is expected that the relevant chief directorates should set guidelines clearly indicating referral patterns (South Africa, 1997). No Referral Policy as such is available in the FS. Currently individual programmes are guided by guidelines indicating specific referral criteria applicable to clients receiving care within a programme. However, these guidelines are not always readily available in the FS (Spies, 2008: conference paper). Should mentioned policy/guidelines not be known to HCW, referrals will be negatively impacted on, as HCW would be unsure as to what information is needed by the site referred to, as well as what the scope and function of the site is. Poor feedback to the referring site is further indicative of poor communication amongst health care team members, leading to further breakdown in the referral chain (Dor, Ehlers & Van der Merwe, 2002:103). It is however the DHS in SA's role, to include the implementation of effective referral mechanisms within and between districts and levels of care (Pillay *et al.*, 2001: online).

The second standard set to ensure a functional referral system states that all clients should be referred to the next level of care when needs fall beyond the scope of clinic staff competence or if they need additional services. This standard is widely accepted. It is taken for granted that all children using public health services should have equal access to available national resources (Sutton in Kibel *et al.*, 2007:297). PHC services are the point of entry into the health system and do not consist of first

contact care only. Should a problem not be solved at this level, the client will be referred to a secondary service (Dennill *et al.*, 1999:3). It is however important that at every point in the continuum clients should be provided with information about what other services they should utilize. Only clear and strong referral systems can ensure access to appropriate services (Heunis & Schneider, 2006:267). Referral to treatment sites closest to the client's home can either be done before initiation of treatment or in the case of sites with less clinical expertise in paediatric HIV, as soon as the child's condition has stabilized on treatment. This will assist larger ART sites to still retain their capacity to enrol new children and that more peripheral ART sites build up experience in the treatment of children (Feucht, Kinzer & Kruger, 2007:401).

Recording of referrals is of utmost importance. Although most care can be rendered at primary care level, some HIV positive children will need referral. In order to maximize the involvement of the child's care giver, he/she needs to receive a clear explanation of the illness and a referral letter with a follow-up plan for the child (South Africa, 2005a: 4). Further recording is needed with referral back to the ART initiation site. A detailed letter of the course of treatment and management decisions should always accompany the care giver (Meintjies *et al.*, 2007:554).

HCW rendering care to HIV exposed and HIV infected children within the public health referral system need to be equipped with knowledge and skills to render this specialized care.

2.7 PAEDIATRIC HIV RELATED TRAINING FOR PROFESSIONAL NURSES

Training is aimed at gaining a skill (Kurtus, 1999: online). The DoH refers to paediatric HIV related courses professional nurses attend, as training courses. The content of many of these courses encompasses more than only gaining specific skills. Knowledge, attitude and problem solving skills are addressed in some of these courses. Such courses could therefore be seen as education and not training programmes. This study will refer to training in order to be in line with terminology

used by the DoH. Such training plays an important role in the expansion of paediatric HIV services.

Establishing an effective HIV programme requires more than just drugs. Without well-trained HCW the implementation of ART in the public sector can not be successful (South Africa, 2004: iii; Chopra, 2005:3; and Stein, 2005:7). In order to be successful, it is expected of HCW to have a high index of suspicion for conditions associated with HIV. Except for identifying these children, the necessary knowledge and skills to manage these conditions is essential (South Africa, 2005a: 32).

2.7.1 Background to paediatric HIV related training

The majority of HCW in SA did not benefit from HIV training in their basic training (Steyn *et al.*, 2006:115). Due to this, PHC nurses feel they lack appropriate skills to deal effectively with HIV and AIDS clients (Lehmann & Zulu, 2005:45). This was also found to be the case in the FS, where an insufficient number of professional nurses who were required to render care for clients receiving ART, were not trained in Clinical Primary Health Care or IMCI. These untrained nurses would therefore be unable to conduct comprehensive physical assessments and be incapable of identifying a child with an IMCI classification of Suspected HIV and AIDS (Botma, 2004:19; Spies, 2008: conference paper). The training need is further complicated by a serious shortage of HCW. The average vacancy rate for professional nurses in PHC facilities in the FS is 39.3%, with variations between different districts. This again lead to inefficient use of professional staff (South Africa, 2006:18; Daviaud & Chopra, 2007:46). A FS study confirmed this predicament, finding that the health system needs strengthening through human resources in order for expansion of HIV to transpire (Steyn *et al.*, 2006:94).

Added to this dilemma, the numerous programmes created in response to the Millennium Development Goals led to a lot of money and effort being directed towards short training courses. These *'epidemics'* of in-service training lack comprehensive workforce strategies (World Health Organization, 2006a: 20). This is also the case in the FS where PHC is packaged into vertical programmes. Managers

often have to decide who attends which course, as each programme has a number of training courses (Fairall, 2005:15). These managers are led by norms such as *"every clinic has nurse practitioners able to treat clients according to IMCI principles", "at least one professional nurse will attend an HIV and AIDS/STI/TB workshop or other continuing education event on HIV and AIDS each year"* and *"at least one staff member who has or has had opportunity for continuing education in TB management"* (South Africa, 2001b: 19,33,38). The paediatric HIV related training presented in the FS is further complicated due to the fact that various directorates and sub-directorates present these training courses.

2.7.2 Paediatric HIV related training presented in the Free State

This study only investigates paediatric HIV related training for professional nurses presented within the public health system in the FS. Figure 2.7 depicts a sample of the FS DoH organogram illustrating the origin of paediatric HIV related training courses as it is presented by various directorates.

The In-Service Training Division, also known as the Skills Development Unit, resorts under the Medical Support Chief Directorate. It is from here the *Comprehensive HIV/AIDS Care and Management Training programme* is presented. Within the Strategic Health Programmes Chief Directorate the HIV and AIDS/STI and CDC Directorate is found, encompassing the Voluntary Counselling and Testing division, where *Voluntary Counselling and Testing Training* is presented. The Health Programmes and Non-Communicable Diseases Directorate is also incorporated in the Strategic Health Programmes Chief Directorate. It is within the Nutrition and Child Health sub-directorate of the latter directorate that *Integrated Management of Childhood Illnesses (IMCI) Training* and *Expanded Programme on Immunisation (EPI) Training* are respectively presented. Another sub-directorate within this directorate is the Reproductive Health sub-directorate, being responsible for presenting *PMTCT Training.* Lastly, the TB Management Directorate within the Strategic Health Programmes Chief Directorate presents *TB/HIV Training*. Each of the mentioned training programmes will be discussed by looking at who is targeted to attend the training, how the training is presented, as well as the content covered by the training.

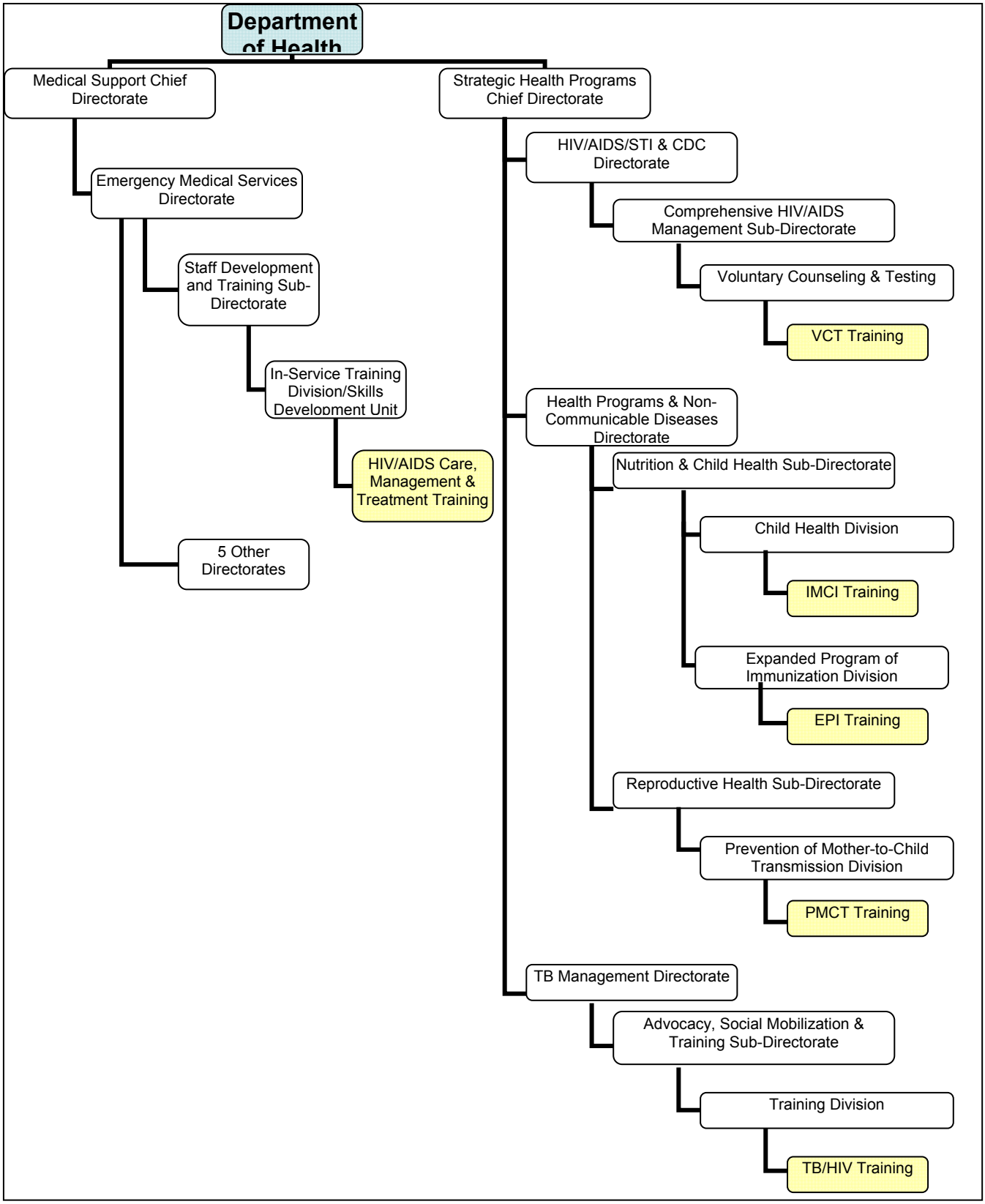

FIGURE 2.7: **Sample of FS DoH organogram depicting the origin of paediatric HIV related training courses for professional nurses (South Africa, 2007)**

- **Comprehensive HIV/AIDS Care and Management Training**

The *Comprehensive HIV/AIDS Care and Management Training programme* targets all HCW. Preference is given to professional nurses rendering services within ART-sites, PHC clinics and those working within antenatal and postnatal wards in hospitals. This five day course is broadcasted over the Interactive Distance Communication and Management System (ICAM). This system enables the DoH to broadcast from two studios, via a satellite, to 40 classrooms distributed in the FS (Barnard, 2004). Course participants receive lectures from HIV and AIDS specialists for four days and write a test on day five. Practical training over an extra four days follows the lecture period. Professional nurses are exposed in this way to activities at assessment and treatment sites. After completion of the practical exposure another test is written and then professional nurses undergo one day's drug readiness training. Four such training courses are scheduled per year, with an average of 400 professional nurses completing the training course per year. Professional nurses who have undergone the training are followed up in their districts by lecturers. They receive face-to-face maintenance training, as well as an opportunity to attend weekly hourly training sessions broadcasted over ICAM in order to keep them updated with the latest HIV and AIDS developments. Paediatric HIV related topics are covered in lectures in the following sequence:

- Infant feeding;
- HIV and AIDS in Infants and Paediatric ART;
- Mother-to-child-transmission; and
- Walk Through Model for Children (scheduled follow-up visits) (Steyn *et al.*, 2006:118; Vanqa, 2008: personal communication).

- **Voluntary Counselling and Testing Training**

Voluntary Counselling and Testing Training is also not exclusively presented to professional nurses, but includes all HCW who may benefit from such training. This ten day course is presented as a workshop, at least once per year, in each of the five districts of the FS. An average of 100 professional nurses undergo the mentioned training per year. The standardized training course is outsourced by the DoH to

various service providers in the districts. Only one module of the 33 module course, concentrates on children with HIV and AIDS. The content of this module consists of:

- Mother-to-child-transmission;
- Management of children with AIDS (very superficially); and
- Counselling of HIV infected children (Stofile, 2008: personal communication).

- **IMCI Case Management course**

The *IMCI Case Management course* targets professional nurses. This two week long course is presented to primary health care nurses, including nurses at hospital outpatient departments, accident and emergency rooms. The training involves rigorous training in the use of algorithms and clinical features as defined in prescribed manuals. At least 30% of training is devoted to clinical practice. Tuition is provided by facilitators who will have completed an additional five-day course. A clinical instructor, who is usually a doctor, provides tuition on seriously ill in-patients (Loenig in Kibel *et al.*, 2007:199). The Strategy for Priorities for South Africa's National Health System 2004 to 2009 required 80% of districts to have 60% of HCW at all facilities caring for children trained in IMCI case management (Loenig in Kibel *et al.*, 2007:201). The FS meets this target easily with 97% of health facilities implementing the strategy and 80% of these facilities meeting the required saturation rate of 60% of their professional nurses being trained in IMCI (Masakala, 2008: personal communication)

- **EPI Training**

It is again professional nurses working within PHC facilities who are mainly targeted to undergo *EPI Training.* The two day training course has no practical component and primarily aims to ensure that professional nurses understand how to implement the national immunization schedule after having received information on the various diseases, contra-indications to immunisation and how to handle possible adverse effects. Principles of disease surveillance are also covered with a further emphasis being placed on recordkeeping and data management (South Africa, 2003c; Furter, 2009: personal communication). In an attempt to keep professional nurses updated

with proposed changes in the national immunization schedule, need specific training is further presented when indicated (Burger, 2009: personal communication). It is not known what the EPI implementation and training targets for the FS DoH are.

- **PMTCT Training**

The *PMTCT Training* is presented to midwives in hospitals and those in PHC clinics who deliver babies and render antenatal care. PHC professional nurses who are involved in rendering child health care also undergo the training. Other categories of nursing staff are given the opportunity to attend the PMTCT training, although the level of difficulty is adapted to suit these categories. The training is presented over five days in the various districts by the PMTCT district co-ordinators. Guest lecturers are used occasionally. Content covered include basic science of HIV and AIDS, counselling skills, maternal care, ART for mothers and nutrition with special emphasis on breastfeeding and replacement feeding for babies. Pre and post-tests are written before and after training. Three hundred nurses undergo this training course per year. Currently the FS has 87% PMTCT training coverage per facility (Mangoejane, 2008: personal communication).

- **TB/HIV Training**

TB/HIV Training is offered to PHC professional nurses rendering care in clinics. As with other training courses, other nursing categories may also attend the same training, which is then presented at a level understandable to them. The three day course is presented in the districts by TB district co-ordinators. The DoH does however, sometimes make use of other service providers to present the training. Emphasis is placed on adult clients, although the training module does address the management of the HIV exposed and HIV positive child. Other topics covered include the interaction between TB and HIV, the diagnosis and management of TB, HIV and STI and the integration of care of these clients. Professional nurses are furthermore trained in the monitoring and evaluation of TB and HIV. An average of two hundred professional nurses undergo the training per year (Motlanke, 2008: personal communication).

As has just been seen, each directorate presents its own paediatric HIV related training course, with the content covered not necessarily correlating.

2.7.3 Content of paediatric HIV related training courses

Table 2.2 will give an overview of topics currently covered by paediatric HIV related training courses presented by the various directorates of the DoH in the FS to professional nurses.

TABLE 2.2: Overview of topics covered by paediatric HIV related training courses presented to professional nurses in the FS DoH

TRAINING COURSE	CONTENT COVERED							
	TB/HIV	Nutrition	ART	Diagnosis of HIV	Routine ART follow-up	Management of opportunistic	PMTCT	Counselling
Comprehensive HIV/AIDS Care & Management		√	√	√	√	√	√	
VCT					√	√	√	√
IMCI-case management	√	√		√		√		√
IMCI-comprehensive		√	√	√	√	√		√
EPI								
PMTCT		√					√	√
HIV/TB	√		√	√	√			

As can be seen in Table 2.2 overlaps, as well as gaps of content covered in the various training courses occurs, whilst addressing aspects related to paediatric HIV. To complicate matters further, content covered by each topic varies from training course to training course. One has to bear this into mind, since it is the same group of professional nurses who undergo these training courses. A discussion follows of the content covered by the various training courses, as is depicted in Table 2.2.

- **TB/HIV content**

Looking at the TB/HIV content covered in training courses the variation in content becomes clear. The *IMCI Case Management Course* includes an algorithm for TB screening. According to identified criteria, the child is classified as TB, TB exposure, or Possible TB. A child whose HIV status is unknown is further counseled and tested for HIV (South Africa, 2008a: 8). Table 2.1 depicted the algorithm used by IMCI to assess and classify children's HIV status. As can be expected, the *HIV/TB training course* covers the interrelationship between TB and HIV in more depth. This includes a thorough discussion of the diagnosis of TB and HIV in children, as well as the management of TB in children co-infected with HIV. The diagnostic criteria and assessment used to diagnose TB in children according to the HIV/TB training course, differs from that depicted in the IMCI Case Management course (South Africa, 2006a: 36). HIV testing guidelines proposed by the HIV/TB training course also differs from the algorithm proposed by the IMCI Case Management course (South Africa, 2006a: 49).

- **Nutritional content**

Nutritional content is covered in three of the six training courses. The *Comprehensive HIV/AIDS Care and Management course* considers the impact of HIV on nutrition and discuss in length the advantages and disadvantages of breastfeeding and replacement feeding (Van der Walt & Brits, 2008: lecture). *IMCI Case Management* and *Comprehensive IMCI* emphasize the importance of feeding assessment and provide standardized feeding recommendations. These recommendations include guidelines for the HIV infected mother, and advice on breastfeeding and formula feeding (South Africa, 2007c). The *HIV/TB training course* include nutritional supplementation as a principle of HIV management in children, but do not expand on this in the training course (South Africa, 2006a).

- **ART regimen**

Paediatric ART regimens are discussed in the *Comprehensive HIV/AIDS Care & Management course.* Regimens are discussed in detail with guidelines as to how dosages should be calculated. Attention is also given to administration of drugs and safekeeping measurements. Nurses are furthermore made aware as to when changing of regimens are indicated (Brits & Tabane, 2008: lecture). The *IMCI comprehensive Course* also discusses paediatric ART drug regimens and how to handle possible side-effects that may occur due to ART usage (World Health Organisation & UNICEF, n.d.). The *HIV/TB training course* explains the recommended child regimen and briefly mentions important issues relating to paediatric ART (South Africa, 2006a).

- **Diagnosis of HIV**

The diagnosis of HIV in exposed children is discussed in the *Comprehensive HIV/AIDS Care and Management course*, both *IMCI courses*, as well as the *HIV/TB training* courses. With the exception of the HIV/TB training course HCW attending the mentioned courses receive the same content as to how to go about in diagnosing HIV in children (South Africa, 2006a: 49; World Health Organisation & UNICEF, n.d.).

- **Follow-up on ART and management of opportunistic infections**

Follow-up of children on ART and the further management of them forms part of the *Comprehensive HIV/AIDS Care & Management course* (Brits & Tabane, 2008: lecture). The *VCT (Voluntary Counselling and Testing) training course* address the management of children on ART very shortly and superficially (South Africa, 2001). During *IMCI Case Management,* as well as *during the IMCI Comprehensive training* guidance is given regarding follow-up care for children with a classification of either Confirmed HIV infection, Suspected Symptomatic or HIV exposed. These guidelines include scheduled follow-up visits, immunization, prophylaxis, growth monitoring and nutritional advice and assessment. Children are referred to a treatment site to

receive their ART (South Africa, 2008a; World Health Organisation & UNICEF, n.d.). The *HIV/TB training course* clearly explores important principles of HIV management in children. After having assessed and classified the child for HIV infection, the child's disease progression is monitored and clinical staging performed. Prophylaxis of opportunistic infections, deworming, the importance of growth monitoring and immunisation are covered in the content. Referral criteria for ART are also included (South Africa, 2006a).

- **PMTCT content**

PMTCT is covered in the *Comprehensive HIV/AIDS Care & Management course.* During this part of the training session the basic principles of the PMTCT programme is revised, the extent ART affects pregnant women, as well as possible future developments of PMTCT. The ART regimens to be followed by mothers and infants in specific scenarios are furthermore discussed (Steinberg, 2008: lecture). The *VCT training course* mentions the PMTCT in a short paragraph (South Africa, 2001). As can be expected the *PMTCT training course* gives a prominent place to PMTCT. The emphasis being antenatal and postnatal follow-up for HIV positive mothers and infant feeding practices (South Africa, n.d.-b). Follow-up of HIV exposed infants are not addressed, thus explaining the more than 70% of infants attending public PMTCT services that are lost to follow-up by 4 months of age.

- **Counselling content**

Counselling is covered in the *VCT training course.* During this training course the TASO model of counselling is discussed. The abbreviation TASO, stands for *"The AIDS Support Organisation".* This Ugandan based organization defines counselling as a helping relationship. The model consists of three stages where the client is helped to tell his story, explore his options and then assisted to make a plan to address problems identified. Attention is additionally given to verbal and non-verbal communication skills. Professional nurses are given the opportunity to practice pretest and post test counselling on clients in the presence of the trainer (South Africa, 2001). Counselling that forms part of the two *IMCI training courses* place

emphasis on listening skills during counselling and how to render support during counselling sessions with the caregiver of the child (South Africa, 2007c). During the *PMTCT training course* counselling highlights listening, how to build confidence and give support and how to assist clients in improving their self-esteem (South Africa, n.d.-b).

Content covered and that not covered, in the various training courses leads to specific challenges being faced by paediatric HIV related training.

2.7.4 Challenges faced by paediatric HIV related training

As could be seen in the discussion of the content of the various training courses, duplication of content occurs with little or no integration of comprehensive paediatric HIV related content in courses. Once-off training courses, as most of these are, often have a short duration. Due to this the required knowledge and skills are not imparted, leading to course participants not feeling confident to implement course content (Lehmann & Zulu, 2005:45). With the exception of IMCI, no structured follow-up training is provided. The most common challenge therefore is that often training interventions are not properly executed (Magnussen *et al.*, 2004:174).

As is the case in the rest of the health sector in SA, a lack of human resources also impacts on paediatric HIV related training (Bekker *et al.*, 2006:319; Population Council & Health Systems Trust, 2006:8; and Steyn *et al.*, 2006:95). To make matters worse the expansion of SA's HIV and AIDS services within the public sector, pose a further challenge, since additional personnel need to be trained and those in the health care system retained (World Health Organisation *et al.*, 2007a: 60). The demands placed on management and nurses alike are great, since it is expected that nurses are to be trained in every aspect of care within in the PHC setting. This being so, since nurses are expected to respond appropriately to clients' diverse needs on first contact with the health system (Fairall, 2005:14). The nurse expected to render paediatric HIV related care is faced with the same situation.

A further challenge faced, is the manner in which training should be presented. The FS DoH is making use of Mindset Health. Mindset Health is a not-for-profit educational organization which aims at the personal, social and economic upliftment of all Africans, through the delivery of quality health education on a mass scale, by making use of satellite technology. Mindset Health is currently installed in 304 public health facilities in SA with 34 being in the FS (Barnard, 2008: personal communication). It offers curriculum based accreditation, on-demand content on HIV, AIDS, TB and other health issues. In spite of the opportunity created forHCW, usage of the content remains relatively low. The primary barrier cited to usage of Mindset Health content was a lack of time and energy, with some HCW stating they would require a financial incentive to participate in further education and training both during work and after working hours (Howard, Deverell & Wilson-Strydom, 2007: conference paper). In the light of these challenges, proposals should therefore be placed on the table to address the identified challenges.

2.7.5 Proposals to address challenges faced by paediatric HIV related training

A new approach towards training is needed to meet the growing demand to care for the increasing number of clients with chronic conditions such as HIV and AIDS (Pruitt & Epping-Jordan, 2005:637). Currently limited integration of comprehensive paediatric HIV related training occurs within the FS DoH, with a number of short courses being presented. Comprehensive paediatric HIV related training is thus needed. These training programmes should consist of initial training, regular refresher training, on-the-job mentoring and coaching as well as systematic and regular supervision. Capacity would only be developed if theory and practice are included and reflection on practise is allowed (Lehmann & Zulu, 2005:45). The FS DoH's management already identified the need for nurses to be competent in VCT, IMCI, PHC, PMTCT and Sexually Transmitted Infections in 2005 (Steyn *et al.*, 2006:117). Although important programmes were highlighted with this decision, the need for working towards an integrated comprehensive paediatric approach in training was not recognized. However, a training course designed to address HIV infected adults needs were compiled by Lung Institute of the University of Cape

Town. The PALSA PLUS is an integration of the National TB Control Programme, ARV Treatment Programme, as well as elements of the revised Essential Drug List guidelines, VCT and PMTCT (Fairall, 2005:14). A similar training course targeting children, much like the IMCI, could form the basis for the implementation of an integrated comprehensive approach to paediatric HIV related training.

The South African Guideline for the Management of HIV infected Children clearly states what should be done at PHC level for HIV exposed children, as well as care needed for HIV positive children (South Africa, 2005a: 23, 24). These expectations can be used as a standard to identify paediatric training content for professional nurses. Whilst the FS DoH is still grappling with the creation of an integrated comprehensive paediatric HIV training programme for professional nurses, the African Network for care of Children Affected by HIV/AIDS (ANECCA) produced the ANECCA Comprehensive Paediatric HIV Care Curriculum. This generic paediatric HIV care training curriculum is used to train various categories of health workers in several countries in Africa. The training aims to build capacity for comprehensive paediatric HIV care and treatment on the continent (ANECCA, 2006). Table 2.3 compares desired paediatric HIV related training content needed in the South African context, with the training content currently being presented by the various paediatric HIV related training courses of the FS DoH. The standard used to decide as to what the training content should consist of has been derived from the South African Guideline for the Management of HIV infected Children. This guideline acts as national policy in SA, guiding HCW in their caring practices for HIV exposed and HIV positive children (South Africa, 2005a). Added to the South African guideline, the ANECCA Comprehensive Paediatric HIV Care Curriculum‘s content has also been incorporated in developing HIV related training content needed in the South African context.

TABLE 2.3: A comparison of desired paediatric HIV related training content needed in the South African context, with the training content currently being presented by the various paediatric HIV related training courses of the FS DoH

DESIRED TRAINING CONTENT (SOUTH AFRICA, 2005A; ANECCA, 2006)	COMPREHENSIVE HIV/AIDS CARE & MANAGEMENT	VCT	EPI	PMTCT	HIV/TB	IMCI – CASE MANAGEMENT	IMCI-COMPREHENSIVE
Overview of infection: epidemiology, biology of HIV, pathophysiology, history and progression of disease in children	All aspects, excluding history and progression of disease in children	Only Epidemiology		All aspects, excluding history and progression of disease in children			
Diagnosis of HIV	√			√	√		
Staging of disease	√				√		√
Paediatric HIV related diseases	√						√
Scheduling of follow-up visits	√						√
Nutritional support	√			√		√	√
Paediatric ART	√				Regime only	Regime only	√
Approach to Comprehensive Care for children living with HIV/AIDS						√	√
Prevention of HIV				√			
Counselling		√		√			
Social support							
Prophylaxis- provide co-trimoxazole					√	√	√
Growth and developmental monitoring					Only growth	Only growth	Only growth
Complete Immunisation schedule			√		Only BCG	√	√
Vit A supplementation/ iron			√		Only Vit A	√	√
Treatment for worms			√		√	√	√
HIV infected adolescent and adolescent HIV care service							
Facility and home based care/ palliative care						√	√
Setting up and management of comprehensive HIV services for children							

As can be seen from Table 2.3, none of the present training courses address all of the desired content of an integrated comprehensive paediatric training course. A discussion highlights what the desired training content entails with that present in the training courses.

- **A comprehensive approach to care for children**

It is only the *IMCI Case Management* and *Comprehensive IMCI* training courses that can boast in following a comprehensive approach of care to HIV-exposed and HIV-positive children. Comprehensive care is accomplished when the ten-point package for comprehensive care is available to children. Such a package consists of:

- Early detection of HIV status;
- Monitoring of growth and development;
- Routine health maintenance for example immunization;
- Early detection of infections;
- Counselling the mother/caregiver on nutritional care, hygiene and follow-up visitations;
- Disease staging of HIV-infected child;
- Offering ART to children when needed;
- Provision of psychosocial support to HIV-affected families and
- Referral for specialized care if needed (ANECCA, 2006:15).

- **An overview of HIV infection**

An overview of HIV infection should ideally consist of the epidemiology of the disease, biology and pathophysiology of HIV, as well as the history and progression of the disease in children (South Africa, 2005a; ANECCA, 2006). Three of the training courses present an overview of HIV infection to a more or lesser degree. The *Comprehensive HIV/AIDS Care Management* training course presents an overview of the epidemiology, biology and pathophysiology of HIV (World Health Organisation & UNICEF, n.d.). The *VCT* training course only addresses the epidemiology of the disease, with the *PMTCT* training course covering epidemiology,

biology of HIV and pathophysiology of the virus (South Africa, 2001; South Africa, n.d.-b).

- **Prevention of HIV**

When addressing prevention of HIV the prevention of primary infection should be highlighted over and above the prevention of unintended pregnancies among HIV infected women. Another aspect to be covered would be actions that can be taken to prevent mother-to-child transmission of the virus (South Africa, 2005a: 10, 11). It is only the *PMTCT* training course that addresses prevention of HIV. Emphasis is placed on antenatal care of HIV-positive women, prophylactic ART and safe nutritional practices in order to prevent mother-to-child transmission of the virus (South Africa, n.d.-b).

- **Counselling**

In order for HCW to be competent in conducting counselling of the mother or other caregivers, it would be necessary for them to conduct pre-test and post-test counselling according to the prescribed South African guidelines. They would have to be in a position to deal with a situation when the HIV result is negative, as well as when the result is positive (South Africa, 2005a: 112, 113). The *VCT* training course provide HCW the opportunity to become competent in the mentioned aspects of counselling and give special attention to the practicing of these skills (South Africa, 2001). Whilst the *PMTCT* training course only addresses the basic principles of counselling and also creates the opportunity to practice counselling skills (South Africa, n.d.-b).

- **Social support**

It is further necessary for HCW to be taught how to identify means and resources of care. They should know how to provide social support, whilst involving caretakers of children throughout the child's illness (South Africa, 2005a: 74; ANECCA, 2006:27).

None of the current paediatric HIV-related training courses presented by the FS DoH's, content covers social support to HIV-exposed and HIV-infected children.

- **Diagnosis of HIV**

In SA laboratory tests are used to diagnose HIV-infection in children. HCW should therefore be well informed as to when the ELISA (Enzyme-linked Immunosorbent Assay) technique is indicated and when the HIV DNA PCR (Deoxyribonucleic Acid Polymerase Chain Reaction) is to be used (South Africa, 2005a: 12). The *Comprehensive HIV/AIDS Care and management* training course and *PMTCT* training course follow the national guideline and make a distinction as to when the ELISA and DNA PCR is to be used (Vanqa, 2008: personal communication; South Africa, n.d.-b: 43). The *HIV/TB* training course do discuss the various tests that could be used to diagnose HIV in children, but are more vague as to when a specific test is indicated (South Africa, 2006a: 49).

- **Staging of the disease**

HCW need to be able to perform a clinical staging of HIV-infection on a child according to the WHO's 4-stage system. The clinical staging assists in determining the prognosis of the child and provides guidance as to when ART is to be initiated to the child. Staging further strengthens the clinical diagnosis when laboratory testing is delayed (South Africa, 2005a: 19). The *Comprehensive HIV/AIDS Care and Management* training course, *HIV/TB* training course and *Comprehensive IMCI* training course use the WHO' 4-stage system to train HCW in staging HIV disease (South Africa, 2006a: 26; Vanqa, 2008: personal communication; and World Health Organisation & UNICEF, n.d.: 9).

- **Paediatric HIV-related diseases**

Paediatric HIV-related diseases refers to common infections in children such as pneumonia and diarrhoea, as well as opportunistic infections that occur in children due to their HIV-positive status. HCW should also be in a position to identify and treat (or refer) other clinical conditions that may occur in these children, for example failure to thrive or HIV-skin conditions (South Africa, 2005a: 32-75; ANECCA, 2006:24). Both the *Comprehensive HIV/AIDS Care* and *Management and Comprehensive IMCI* training courses do cover the identified paediatric HIV related diseases in their training (Vanqa, 2008: personal communication; World Health Organisation & UNICEF, n.d.).

- **Prophylaxis: Co-trimoxazole**

The reason for providing Co-trimoxazole, the target group who would benefit from it as well as the time period of dosaging and the dosage itself are important aspects HCW should be aware of (South Africa, 2005a: 40, 41). The *HIV/TB* training course and both *IMCI* training courses reflect the same content as the national guideline, with only the *HIV/TB* course adding what the benefit of Co-trimoxazole prophylaxis to child would be (South Africa, 2006a: 49; South Africa, 2008a; and World Health Organisation & UNICEF, n.d.).

- **Scheduling of follow-up visits**

Whether on ART or not, HCW should know when to schedule follow-up visits for HIV-exposed and HIV-positive children, as well as what should be done during these visits (South Africa, 2005a: 79, 80). The *Comprehensive HIV/AIDS Care* and *Management and Comprehensive IMCI* training courses do provide guidance to HCW as when to schedule follow-up visits and what actions should be performed during these visits, with the same content being reflected in both training courses (Vanqa, 2008: personal communication; World Health Organisation and UNICEF, n.d.).

- **Growth and developmental monitoring**

HCW should further have knowledge of how to perform growth and developmental monitoring on HIV-infected children and especially how to interpret the Road-to-Health Chart used in the South African context for this specific purpose (South Africa, 2005a: 20; ANECCA, 2006:15). The *HIV/TB* training course only addresses growth monitoring, but omit to address developmental monitoring (South Africa, 2006a:71). Both *IMCI* training courses also only concentrate on growth monitoring and the interpretation of the Road-to-Health Chart, without including developmental monitoring of children (South Africa, 2008a: 51; World Health Organisation & UNICEF, n.d.: 6).

- **Nutritional support**

Since HIV disease is associated with nutritional deficiencies, the HCW need to assist the mother to make safe infant feeding choices and to be able to care for malnourished children. Feeding problems that occur due to disease specific conditions, such as sores in the mouth, need also to be addressed (South Africa, 2005a: 26-31; ANECCA, 2006:33). Again both *IMCI* training courses provide the necessary guidance for HCW to do exactly that (South Africa, 2008a: 49; World Health Organisation & UNICEF, n.d.: 25,26). The *PMTCT* training course addresses safe infant feeding choices in great depth, but does not cover the handling of malnourishment or feeding problems that often occur with HIV-infected children (South Africa, n.d.-b: module 6-9).

- **Complete immunization schedule**

Since HIV-exposed and HIV-positive children need to receive all vaccinations according to the national immunization schedule; it is of utmost importance that HCW are knowledgeable on this routine health maintenance procedure (South Africa, 2005a: 21; ANECCA, 2006:15). The *HIV/TB* training course only address BCG vaccination, with both *IMCI* training courses covering the full immunization

schedule that (South Africa, 2008a: 74; World Health Organisation & UNICEF, n.d.: 8). .

- **Vit A / Iron Supplementation**

Vitamin A and iron supplementation forms part of the national immunization schedule, with HIV-infected children also benefiting from this supplementation (South Africa, 2005a: 21). As with the immunization schedule previously discussed, the *HIV/TB* training course do not cover all content, only highlighting Vit A supplementation (South Africa, 2006a: 69). The *IMCI* training courses address Vit A and iron supplementation as part of the immunization schedule, indicating time interval and dosage (South Africa, 2008a: 74; World Health Organisation & UNICEF, n.d.: 8).

- **Treatment for worms**

HCW need to be able to offer routine treatment for worms and be able to provide the correct dosage at the correct interval (South Africa, 2005a: 22; ANECCA, 2006:15). Since de-worming forms part of the immunization schedule, the *IMCI* training courses and the *HIV/TB* training course have addressed this aspect, thus empowering HCW to successfully treat worms (South Africa, 2006a: 71; South Africa, 2008a: 74; and World Health Organisation & UNICEF, n.d.: 8).

- **Paediatric ART**

In order for HCW to be involved in paediatric ART services, they need to understand the pharmacological principles of ART, know how to prepare and initiate children for treatment and how to monitor drug taking and thus ensure adherence to the drugs (South Africa, 2005a: 76-95; ANECCA, 2006:20). All the mentioned aspects have been included in the *Comprehensive HIV/AIDS Care and Management* and *Comprehensive IMCI* training (Vanqa, 2008: personal communication; World Health Organisation & UNICEF, n.d.: 50-51). Whereas the *HIV/TB* and *IMCI Case*

Management training courses have only reflected the ART regimes (South Africa, 2006a : 68; South Africa, 2008a: 63).

- **HIV infected adolescent**

Although none of the training courses presently presented by the FS DoH reflect any content on the care of the HIV-infected adolescent, HCW should ideally be able to provide health care to this group of individuals. Aspects HCW should be knowledgeable on is the epidemiology of the disease in this group, their growth and development, the need for reproductive health services for those infected with HIV and the ability to impart life skills to the adolescent in order to strengthen drug adherence (ANECCA, 2006:25).

- **Facility and home based care/ palliative care**

HCW need to promote and strengthen palliation as a critical component of care. This can only happen when HCW know what is expected of them and they have the knowledge and skills to deliver care to HIV-exposed and HIV-positive children. They would then be in a position to advise affected families on how to care for these children (South Africa, 2005a: 16; ANECCA, 2006:36). It is only the *IMCI* training courses that make an effort to structure facility care and place emphasis on how to involve caregivers in the palliative care of their children (South Africa, 2008a: 82; World Health Organisation & UNICEF, n.d.: 23-29).

- **Setting up and management of comprehensive HIV services for children**

As was the case with the HIV-infected adolescent, none of the training courses presently presented by the FS DoH reflect any content on the setting up and management of comprehensive HIV services for children. Aspects to be covered in this component of the training would be the identification of clear entry points for children, the referral mechanism to be in place to ensure comprehensive care, the

various components of a comprehensive service to children, what the health support system would consist of and how monitoring and evaluation of the service would be conducted (ANECCA, 2006:37).

The investigation into paediatric HIV related training presented by the FS DoH for professional nurses are hereby concluded. A background to paediatric HIV related training has been given. It was followed by a discussion of training courses presented, emphasizing the content covered by each training course. The challenges faced by these training courses have been highlighted and proposals made as how these challenges could be addressed. A standard has been proposed as to what the content of an integrated comprehensive paediatric HIV related training course in SA could be and current training courses presented by the FS DoH have been measured against the proposed standard.

CHAPTER 3

Nominal group discussions

3.1 INTRODUCTION

This chapter deals with Phase 1b of the study and will be set out as follows. Firstly a discussion will be done of the methodology concerned. The methodology refers to the research design, analysis unit, research technique, data collection, data analysis, trustworthiness of the study and ethical considerations taken into account during this phase of the study. Then a discussion of the research findings will follow together with specific recommendations regarding the findings. Finally a discussion of the possible limitations of this phase of the study will be presented.

Figure 3.1 below places the chapter and Phase 1b in the context of the study. Phase 1b followed on Phase 1a, the phase where data was gathered in order to describe the health care services rendered to HIV exposed and HIV positive children in public health sector of the Free State.

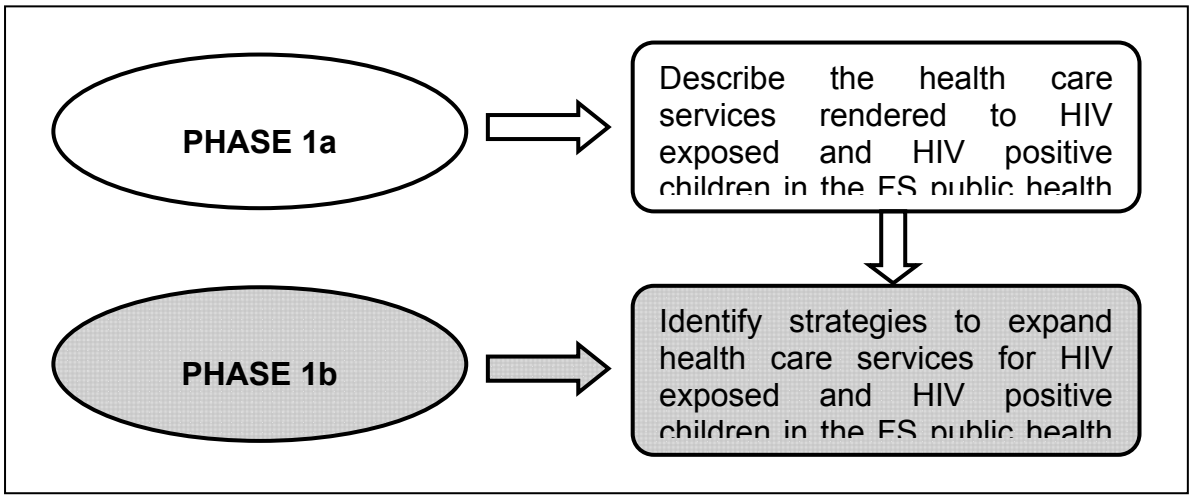

FIGURE 3.1: Placement of content of chapter 3 in the study – Phase 1b

The initial feedback on data obtained during Phase 1a of the study was given to a group of stakeholders. The group consisted of representatives from management structures of various programmes developed by the FS DoH to render health care services to the children in question, as well as representatives from other important stakeholders outside the DoH who are also involved in care for the children. The feedback was given directly prior to the process of obtaining stakeholders' input in order to identify strategies to expand health care services of the children.

The methodology put into practise in Phase1b will now be discussed, by looking at the research design for this phase.

3.2 RESEARCH DESIGN

The term *"research design"* is generally interpreted in two ways. It is mostly seen as a logical strategy or blueprint for gathering evidence regarding a research question (Burns & Grove, 2005:211; De Vos *et al.*, 2005:389). Reflecting on suitable strategies in order to deal with a specific research problem before embarking on the study itself will enhance its integrity since factors that could interfere with the validity of the findings can be eliminated in advance (Burns & Grove, 2005:211; Polit & Beck, 2006:509). The second interpretation of the term *"research design"* refers to the structural framework within which a study is implemented: thus the idea of designing a study in the broadest sense of the word is invoked (Burns & Grove, 2005:211; De Vos *et al.*, 2005:132; and Uys & Basson, 2005:37-38). In health care research such a framework will be the set of decisions regarding the topic to be studied, the population studied, the research methods employed and the purpose of the study (Babbie, 2007:112).

The research design is at its most efficient if it yields the knowledge required in the simplest and cheapest way, all the while being acceptable to both researcher and participant. If it is kept as methodologically *"tight"* as possible, the research design increases the probability that results will be accurately reflect reality (Burns & Grove, 2005:211; De Vos *et al.*, 2005:389). The researcher used health systems research as the vehicle to accomplish above mentioned outcomes.

3.2.1 Health System research

Health system research is practised when a researcher is concerned with enhancing the health of people and communities, by improving the effectiveness of the health system, with full involvement of the relevant partners (Varkevisser *et al.*, 2003:16). The researcher's task is thus to utilize this type of research to provide information to health managers (always with their involvement), so they can make appropriate decisions on health related problems they face. The policy options and practical information provided are the reason why health systems research is seen as applied[4] research.

Although all health systems research eventually informs policy, it can be divided into two broad categories, namely operational research and health policy research. *"Operational research"* is the term used when examining the service delivery of health services and is not relevant to this particular study. On the other hand, the second category is indeed applicable. Health policy research, as a type of health systems research, aims at informing higher levels of health policy choices (Barron *et al.*, 1997:4-5; Varkevisser *et al.*, 2003:21). It should therefore be made clear how the researcher identified strategies to expand health care services for HIV exposed and HIV positive children in the FS public health sector.

In order to do this the concepts *"unit of analysis", "population"* as well as *"sample"* and *"sampling"* will be explained and related to the study.

3.3 UNIT OF ANALYSIS

A unit of analysis is the basic unit or focus of analysis, thus relating to the *"what"* or *"whom"* that is being studied. Most typically the units of analysis are individuals, but they could also be groups or organizations (De Vos *et al.*, 2005:104; Uys & Basson, 2005:87; Polit & Beck, 2006:512; and Babbie, 2007:94). When the unit of analysis is

[4] Applied research generates knowledge that directly improves practice

a group or an organization, it is customary to talk about a *"population"* and there are specific criteria that hold.

3.3.1 Population

It is possible to speak about a population when a group includes all individuals, objects or events with some common characteristic. Should such a group meet the sample criteria for inclusion in the study, it is sometimes referred to as the *"target population"* (Burns & Grove, 2005:746; De Vos *et al.*, 2005:193; Uys & Basson, 2005:86; and Polit & Beck, 2006:506). It is possible that conclusions can also be drawn from such a group (Babbie, 2007:111). It is further important to identify a population appropriate to the specific study, based on their expertise on the matter and not merely on their accessibility (Potter *et al.*, 2004:127; Berg, 2007:40).

In this study representatives were purposefully selected, on the ground of them providing care to HIV exposed and HIV positieve children. Therefore representatives from three chief directorates within the Strategic Health Programme of the FS DoH, as well as from other important role-players in providing care to HIV exposed and HIV positive children made up the population. Figure 2.1 depicts an adaption of the Strategic Health Programmes Chief Directorate, simultaneously indicating directorates and sub-directorates resorting under it. The three directorates in question were the HIV and AIDS/STI & CDC Directorate; the TB Management Directorate and the Health Programmes & Non-Communicable Disease Directorate. They were chosen to form part of the population as all of them shared the common characteristic of giving some form of care to the children in question. As has been said, the representatives were managers of various programmes within their identified directorates and their representation was constituted in the following way:

- HIV and AIDS/STI & CDC Directorate (4) – One representative each from the:
    - Directorate;
    - Comprehensive HIV & AIDS Management Sub-Directorate;
    - Partnership Sub-Directorate; and
    - Communicable Diseases Control Sub-Directorate

- TB Management Directorate (4) – One representative each from the:
    - Directorate;
    - Advocacy and Social Mobilization and Training Sub-Directorate;
    - Technical and Clinical Support Sub-Directorate; and
    - Clinical Advisory Services Sub-Directorate
- Health Programmes & Non-Communicable Disease Directorate (3) – One representative each from the:
    - Directorate;
    - Nutrition & Child Health Sub-Directorate; and
    - Reproductive Health Sub-Directorate.

An additional four representatives from other important stakeholders who are also involved in providing care to these children also formed part of the population. These stakeholders consisted of a medical officer, researchers doing related research and a representative of a private sector paediatric HIV service.

The population for this study therefore consisted of fifteen representatives in total, eleven from the Strategic Health Programmes Chief Directorate and four others from stakeholders outside the Directorate. The selection of the population was suitable for this study as all representatives had the interest of HIV-exposed and -infected children at heart (Delbecq *et al.*, 1975 80).

Another important concept regarding units of analysis is that of sampling which will now be discussed in brief.

3.3.2 Sampling

The term *"sample"* is used to refer to a subset of a population that is selected for a specific study (Burns & Grove, 2005:750; De Vos *et al.*, 2005:194; and Polit & Beck, 2006:509) and the term *"sampling"* is used to refer to the process through which the sample is taken from the population (Uys & Basson, 2005:87). Due to the fact that the size of the population in the study was very small, no active sampling was done. All managers of the three directorates within the Strategic Health Programmes as

well as the representatives from other stakeholders that were available were invited to take part in the study. However, from the eleven managers within the Strategic Health Programmes only seven were available to participate in the research. The representatives from all four other stakeholders were able to take part. The *"response rate"* of 73% compares well with the generally accepted satisfactory response rate of 70% to written surveys (Dobbie, Rhodes, Tysinger & Freeman, 2004:403). Table 3.1 gives an outline of the composition of the population and the actual participants of Phase 1b of the study.

TABLE 3.1: Population and actual participants in Phase 1b

ORIGIN OF STAKEHOLDERS	POPULATION	PARTICIPANTS IN STUDY
Strategic Health Programmes Chief Directorate	11	7
Other stakeholders	4	4

The discussion will now turn to the specific research technique followed and its strengths and limitations.

3.4 RESEARCH TECHNIQUE

In this phase of the study the so-called Nominal Group Technique (NGT) developed by Andre Delbecq and Andrew Van de Ven in 1968 was followed in order to propose strategies for expanding health care services for HIV exposed and HIV positive children in the FS public health sector (Delbecq *et al.*, 1975:7).

The word *"nominal"* suggests that although participants are in a group setting when this technique is followed, they are not allowed to interact directly with one another, therefore the groups are nominal – in name only (Ihuseman *et al.*, 2000: online; Macphail, 2001:164; and Taylor-Powell, 2002: online). In fact, the NGT is an interview technique allowing structured group work to take place, while obtaining input from several people on a particular problem or issue. Participants work in the presence of one another, but write down ideas independently from another rather than voicing them to the whole group. This idea-generating strategy acts as a consensus-planning tool that helps to prioritise issues according to a prescribed

sequence of problem-solving steps (Delbecq *et al.*, 1975:33; Sample, 1984: online; University of Vermont, 1996: online; Center for Rural Studies, 1998: online; Ihuseman *et al.*, 2000: online; Macphail, 2001:162; Taylor-Powell, 2002: online; and Potter *et al.*, 2004:126). A *"third party"* is included in the process in order to identify and rank issues identified by the group (Delbecq *et al.*, 1975:8; Debold, 1996: online). The suggested size of a group of participants is five to ten and such a meeting usually lasts up to two hours (Delbecq *et al.*, 1975:69; Taylor-Powell, 2002: online; Potter *et al.*, 2004:126). Figure.3.2. below indicates the flow of the NGT.

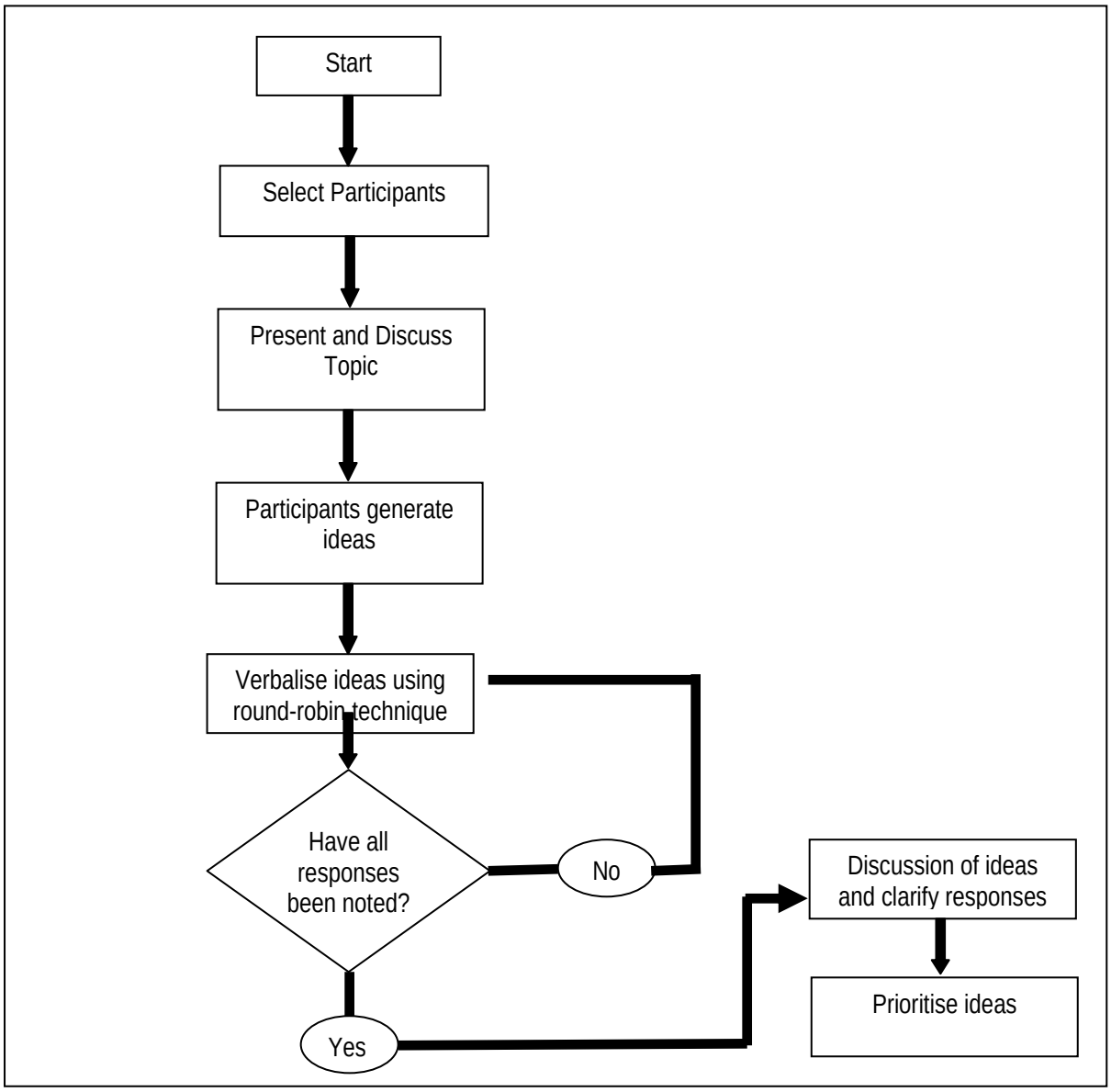

FIGURE 3.2: Flowchart for the Nominal Group Technique

From Figure 3.2 it is clear that participants in the NGT have to be selected. In this particular study the selection process was done when the population was chosen and sampling (albeit not active) was done. In the next step, the researcher gave feedback regarding Phase1a of the study. That is, the current status of health care services rendered to HIV exposed and HIV positive children was outlined prior to the actual group discussion. Participants were then given the opportunity to generate ideas, which were verbalized using the round-robin technique. When all responses of the participants had been noted down, their ideas were clarified. The prioritization of ideas at the end of the discussion informed the researcher's report on planned strategies. Since the NGT provides both quantitative data in the sense of voted-upon priorities and qualitative data in the terms of rich, descriptive discussions taking place during the course of the nominal group activity (Delbecq & Van de Ven, 1971:477).

The study clearly benefited enormously from the strengths inherent to nominal group discussions. Some of the aspects of the NGT that can enhance studies in health systems research are discussed below.

3.4.1 Strength of nominal group discussions

Sharing ideas leads to pooled judgments, thereby creating a greater number and breadth of ideas than would have been the case in interacting groups. Because many ideas are generated in a short span, the NGT promotes a sense of involvement and motivation within the group of participants and, in so doing each person's knowledge and experience is put to use (Delbecq & Van de Ven, 1971:473; Delbecq *et al.*, 1975:81; University of Vermont, 1996: online; Dunham, 1998: online; Ihuseman *et al.*, 2000: online; Taylor-Powell, 2002: online; Dobbie *et al.*, 2004:405; Jones, 2004:23; and Mycoted, 2007: online). The way in which ideas are generated counters the reluctance participants may have to express uncommon views and prevents single ideas from being pursued at the expense of other more important topics (Trickey, Harvey, Wilcock & Sharp, 1998:195). Creative thinking is further stimulated and effective dialogue allows for clarification of ideas (University of Vermont, 1996: online).

The *"round robin"* element encourages participants to contribute and provides *equal opportunities for contribution to all*. Every participant also has an equal say in generating ideas and in ranking or ordering the items when prioritization takes place (Delbecq *et al.*, 1975:9; Sample, 1984: online; Center for Rural Studies, 1998: online; Ihuseman *et al.*, 2000: online; Macphail, 2001:162; Dobbie *et al.*, 2004:402; and Mycoted, 2007: online). Presenting equal opportunities balances participation and reduces the pressure to conform to the dominant group opinion (Delbecq & Van de Ven, 1971:474; Dunham, 1998: online; Ihuseman *et al.*, 2000: online; and Dobbie *et al.*, 2004:405).

Group dynamics further allows participants to reduce the conforming influence common face-to-face meetings can have (Dunham, 1998: online). It further encourages participants to confront issues on a problem-solving basis rather than on a personal-assault basis (Dunham, 1998: online). All of this makes it possible for the group to reach consensus faster (University of Vermont, 1996: online; Center for Rural Studies, 1998: online).

The *NGT process* does not allow verbal interaction between participants even though all dimensions of a problem are being identified in the process. The fact that no evaluation is made initially, creates a freer climate. When evaluation is done prematurely some dimensions of a problem may be overlooked (Delbecq & Van de Ven, 1971:474; Ihuseman *et al.*, 2000: online). The process also allows for anonymous voting, thus protecting group participants (Sample, 1984: online). In addition, researcher bias is minimized due to the highly structured nature of the process, which makes it unlikely that the procedure would differ significantly between groups (Macphail, 2001:162; Potter *et al.*, 2004:127).

Results are also *easily interpreted* since the ideas are generated, ranked and evaluated during the session. No need therefore exists for participant validation, as they themselves have weighted the importance of statements in the process of engaging in the NGT (Macphail, 2001:162; Jones, 2004:23).

A *high satisfaction rate* occurs amongst *participants* of the NGT due to the sense of closure participants experience when they accomplish immediate results with this technique (Delbecq *et al.*, 1975:78; Dunham, 1998: online; Jones, 2004:23; and Potter *et al.*, 2004:127).

The fact that *limited resources are needed and time is used efficiently* is another strength of this technique. In fact, minimal pre-meeting preparation is required of participants, and their input is limited to a single meeting lasting up to only two hours. Task completion is further accomplished and results are immediately disseminated to the group (Delbecq & Van de Ven, 1971:477; Dobbie *et al.*, 2004:405; Jones, 2004:23; and Potter *et al.*, 2004:126).

However, the NGT does have certain limitations.

3.4.2 Limitations of nominal group discussions

The limitations of the NGT already identified in literature will be discussed as well as how these limitations could have impacted on the study.

The NGT cannot be used spontaneously, as it requires extensive advance *preparation* (Delbecq *et al.*, 1975:34; Dunham, 1998: online). *Time commitment* is also required from participants and the necessity for them to attend a specific location at a given time may limit participant numbers (Delbecq *et al.*, 1975:81; Bezruchka, 1998: online; and Jones, 2004:24). Since the session during which the NGT was put to use was planned in collaboration with the DoH (and therefore not a spontaneous event), the researcher had sufficient preparation time. Time commitment from participants could have influenced participants' attendance, but did not impact on the number of participants who partook in the discussion, since a secundi for a representative of a specific sub-directorate within the FS DoH attended the discussion.

Participants need to be in agreement with the *structured nature of the NGT*. It is necessary for them to feel comfortable with a process that may appear very rigid and mechanical. Not all participants may be receptive to expressing their ideas in writing and to then communicate them verbally to the group (Delbecq *et al.*, 1975:34; Sample, 1984: online; University of Vermont, 1996: online; Dunham, 1998: online; and Jones, 2004:24). Due to the structured nature of the technique it is limited to a single-purpose, single-topic meeting, making it difficult to change topics in the middle of a meeting (Delbecq *et al.*, 1975:34; Dunham, 1998: online; and Jones, 2004:24). The structured nature of the discussion was explained to participants and their consent to taking part in the discussion was obtained prior to the discussion. Participants were also free to withdraw from the discussions at any time. The single topic discussion suited the study, aiding the group to identify strategies to expand health care services for HIV positive children.

The limitation imposed on the *generation of ideas* only to the meeting itself may be seen as a limitation to nominal group discussions (Jones, 2004:24). One could also feel that cross-fertilization of ideas may be constrained (Sample, 1984: online; Bezruchka, 1998: online) It is possible that an overlap of ideas due to unclear wording or inadequate group discussion may occur, or that opinions may not converge in the voting process (Sample, 1984: online; University of Vermont, 1996: online). A lack of anonymity may also limit participants' willingness to express their views (Jones, 2004:24).

The concern raised about fore mentioned concerns was addressed as follows during the study. It is so that the structure of NGT did not allow participants to add any ideas after completion of the discussion. The facilitator used the *"round robin"* technique to ensure that all participants had the opportunity to add on to the strategies proposed by others, thus limiting the possible constraining of ideas. During the discussion of ideas, clarification of concepts took place and misunderstandings were eliminated in the process. Participants' feedback on small index cards was shuffled, making it impossible to link a response to a specific participant. This addressed participants' possible unwillingness to express their views due to a lack of anonymity. Participants were given the opportunity to prioritise strategies from all the proposed strategies. Though not all strategies received a vote, all strategies were

incorporated in the analysis of the data and therefore all opinions were taken into account.

The c*omposition of a group* may limit participation as a minimal level of education is needed to take part in discussions (Bezruchka, 1998: online). It is further possible that *"knowledgeable"* individuals selected to participate may not represent who they are supposed to represent (University of Vermont, 1996: online). This possible limitation of the NGT identified in the literature had no impact on the study, seeing that professionals who took part in the study were able to follow procedures. The participants of the study were true representatives who were directly involved in rendering health care services to HIV exposed and HIV positive children.

The *data* analysis of the qualitative aspect, is a time consuming process due to the volume of information collected and the nature of the analytical procedures required (Potter *et al.*, 2004:127). In spite of the volume of collected data, the limited nature of data (in terms of number of respondents) often requires a follow-up survey or other quantitative methodology prior to making final decisions about an issue. Results obtained can also not be generalized to the wider population due to the specific characteristics of the participants - both in terms of who is nominated to attend and who agrees to participate (Jones, 2004:24). Although the qualitative data analysis is time-consuming, the structured guidelines Van Breda (2005) provides what was followed in this study, considerably speeds up this process. Because quantitative data gathered during Phase 1a of the study informed participants prior to the nominal group session of health care services rendered to HIV exposed and HIV positive children in the FS DoH the proposed strategies to expand services to these children were thus well informed. It was not the aim of the study to generalise results, but to address health care services rendered to the children in the FS DoH. Managers of the various programmes giving care to these children were involved and are in a position to influence implementation of proposed strategies.

Applying the NGT successfully requires a skilled *facilitator* (University of Vermont, 1996: online) This person should be an expert on the topic for discussion or a credible non-expert. The facilitator must also be familiar and comfortable with the group meeting process so that quality leadership can be provided (Delbecq *et al.*,

1975; Potter *et al.*, 2004:127). It requires someone who has the ability to impose structure in a non-threatening way and during the clarification phase the facilitator must be able to move the discussion along briskly, without imposing on anyone's feelings (Delbecq *et al.*, 1975). The facilitator was a highly accredited researcher and expert in the field of HIV and had already facilitated several nominal group discussions before. She was therefore capable of facilitating the discussions in an amicable way.

Before commencing any data collection an explorative interview is usually conducted.

3.5 EXPLORATIVE INTERVIEW

An explorative interview poses the opportunity for the researcher to have a small scale exercise of the data collection process. The chance to ensure that the question posed to participants is clear and stimulating and will allow participants to make meaningful contributions is guaranteed in this way (Thomas in Potter *et al.*, 2004:127). The identified population of this phase of the study were the only participants who could partake in the discussion and therefore an explorative interview could not take place. In order to meet the requirement of pre-testing the question, the question was posed to colleagues to clarify their understanding of the question (Bezruchka, 1998: online; De Vos *et al.*, 2005:331). Their response satisfied the researcher that the desired information would be collected during the nominal group discussion. After having ensured a workable question would be at hand, the data collection process commenced.

3.6 DATA COLLECTION PROCESS

The nominal group discussion was held at a venue on the campus of the University of the Free State. A date was convened in collaboration with the relevant stakeholders six weeks prior to the week day morning of the discussion. The discussion was held in November 2008. Invitations sent to prospective participants explained the nature of the discussion and a copy of the permission form (Addendum

C) from the head of the FS DoH was attached to the invitation. The invitation indicated that the invitation was not addressed to a specific person, but to a representative from management from the programme in the directorate or sub-directorate to whom the invitation was addressed.

After ensuring all invitations were delivered, preparation for the nominal group discussion had to be done.

3.6.1 Preparation for the nominal group discussion

Nominal group discussions have to be conducted in a *meeting room* large enough to accommodate participants at individual tables. These tables need to be placed in a U shape, with a flip chart at the open end of the U (Delbecq *et al.*, 1975:41; Dunham, 1998: online). The venue used was large enough for the eleven participants. It was also possible for participants to work in silence, free from any environmental distraction. Figure 3.3 illustrates the seating arrangements for the nominal group session. As can be seen a laptop and screen was added to the conventional using only of a flip chart.

The structured nature of the NGT necessitated specific *supplies*. Each table and therefore each participant received a file containing a pack of 5 index cards with paper and a pen. A consent form to partake in the research was also included in each file. Tables were further provided with bottled water and sweets. At the open end of the U shape a flip chart and its stand was placed, as well as mark pens and Prestic (Delbecq *et al.*, 1975:41; Bezruchka, 1998: online; Dunham, 1998: online; and Taylor-Powell, 2002: online). A laptop and screen were added to the open end of the U formation.

With preparation completed, the nominal group discussion itself could get underway.

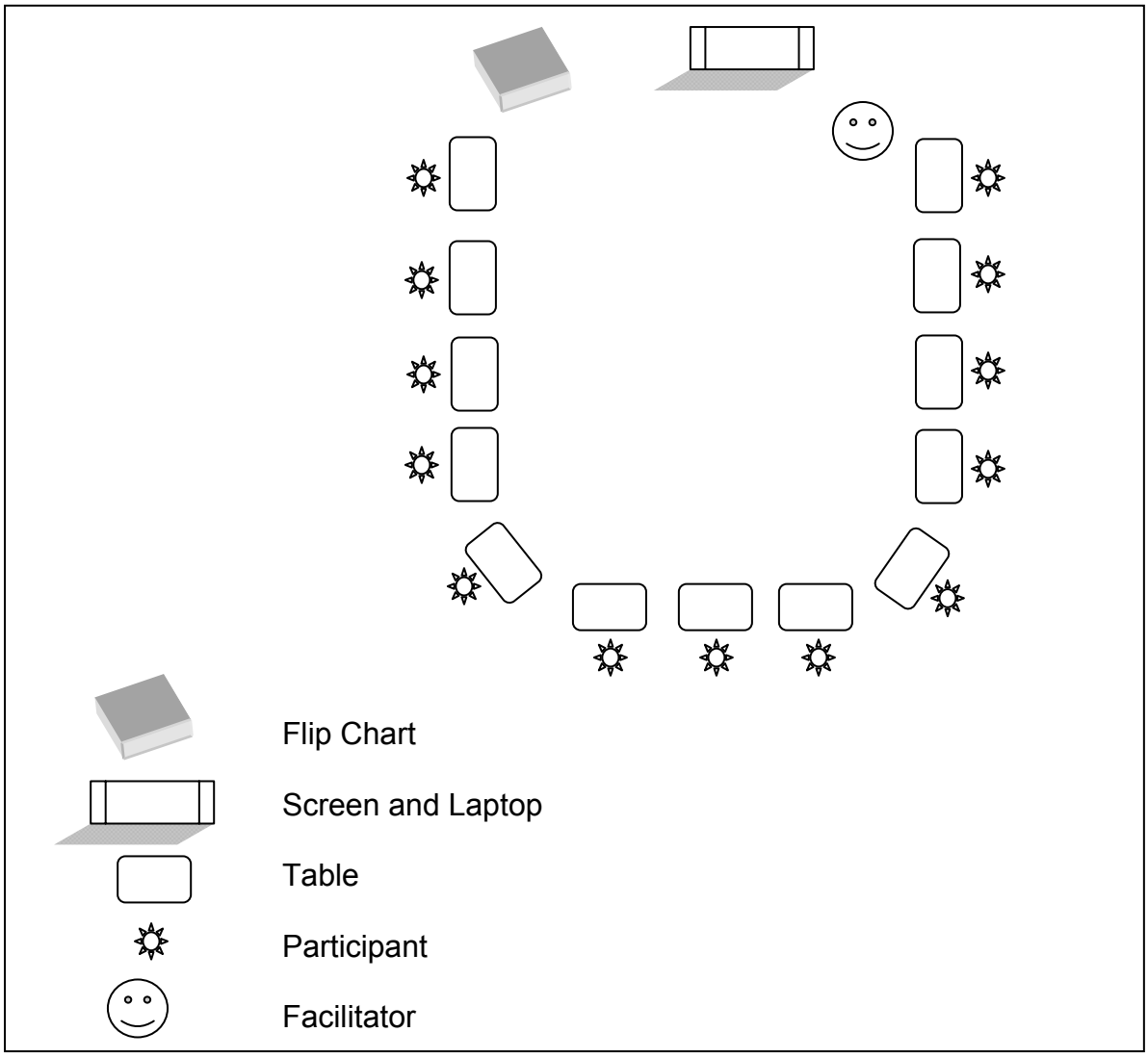

FIGURE 3.3: Seating arrangements for the Nominal Group Discussion

3.6.2 Conducting the nominal group discussion

The facilitator's *opening statement* included various aspects. After a warm welcome, a brief power point presentation clarified participants as well as a brief explanation of the steps to be followed during the nominal group discussion. The importance of each participant's contribution was stressed. The group's objectives were clearly outlined as well as how the group's output would be used (Delbecq *et al.*, 1975:43; Dunham, 1998: online; and Taylor-Powell, 2002: online). The researcher then gave participants the opportunity to complete the consent forms (See Addendum B).

The facilitator followed the four steps of nominal group discussion as described by Dunham (1998: online) when conducting the discussion.

STEP 1: Generating ideas in silence (5-10 min)

The facilitator presented the nominal question to the group on a power point slide and followed the slide up by verbally reading the question (Taylor-Powell, 2002: online). The question read as follows: *"Propose strategies to expand health care services for HIV exposed and HIV positive children in the Free State public health sector".* Participants were asked to write proposed strategies as brief statements on paper provided. Emphasis was placed on participants silence and independent working. Any disruption of the silence or tendency not to work independently was sanctioned and addressed to the group as a whole. The facilitator illustrated the level of abstraction and scope desired with an example, which did not lead participants' responses. In this way she could simultaneously model good group behaviour (Delbecq *et al.*, 1975:67; Sample, 1984: online; and Taylor-Powell, 2002: online). Participants were requested to indicate when they were finished by putting their pens down, allowing the round-robin technique to be used.

STEP 2: Verbalizing ideas, using round-robin technique (20-40 min)

The facilitator indicated the objective of step two was to map the group's thinking. Participants were asked to present ideas as brief words, allowing a process of one idea serially taken from each participant. Participants were told they may pass when no further items could be added, but that they may *"re-enter"* at a subsequent turn with an idea. Participants were encouraged to *"hitchhike"* new ideas, even if it was not on the participant's own original list of ideas. However, combining ideas was discouraged, unless they were exactly the same. It was the responsibility of the participants to decide whether items were duplicates or not. No discussion of ideas was allowed prior to completion of listing, including questions for clarification. The discussion continued until all ideas were depleted (Delbecq *et al.*, 1975: 67; Sample, 1984: online; and Taylor-Powell, 2002: online).

Quick effective mechanical recording posed to be a challenge with many (46) statements put forward by participants. The researcher assisted the facilitator by recording statements as rapidly as possible on a flip chart, using words used by participants themselves. A colleague simultaneously recorded the statements on a computer, linked to an overhead screen. Utilizing the additional resource ensured that the entire list was visible to all participants (Delbecq *et al.*, 1975:68). Having the list of statements available to all participants enabled a productive discussion of ideas to take place.

STEP 3: Discussion of ideas (20-40 min)

The facilitator explained that step three was primarily for clarification of ideas (Delbecq *et al.*, 1975:8). It was not expected of the participant who was originally responsible for an item to clarify the item. It could have been done by any other person. The facilitator also emphasized that final judgments would be expressed by voting and therefore the merit of ideas were not discussed. The facilitator was challenged to pace the discussion so that all ideas received sufficient time for clarification (Delbecq *et al.*, 1975:68). With participants being clear on the meaning of listed ideas, they were in a position to prioritize ideas.

STEP 4: Prioritizing ideas (20-40 min)

During step four voting on priority ideas took place, with the group decision being mathematically derived through rank ordering (Delbecq *et al.*, 1975:8). Participants were asked to select five priority items from the entire list. They were asked to place each priority item on a separate 3 x 5 card. Each of the five items then had to be rank - ordered one at a time. A score of five had to be allocated to the highest priority, decreasing the score to one for the item with the lowest priority. The score was indicated in the upper right-hand corner of the card. The facilitator collected the cards and shuffled them to retain confidentiality (Delbecq *et al.*, 1975:68; Sample, 1984: online).

The researcher had in the meantime prepared a tally sheet on the flip chart, as well as on the computer, consisting of four columns. Table 3.2 gives an example of the tally sheet used during the NGT.

TABLE 3.2: Example of tally sheet used during NGT

ALLOCATED NUMBER	IDEA/ STATEMENT GENERATED	SCORES ALLOCATED	TOTAL SCORE
1.	All personnel trained and refreshed in HIV component of IMCI *PN, Aux Dr,*	3, 4, 1	8
2.	Decentralization of paediatric ART to PHC facilities *All facilities to be paediatric ART treatment sites Medications should be available at pharmacy of local clinic*	5, 5,	10

These columns respectively reflected the numbers allocated to ideas generated during the round-robin technique, the idea/statement generated by participants, a column reflecting scores allocated to each statement and lastly a column reflecting the total score of a specific statement. The voting and recording of results was done with the participants assistance (Delbecq *et al.*, 1975:68; Sample, 1984: online). Data analysis could then commence, using the provided semi-quantitative, rank-ordered feedback from the participants (Dobbie *et al.*, 2004:402).

3.7 DATA ANALYSIS

Data analysis refers to the systematic organization and synthesis of research data, which allows the researcher to reduce, organize and give meaning to data (Burns & Grove, 2005:733; Polit & Beck, 2006:498). Although the NGT can be seen as a mixed method approach, using qualitative and quantitative methods in the analysis and reporting of results, the emphasis in this study will mainly fall on the analysis of the qualitative data provided by participants (Potter *et al.*, 2004:128). Patton (in De Vos *et al.*, 2005:333) states that "*qualitative analysis transforms data into findings*", which is what the researcher aimed to accomplish.

The researcher was assisted in the process of analyzing the data and therefore the findings, in that participants already listed all possible strategies to expand health care services for HIV exposed and HIV positive children during step two of the nominal group discussion. Step three allowed clarifications of proposed ideas, with step four prioritizing these ideas. The analyses of data had to be taken a step further.

The researcher then adapted the guideline van Breda (2005:4-11) proposed to analyze multiple NGT data, to analyze the data of a single NGT - as was the case in this study. This was possible due to van Breda's guideline building on the premise that whatever steps are followed in the analysis of one group's data should be mirrored in the analysis of the other group's data. It is important to note that although van Breda also refers to steps in the process of analyzing NGT data, these steps should not be confused with steps taken in conducting the nominal group discussion as was discussed in 3.6.2.

A discussion of the steps in analyzing data as proposed by van Breda will follow, namely:

- Capture data on computer;
- Identifying top five;
- Content analyses;
- Confirm content analysis;
- Calculating ranks; and
- Reporting of data.

Tables used to explain the methodology of the mentioned steps, do not attempt to analyze data, but to guide the reader through the data analysis process.

STEP 1: Capture data on computer

The process to analyze data started by capturing data in a specific format on a spreadsheet. This assisted the researcher in the analysis of data later on. Table 3.3 is an illustration of NGT spreadsheet used in the study.

TABLE 3.3: Illustration of NGT spreadsheet

CATEGORY (1)	THEME (2)	STATEMENT (3)	SCORES (4)	TOTAL AND AVERAGE (5)	TOP 5 (6)
Health Care	Quality assurance and improvement	Monitoring and evaluation of paediatric ART *& training, DOT and Home Based Care*	4, 5, 4, 3	16 (1.45)	1
	Health care system	Test, treat and follow up at one facility	4, 5, 5, 1, 1	16 (1.45)	1

Although the completed spreadsheet looked like the illustration in Table 3.3, the completion of the spreadsheet followed a staggered process. Initially only column thee, four, five (only reflecting the total) and column six were completed. The correctness of data from these columns was again checked against statements and scores recorded during the nominal group discussion as it was captured on the flip charts and computer. Column five was then completed by dividing the total score by the number of participants (N=11) to obtain the average score a specific statement obtained (Van Breda, 2005:4). At the end of Step one, column one and two were as a result not completed. Columns that were completed assisted the researcher to go onto Step two of analyzing the data.

STEP 2: Identifying top five

The second step provided the opportunity for the researcher to order the participants statements according to how important the group felt a specific statement was. From this data the five most important statements were identified. This was done by sorting the data of Column five in descending order, automatically identifying the top five statements identified by participants (Van Breda, 2005:5). Table 3.4 depicts these top five statements.

TABLE: 3.4: Top five statements of NGT

STATEMENT	SCORES	TOTAL AND AVERAGE	TOP 5
Monitoring and evaluation of paediatric ART *& training, DOT and Home Based Care*	4, 5, 4, 3	16 (1.45)	1
Test, treat and follow up at one facility	4, 5, 5, 1, 1	16 (1.45)	1
Paediatric trained PN empowered to implement "child STRETCH" *Paediatric trained PN– long term, Short term all PN in PHC should be*	3, 4, 3, 5	15 (1.36)	2
PMTCT has to be prioritized	5, 5, 3	13 (1.18)	3
Decentralization of paediatric ART to PHC facilities *All facilities to be paediatric ART treatment sites Medications should be available at pharmacy of local clinic*	5, 5	10 (0.91)	4
All personnel trained and refreshed in HIV component of IMCI *PN, Aux Dr,*	3, 4, 1	8 (0.73)	5
Link ART site with NGO for compliance support	2, 3, 3	8 (0.73)	5

Participants felt very strongly about the monitoring and evaluations of paediatric ART, as well as that testing, treatment and follow up care should take place at one facility. These two statements shared the number one position under the top five statements. The priority ranking of the other statements was also very apparent. The actual analyses of the content followed the prioritizing of the statements.

STEP 3: Content analyses

It was only at this third step that categories and themes depicted as column one and column two in Table 3.3 were concluded, which made the data more interpretable. Before arriving at these categories and themes, the researcher had to follow a rigorous process.

Reading through the list of NGT statements, statements saying much the same was noticed. By re-reading the list, certain themes emerged. As a result of repeating this exercise a few times, the researcher was in a position to write these emerging themes on a separate sheet. Each statement was then classified under a specific

theme. All statements had to be classified under a theme, even if it meant the creation of a new theme that applied to these statements. Created themes had to be so distinctive that statements were not able to be classified under more than one theme (Van Breda, 2005:5-6). In this study themes could be grouped under a specific category. A written definition for each theme and category ensured that statements could only be classified once.

This reduced the many specific statements into the categories and themes as can be seen from Table 3.5.

TABLE: 3.5: Categories and themes from statements of NGT

CATEGORY	THEME
Health Care	Quality assurance and improvement
	Health Care System
	Referral
	Implementation of guidelines
	Human resources
Training	Outcomes
Research	

The list of categories and themes in Table 3.5 represented the issues that the group of participants raised in response to the NGT question put to them (Van Breda, 2005:6). The researcher then used the NGT spreadsheet in Table 3.3 to meticulously classify each statement under a theme (and therefore also a category). A printout of this spreadsheet enabled the researcher to again critically review statements' classification under specific themes. The researcher did not, however, rely on her own insights.

STEP 4: Confirm the content analysis

A peer review session by colleagues who were skilled in NGT and who have not been involved in the research process was arranged. They were briefed on the background of the study and the NGT question posed to participants. Each was provided with a printed copy of the list of statements gathered during the nominal group discussion, as well as the researcher's attempt to classify statements into categories and themes (Van Breda, 2005:7). A fruitful discussion followed that acted

as a confirmation of the analysis of the content. This step concluded the qualitative analysis of data, allowing the researcher to perform quantitative analysis of data.

STEP 5: Calculating ranks

Step five guided the researcher through a number of sub-steps in order to determine the relative importance of each theme. Although the researcher grouped themes into categories, step five investigated the final ranking specific themes received. Calculations forming part of step five were confirmed by a colleague who is an expert in the NGT and specifically the calculation of ranks (See Addendum D for a detailed version of calculation of ranks according to Van Breda). The calculation was made possible by again drawing a spreadsheet. Table 3.6 depicts this spreadsheet presenting the calculated ranks of themes occurring in the NGT

Categories and themes have already been identified as was discussed in step three and depicted in Table 3.5. These categories and themes were thus inserted on the spreadsheet as depicted in Table 3.6. The next column was completed by stating the number of statements in a specific theme that received a Top5 ranking. Before attempting to complete the adjacent column namely Top5 b, the researcher firstly completed the column nr 1. Here the number of statements per theme was noted. Now only the researcher went back to column Top5 b. A ranking of the number of priority statements per theme was conducted. Completing Column nr 2 allowed the researcher to rank the number of statements per theme. In the column identified as Average a, two scores can be found. The score depicted in brackets reflect the average of statements and the score that is not bracketed the average for the theme. The column depicting the Average b, ranks the theme averages, with one being the lowest score. The last column presents the final ranking of a specific theme and has been calculated by adding the scores in column Top5 b and column nr 2 and Average b, (e.g. 1,5 + 1 + 7 = 9,5).

TABLE 3.6: Calculated ranks of themes occurring in NGT

	THEME	TOP5 A NUMBER OF STATEMENTS PER THEME	TOP5 B RANKING OF NUMBER OF PRIORITY STATEMENTS PER THEME	NR1 NUMBER OF STATEMENTS PER THEME	NR 2 RANKING OF NUMBER OF STATEMENTS PER THEME	AVER A (AVERAGE OF STATEMENTS) AVERAGE FOR THEME	AVER B RANKING OF THEME AVERAGES	CATEGORY
Health Care	Quality assurance and improvement	1	1,5	1	1	(1,45) 1,45	7	9,5
	Health Care System	3	4	19	7	(5,53) 0,291	3	14
	Referral	1	1,5	4	3,5	(1,18) 0,295	4	9
	Implementation of guidelines	0	0	4	3,5	(1,72) 0,43	6	9,5
	Human Resources	0	0	7	5	(0,9) 0,128	1	6
Training	Outcomes	2	3	8	6	(3,36) 0,42	5	14
Research		0	0	2	2	(0,36) 0.18	2	4

According to the final ranking of themes occurring in the NGT, the health care system theme and outcomes theme scored the highest ranking. These themes were followed by two themes that shared the second ranking position, namely quality assurance and implementation of guidelines. Referral was placed thirdly, followed by human resources and research as themes. Having reached so far with the analysis of the data, reporting of data could commence.

STEP 6: Reporting of data

Reporting of data is the final step van Breda proposes when analyzing data (van Breda, 2005:11). The data analyzed from the NGT will be comprehensively discussed later in this chapter.

3.8 MEASURES TO ENSURE TRUSTWORTHINESS OF THE RESULTS

Trustworthiness of results refers to the degree of confidence qualitative researchers have in their data. The data was assessed using the following criteria: credibility, dependability, confirmability and transferability (Polit & Beck, 2006: 511; Speziale & Carpenter, 2007:49). The manner, in which the researcher strived to ensure trustworthiness of the results of this study, is discussed by following the mentioned criteria.

3.8.1 Credibility

Credibility refers to the criterion for evaluating data quality in qualitative studies. It reflects the confidence of the researcher in the truthfulness of the data (Polit & Beck, 2006:498). In order to produce credible results the inquiry has to be conducted in such a manner as to ensure that the subject was accurately identified and described (De Vos *et al.*, 2005:346). The researcher consequently has to ensure that activities that increase the probability that credible findings will be produced are part of the study (Lincoln & Guba in Speziale & Carpenter, 2007:49). When research participants recognize the findings of the study to be a true reflection of their expressions, the results may be deemed credible. This is also known as member checking (Yonge & Stewin in Speziale & Carpenter, 2007:49).

This phase of the study aspired to ensure credibility of results by identifying the correct participants to partake in the nominal group discussion. All participants were involved in rendering care to HIV exposed and HIV positive children and were in a position to make recommendations regarding strategies that could be followed to expand health care services to these children. The very structure of the NGT assisted the credibility of findings further. All participants had an equal opportunity to partake in verbalizing ideas through usage of the round-robin technique, as well as the clarification of these ideas. Member checking forms part of the NGT in that participants themselves prioritize ideas and as a result are in agreement with

research findings. Peer review conducted on data analysis increased credibility further (Van Breda, 2005:6).

3.8.2 Dependability

The increased credibility, due to peer review of data analysis, demonstrated the presence of dependability (Van Breda, 2005:6). This statement can be made because credibility and dependability goes hand in hand. Dependability is reached when a researcher has demonstrated credibility of findings (Speziale & Carpenter, 2007:49). At the same time one has to note that dependability is also not possible without credibility (Lincoln & Guba in Speziale & Carpenter, 2007:49). Dependability is additionally guaranteed when stability of data over time and over conditions occur (Polit & Beck, 2006:498). Should any changing conditions occur, the researcher should attempt to account for these conditions (De Vos *et al.*, 2005:346).

The step-by-step process of the NGT that had a positive influence on the credibility of the results had a spill-over effect on the dependability of the results. The manner, in which the process was explained, ensured dependable repetition of the technique. Any major changes within health care services rendered to HIV exposed and HIV positive children in the public health sector in the FS, seems unlikely for the medium term. The processed data can therefore be deemed dependable. Even if results are dependable, confirmibility also influences the trustworthiness of these results.

3.8.3 Confirmability

Confirmability refers to the objectivity or neutrality of the data or the analysis and interpretation of this data (Polit & Beck, 2006:497). This objectivity or neutrality of data can only transpire if documentation of research findings leaves an audit trail. This trial should consist of a recording of activities over time that another individual can follow. In this way the evidence and thought processes that lead to conclusions can be illustrated (Speziale & Carpenter, 2007:49). The traditional concept of objectivity is thus captured, namely: Can the findings of the study be confirmed by another? (De Vos *et al.*, 2005: 347).

The approach followed strengthened the confirmability of the results. The facilitator of the NGT was in a position to act objectively during facilitation of the discussion. Her professional background and being unknown to most of the participants assisted in this. The analysis of the data was commenced by the participants themselves, with the researcher following a further structured process. Interpretation of the data was peer reviewed, which meant that several researchers all came to the same conclusion independently (Van Breda, 2005:6). An audit trial captured the step wise manner in which the NGT was conducted. The way in which the analysis of the data was done too has been extensively audited. The last criterion data that was assessed was that of transferability.

3.8.4 Transferability

Transferability refers to the extent to which findings can be transferred to other settings and the probability that the study findings have meaning to these settings (Polit & Beck, 2006:511; Speziale & Carpenter, 2007:49). The decision whether these findings are actually transferable or applicable in another setting, rest with the potential users of the findings and not with the researcher (De Vos *et al.*, 2005:346; Speziale & Carpenter, 2007:50).

The aim of the NGT discussion in this phase of the study was not to create transferable findings, but to facilitate the identification of strategies to expand health care services for HIV exposed and HIV positive children within the FS DoH. An investigator who would be interested to use these findings in another setting may do so on own accord. The researcher has thoroughly discussed and recorded the data collection process that was followed, as well as how data analysis was performed. This would assist such an investigator to determine whether the findings can indeed be transferred to another setting.

Although the researcher aspired to meet the criteria of credibility, dependability, confirmability and transferability to ensure trustworthiness of data, she furthermore had to take certain ethical considerations into account.

3.9 ETHICAL CONSIDERATIONS

Ethical considerations refer to a set of widely accepted moral principles to which research procedures should adhere to. All involved in the research, from the researcher to the participant, right through to the employer, should accept and adhere to these principles. The principles further encompass the professional, legal and social obligations to study participants (De Vos *et al.*, 2005:57, 69; Polit & Beck, 2006:499). Various codes of ethics have been developed in response to violations of moral principles and human rights in the conduct of research.

The Nuremberg code being the first internationally recognized efforts to establish ethical standards after wartime medical research, with the Declaration of Helsinki going further by differentiating between research with therapeutic value and those that without therapeutic value (Burns & Grove, 2005:177; Uys & Basson, 2005:97; Polit & Beck, 2006: 84; Berg, 2007:55; Speziale & Carpenter, 2007:61). In SA the SA Medical Research Council, the Human Science Research Council and the Democratic Nursing Organisation of SA have all set guidelines for research conducted in this country (Brink, 2006:31). Standards and guidelines emerged from these ethical principles.

The Belmont report expressed three primary ethical principles on which standards of ethical conduct in research should be based, namely beneficence, respect for human dignity and justice. These principles are briefly discussed followed by procedures that the researcher adopted to comply with each of these principles (Burns & Grove, 2005:735; Polit & Beck, 2006:87).

Beneficence

Beneficence is a fundamental ethical principle. It requires from the researcher to minimize harm and maximize possible benefits participants can derive from a study. Doing good should therefore always override doing harm, with any harm being excluded as far as possible (Burns & Grove, 2005:728; Polit & Beck, 2006:87).

Beneficence incorporates participants' right to protection from harm and discomfort and the right to protection from exploitation.

An ethical obligation rests on the researcher to *protect participants from harm and discomfort.* Participants can be harmed in a physical or emotional manner, with emotional harm being more difficult to determine. The researcher, as a result has to be very sensitive to possible harm that could be imparted on participants (Burns & Grove, 2005:190; De Vos *et al.*, 2005:58; Polit & Beck, 2006:85; and Babbie, 2007:63). Sensitivity towards harm being inflicted on participants is not enough. The researcher should inform participants beforehand about the potential impact of the study and give them the opportunity to withdraw whenever they want to (De Vos *et al.*, 2005:58; Uys & Basson, 2005:100). Unfortunately it is not possible to foresee all possible situations and so rule them out in advance (De Vos *et al.*, 2005:58). Through accurate documentation the researcher may, however, monitor possible harm experienced by participants (Uys & Basson, 2005:100).

The researcher was not aware of any harm or discomfort participants could have undergone whilst participating in the NGT. The facilitator was sensitive towards participants' reactions whilst facilitating the discussion and did not report any harm experienced by participants to the researcher. The consent form signed by participants prior to partaking in the study, clearly outlined the researcher's expectations of participants and gave them the opportunity to withdraw from the study whenever they felt so inclined. The structured manner of documentation of the NGT did not provide the opportunity to document possible harm experienced by participants, but as has been stated the researcher was satisfied that the facilitator acted in a sensitive way on the subject.

The researcher further has to acknowledge the participants' *right to protection from exploitation.* Involvement in a study may never place them at a disadvantage. They should be assured that any information provided by them, would not be used against them (Polit & Beck, 2006:88). Again participants received this assurance verbally and in writing (via consent form), prior to the study. Facilitator and researcher alike had to be sensitive towards this possible threat that participants could have experienced, seeing that they were in managerial positions, being asked to propose

strategies to better service rendering. They could have felt threatened by proposing strategies that are currently not part of departmental policies. Apart from the rights discussed underlining beneficence, the respect for human dignity needed to be explored.

Respect for human dignity

Respect for human dignity is upheld in research when participants' right to full disclosure, right to self-determination and right to informed consent is adhered to. In this discussion anonymity and confidentiality are being linked to the right of privacy that is intertwined with the right to informed consent.

The *right to full disclosure* implies that the researcher has comprehensively explained the nature of the study to participants, conveyed the participants' right to refuse participation, clarified the researcher's role, as well as discussed the likely risks and benefits participants would incur (Polit & Beck, 2006:89). Researchers have to be very careful not to deceive participants by misrepresenting research purposes or deliberately withholding information in order to ensure participation that would otherwise have been refused (De Vos *et al.*, 2005:60; Polit & Beck, 2006:498; and Babbie, 2007:67). Again the consent form discussed with participants in this study disclosed fore mentioned information to participants. The nature of this study was uncomplicated, so deception was not an issue.

The *right to self-determination* links closely with researcher's respect for participants' right to full disclosure. Respect for self-determination accepts participants voluntarily participation in the study, them not being discriminated against in any way and being able to control their own destiny (Burns & Grove, 2005:181; Polit & Beck, 2006:89). Again researchers should be conscious of violating this right through the use of coercion, covert data collection and deception in the research process (Burns & Grove, 2005:751). Obtaining permission from participants prior to research and acknowledging participants' right to full disclosure made certain that participants' right to self-determination was adhered to. The right to self-determination and the

right to full disclosure discussed are the two major elements on which informed consent is based (Polit & Beck, 2006: 89).

Informed consent can only happen in the presence of acknowledging the right to full disclosure. It is grounded in the ethical principle of autonomy, recognizing a participant as a self-governing person with decision-making capacity (Polit & Beck, 2006:85; Speziale & Carpenter, 2007:63) Informed consent implies that all possible information on the purpose of the research, procedures which will be followed, possible advantages and disadvantages of the research, how results will be used and how participants' anonymity will be protected are discussed with participants. The credibility of the researcher should also be discussed with participants (Williams *et al,* in Burns & Grove, 2005:193; De Vos *et al.*, 2005:59; Uys & Basson, 2005:99; Babbie, 2007:64; and Speziale & Carpenter, 2007:63). The fact that participation in the study is voluntarily should be emphasized (Polit & Beck, 2006:501; Berg, 2007:78). After having received above mentioned information, participants should be in a position to make a reasoned decision about possible participation. They would for example be able to calculate the demands to be put on their time. The researcher should create opportunities to address any unclear issues before and during the study (De Vos *et al.*, 2005:58, 59). Since informed consent is a prerequisite for all research involving participants, an informed consent procedure in the format of a written form is advisable. This written agreement should contain all the elements discussed and signed by the study participants and researcher (Burns & Grove, 2005:193; De Vos *et al.*, 2005:60; Polit & Beck, 2006:497; and Speziale & Carpenter, 2007:62).

This study made use of an informed consent form (Addendum B) which adhered to the prerequisites set out in literature discussed. Participants were given the opportunity to clarify any uncertainties prior to the research and signing the consent form. In addition the credibility of the researcher and the research project was ensured. The researcher is skilled in the NGT and reported the collection and analyses of data meticulously. No value judgments were made by either the facilitator or researcher whilst conducting and reporting on the NGT. It was however not only the participants who were well informed of the study. Obtaining further permission for the study, the study was presented to the Ethics Committee of the

University of the Free State (Addendum A) and the FS DoH (Addendum C). It is an accepted practice to get informed consent from these institutions before commencing research (De Vos *et al.*, 2005:68; Uys & Basson, 2005:99). The right to informed consent is intertwined with the right to privacy.

A participant's *right to privacy* implies that he/she determines their own conditions under which private information may be shared or withheld (Burns & Grove, 2005:747; De Vos *et al.*, 2005:61; and Berg, 2007:79). Researchers have to be sensitive to ensure that their research is not more intrusive than it needs to be (Polit & Beck, 2006:91). Taking anonymity and confidentiality issues into consideration researchers can protect participants right to privacy (Polit & Beck, 2006:95).

Anonymity occurs when the researcher cannot link individual participants with data obtained. This is however not always possible in qualitative research (De Vos *et al.*, 2005:62; Uys & Basson, 2005:98; Polit & Beck, 2006:495, 497; Babbie, 2007:64; and Berg, 2007:79). The very nature of data collection in qualitative investigation makes anonymity impossible. Research conducted in a nearby setting with a familiar sample may complicate matters further for the researcher, in that participants' identities may be revealed. The researcher therefore, has to ensure that every effort is made to keep confidentiality as promised (Speziale & Carpenter, 2007:66). The NGT as an interview technique does not allow anonymity. The fact that the population who partook in the research was small and very specific could have influenced anonymity negatively. Representatives and not specific persons, being sent per identified sub-directorate and other stakeholders counteracted this possibility.

Confidentiality on the other hand, does not refer to personal data, but rather to the handling of information in a confidential manner. All attempts should be made by the researcher to remove any element that may indicate the identity of a participant (Burns & Grove, 2005:188; De Vos *et al.*, 2005:61; and Berg, 2007:79). Usually when keeping information confidential, the assumption is made that the information is never publicly divulged. When a participant however agrees to partake in research, this premise falls away, since the information must be included in the research project report (De Vos *et al.*, 2005:62; Uys & Basson, 2005:98; Polit &

Beck, 2006:495, 497; Babbie, 2007:64; and Berg, 2007:79). The manner, in which data was obtained when conducting the nominal group, enabled the researcher to depersonalize data and so enhance confidentiality. When participants gave in their cards stating their prioritized ideas (step four of conducting NGT), these cards were shuffled by the facilitator and as a result data could no longer be linked to a specific participant. Although participants and the DoH gave permission to publish research findings, raw data have been kept in a safe environment with no unauthorized access possible. The last principle discussed is that of justice.

Justice

Justice goes hand in hand with participants being treated fairly (Burns & Grove, 2005:740). Added to that the principle of resource allocation is included (Pera & van Tonder, 2005:35).

The *right to fair treatment* entails that participants should be treated fairly. This fairness is based on the way study participants are selected and whether these participants receive remuneration or not (Burns & Grove, 2005:189; Polit & Beck, 2006:90). In this phase of the study participants were selected based on research requirements, namely them representing a specific programme within a directorate or sub-directorate or an institution or group outside the FS DoH. Only these participants were in the position to give meaningful contributions to the study. The agreement (consent form Addendum B) between the researcher and participants did not anticipate any remuneration, therefore participants could not have had unmet expectations in this regard. Resource allocation was not applicable to this study as no allocation of any resources were made.

As has been stated in Step six of data analysis, the research findings of the nominal group discussion will now be discussed in detail.

3.10 RESEARCH FINDINGS

Table 3.7 reflects the responses of participants on the question posed during the nominal group discussion, namely "*Identify strategies to expand health care services for HIV exposed and HIV positive children in the FS public health sector*". The research findings will be discussed according to the sequence of categories and themes as set out in Table 3.7 and not necessarily according to priority ranking specific statements within themes received. Van Breda (2005: 10) emphasizes the fact that the more statements occur within a specific theme, the more important it is likely to be. This being the case even when the statements did not receive many votes, as can clearly be seen in the theme "*Health care system*" that resorts under the category "*Health care*".

3.10.1 Health care

Health care was the first category identified when analyzing responses on the nominal group question. The concept *health care* is a combination of the concepts *health,* as well as the concept *care*. The World Health Organisation's (WHO) concept clarification is widely accepted that health refers to a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, therefore referring to health as a holistic state of well-being (Young, Van Niekerk & Mogotlane, 2003:18; Allender & Spradley, 2005:909). Virginia Henderson added that health can only be attained when the individual has the necessary strength, will or knowledge (Young *et al.*, 2003:13). Leininger (cited in Tjale & De Villiers, 2004:142) a well known anthropologist and nurse, explains care as the provision of personalized and necessary services to help people maintain their health or to recover from sickness.

TABLE 3.7: Responses on nominal group question

CATEGORY	THEME	STATEMENT	SCORES	TOTAL AND AVERAGE	TOP 5
Health Care	Quality assurance and improvement	Monitoring and evaluation of paediatric ART ***& training, DOT and Home Based Care***	4, 5, 4, 3	16 (1.45)	1
	Health care system	Test, treat and follow up at one facility	4, 5, 5, 1, 1	16 (1.45)	1
		Get away from vertical PHC towards comprehensive PHC**. *Nurse render comprehensive care***	2	2 (0.18)	
		Ensure the availability of treatment at sites where needed	5	5 (0.45)	
		Decentralization of paediatric ART to PHC facilities. ***All facilities to be paediatric treatment sites. Medications should be available at pharmacy of local clinic***	5,5	10 (0.19)	4
		Professional nurses within paediatric hospital ***wards and clinics that render services*** to take greater responsibilities. ***Comprehensive management of HIV***	1,5	6 (0.55)	
		Provide baby friendly facilities in all health care institutions	5	5 (0.45)	
		Total integration of HIV &TB in all PHC services	4, 1	5 (0.45)	
		Family centered care provided to families – ***mother, father and caregivers should be tested***	1,1	2 (0.18)	
		Health Care Worker should initiate counselling and testing via parents/ guardians all the time	0	0	
		Drug readiness to be combined with other interventions	0	0	
		PMTCT has to be prioritized	5, 5, 3	13 (1.18)	3
		Start Highly Active ART in pregnancy	0	0	
		Working harder to reduce stigma in community	3, 2	5 (0.45)	
		Put measures in place to trace ART defaulters	0	0	
		Use Road to Health Card with every visit to make sure child is growing and receives immunizations	0	0	
		Identify if mothers are terminally ill as to identify caregivers who will see to ART treatment before mothers pass away	0	0	
		Integrate Information, Education and Counselling material	0	0	
		Pre-school training for HIV affected and infected children to provide pre-school stimulation	0	0	
		School health nursing to be re-instated to help with ART programme	0	0	
	Referral	Link ART site with Non-Governmental Organizations for compliance support	2, 3, 3	8 (0.73)	5
		Willingness of health care workers to work with ***Non-Governmental Organizations's Home Based Carers***	0	0	
		Strengthen and improve referral system within PHC facilities	2,1	3 (0.27)	
		No misunderstanding in coding and de-coding system ***various programmes do not know how to interpret the codes used eg TB***	2	2 (0.18)	
	Implementation of guidelines	Screen children for clinical signs of AIDS and not only CD4 ***and World Health Organisation-staging***	2, 4	6 (0.55)	

CATEGORY	THEME	STATEMENT	SCORES	TOTAL AND AVERAGE	TOP 5
		Test all HIV exposed children at 6 weeks	1,4	5 (0.45)	
		All exposed children should be on Bactrim as of 6 weeks	3	3 (0.27)	
		Screen for TB ***and HIV*** at each visit	1, 2, 2	5 (0.45)	
	Human resources	Keep Registered Nurse motivated to render the best service patients deserve	4	4 (0.36)	
		Appoint more Professional Nurses and doctors ***– Not realistic***	2	2 (0.18)	
		Making best use of all resources available ***utilization of paediatricians, session doctors and ART trained Professional Nurses and home based carers - can go to patients at different sites All programmes to be used not only ART***	2	2 (0.18)	
		Clinics ***(Level 1 – do not have a doctor)*** need session doctors	0	0	
		Health care workers must rope in services of social workers ***Scarce but very effective***	0	0	
		Use of People Living with AIDS for management of paediatric patients	0	0	
		Support structure for caregivers	2	2 (0.18)	
Training	Outcomes	Paediatric trained Professional Nurses empowered to implement "child STRETCH" ***Paediatric trained Professional Nurses– long term, short term all Professional Nurses in PHC should be trained***	3, 4, 3, 5	15 (1.36)	2
		Paediatric training of Professional Nurses should be priority– empower Professional Nurses	3	3 (0.27)	
		To have integrated training for Professional Nurses included (information regarding children) in all programmes	3,4	7 (0.64)	
		All personnel trained and refreshed in HIV component of IMCI ***Professional Nurses, Auxiliary Nurses,*** *Doctors*	3, 4, 1	8 (0.73)	5
		Have refresher training for doctors in paediatric ART	0	0	
		HIV and AIDS management included in pre-service training	4	4 (0.36)	
		Training of lay people to assist families of HIV positive children ***Home-Based Carers to assist parents***	0	0	
		Private doctors to receive training on National Paediatric ART treatment Guidelines	0	0	
Research		Encourage more research on effective training regimes especially in children	1	1 (0.09)	
		Enhance communication on international, national and inter provincial level ***Research should be made available, Policy development***	3	3 (0.27)	

Highlighted sections of statements reflects clarification on statement added by participants during Step 3 of nominal group discussion

The themes discussed under the category *Health care* are quality assurance and improvement, health care system, referral, implementation of guidelines and human resources.

Quality assurance and improvement

Quality assurance and improvement emerged as a significant theme within the *Health care* category. The concepts quality assurance and quality improvement are intertwined. Assurance implies a guarantee of quality, whereas it is only possible for quality improvement to occur within a health care programme when a formal monitoring programme exists, that is able to measure and evaluate the quality of services delivered and simultaneously identify opportunities to improve these services. Transformation needs to follow and therefore remedial steps should be put into place to maintain improvements. The cyclic process of quality improvement therefore consists of standard formulation, evaluation of performance against set standards and implementing remedial actions to ensure that the desired quality of a heath programme is reached (Booyens, 2005:597, 605).

An efficient monitoring and evaluation system would aid quality assurance and improvement within health care. Monitoring and evaluation are crucial to programme management, given that it provides a basis for assessing progress in reaching goals. This data is used for strategic planning and weaknesses in programme design can be addressed. Monitoring therefore refers to the routine tracking of key elements of performance through meticulous record keeping and regular reporting. Whereas evaluation refers to an episodic, in-depth analysis of programme performance (South Africa, 2007b: 90; South Africa, 2008b: 77-78). The following response indicated participants need for monitoring and evaluation within the paediatric ART programme:

"Monitoring and evaluation of paediatric ART ***& training, DOT and Home Based Care****"*

This need is understandable seen in the light of the ART programme in the Free State being introduced without proper monitoring and evaluation systems, in spite of chapter twelve of the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for SA proposing the integration of monitoring and evaluation into programme implementation. The National Strategic Plan (NSP) 2007-

2011 again identified monitoring and evaluation as an important policy and management tool, addressing the lack thereof in the previous NSP (South Africa, 2003b: 33; Van Rensburg, 2006:84; and South Africa, 2007a: 13, 51, 101). According to Schneider (2006:32): "*The culture of monitoring and evaluation at facility as well as sub-district and district levels is poorly developed in the health system. Building this culture is a core challenge of the roll-out process and will require direct support to facilities and strengthening of managerial capacity at sub-district and district levels*."

It therefore seems as if steps taken by the FS DoH to address quality assurance and improvement within the paediatric HIV programme have not as yet had the desired effect. This in spite of the Elizabeth Glazier Foundation being contracted to assist in monitoring and evaluation of PMTCT and Comprehensive Management and Treatment of ART (Magagula, 2009: personal communication).

Quality of data and the way in which it is used at various levels in the health system further unfortunately limit the benefits that could be derived from data gathered (South Africa, 2007b: 95).

Health care system

Participants overwhelming response concerning statements clustered under the "*Health care system*" theme, is evidence to the importance they place on these strategies to be put into place, in order to address the expansion of paediatric HIV services. A health care system can be seen as an institution of health service delivery, promoting, protecting or restoring the health of individuals and populations. This may be done at a narrower level, such as at hospitals, PHC clinics or at a broader level referring to services such as medical and nursing services. Health care systems do not function within a vacuum, but forms part of a tripartite relationship between the health care system itself, the environment it is surrounded by and the clientele the health care service serves. The health care system needs to be tuned into the needs of their clientele, therefore forming a repetitive circuit between

suppliers always aiming to meet the need(s) of their clientele (Dennill *et al.*, 1999:3; Van Rensburg, 2004:1-2; and Schneider & Barron, 2008: ii).

These needs are identified within a District Based PHC approach (South Africa, 1994; Harrison, 1997:26). A health care system following this approach is therefore measured against the following criteria, whether the service:

- Responds to health needs;
- Views people as a whole;
- Is concerned with people's health, not just disease;
- Includes district hospital care; and
- Has clear systems of referral (Harrison, 1997:27-35).

Even though criteria has been set, it does not necessarily reflect the current status in the health care system. The disorganized and fragmented health care system in Sub-Saharan Africa is a pitfall associated with rapid expansion of ART in this area. This state of affairs is maintained partly as a consequence of inadequate skilled human resource capacity within health and partly due to the collection of health initiatives that countries have become dependant on. *"Vertical programmes"* that developed as a consequence to this have been capable to bypass systemic deficiencies of the public health care system, but simultaneously accentuating its fragmentation, incoherence and disorganization (Young *et al.*, 2003:26; McCoy, 2006:3).

The National DoH acknowledges verticalisation of programmes as a weakness within the health system and aims to have 80% of health facilities rendering comprehensive HIV care by 2011, thus following the advice of the WHO in focusing on integrating HIV services into PHC as part of managing chronic diseases (South Africa, 2007a: 12, 50, 88; World Health Organisation *et al.*, 2008:115). However, this has not transpired as yet, with the establishment and expansion of key programmes such as PMTCT, VCT, ART (and others discussed in chapter two), since the National Strategic Plan (NSP) 2000-2005. These programmes have been, and are still vertically implemented, with capacity deficits evident in their implementation (Van Rensburg, 2004:158; Schneider, 2006:33; and South Africa, 2007a: 50). The reason

for the vertical implementation being the urgency and priority assigned to the ART programme on national and provincial level. Nationally ART emerged as a vertical programme with its own finances, personnel, facilities and segregated filing registering and recording systems (Van Rensburg, 2006:61). McCoy (2006:4) makes the following comment: "*although some single-focused and dedicated structures are necessary to catalyse the scale-up of ART access for AIDS, 'over-verticilasation' can result in a vicious cycle between fragmented, uncoordinated and poorly governed health care systems and ever greater reliance on vertical programmes*."

The FS has followed suit in not endorsing the key principles of comprehensive PHC approach. This being evident in weaknesses demonstrated in intra- and interdepartmental and intersectoral collaboration in the management of the HIV programme. Key role players did not form part of policy making structures and civil society had limited involvement in its everyday running (Van Rensburg, 2006:62). Although the FS opted for a PHC approach in delivering the HIV programme, which implies the provision of services in a decentralized manner within PHC clinics, the *"decentralization"* needs further explanation. Specified HIV services are currently only available at 23% of all PHC clinics, Community Health Care centres and District Hospitals in the FS (Steyn *et al.*, 2006:99; Van Turha, 2008a: personal communication; and Tshegare, 2009: correspondence). These specific and therefore often fragmented services target adults and not children. PHC programmes in the FS is also conceptualized by health care managers and providers as a collection of specific programmes rather than a holistic and integrated approach as proposed by the Alma Ata Declaration (Heunis & Schneider, 2006:271). Proposed strategies from participants reflect this sentiment:

"Test, treat and follow up at one facility"

"Get away from vertical PHC towards comprehensive PHC. ***Nurse render comprehensive care****"*

"Decentralization of paediatric ART to PHC facilities. ***All facilities to be paediatric treatment sites. Medications should be available at pharmacy of local clinic"***

In order to rectify this situation, the DoH has planned various interventions, guiding the scaling up of the coverage of a comprehensive care and treatment package in the health sector. Accepting therefore the right of every HIV exposed and HIV infected child to comprehensive therapy, and thereby improving the morbidity and age-related mortality from HIV infection (South Africa, 2005a: 76; South Africa, 2007a: 84). The DoH agrees that PMTCT has to be prioritized, and aspire to do so by increasing the proportion of public sector antenatal services providing PMTCT (South Africa, 2007a: 76). Although the national target has been set at 100% of all fixed PHC facilities providing PMTCT services by 2008, the FS's target for 2007 to 2008 has been set at 50% (South Africa, 2006:37). The mere provision of PMTCT services might however not be enough. Various SA researchers argue that the vertical provision of PMTCT and HIV services and the weak integration into maternal child health services result in poor access to HIV care in children (Schneider, Van Rensburg & Coetzee, 2008b: 25). Participants however felt that the prioritization of PMTCT could benefit the expansion of paediatric ART services:

"PMTCT has to be prioritized"

It therefore seems that barriers between departments need to be broken down in order to prevent isolated functioning, resulting in a reduced quality of care being rendered (Booyens, 2005:603). However, this can only be successful if all actors make a commitment to develop the capacity of health departments, strengthening public health care systems and reverse the fragmentation of health care services (McCoy, 2006:6). A way in which health care systems can be strengthened is by means of an operational referral system.

Referral

Strategies clustered under the "*Referral"* theme called attention to the dependence of a well - functioning PHC system on the smooth flow of referrals between:

- primary (PHC clinics and Community Health Centres);
- secondary (District hospitals) and

- tertiary levels (Tertiary hospitals) of care (Dennill *et al.*, 1999:43; Van Rensburg, 2004:414).

Most care and support for HIV infected children can be provided at primary care level (South Africa, 2005a: 4). In cases where referral is indicated, the child's caregiver is to be provided with a clear explanation of the illness and a referral letter and follow-up plan should be provided (South Africa, 2005a: 4). It is foreseen that tertiary care facilities will become referral centres for complicated cases. These facilities will thus initiate ART and refer stable patients to PHC facilities where the necessary expertise, drug stocks and nutritional support are available (South Africa, 2005a: 78).

A further distinction in level of care being rendered is made within the HIV programme in the Free State. *Assessment sites* are primarily nurse driven and assess adults and children for eligibility for ART. Children may however also be identified in other programmes such as TB or by professional nurses following the IMCI strategy. These children are then also referred to the nearest assessment site. Children are subsequently referred from the assessment site to the *treatment site*, which is doctor driven. Children's ART is initiated by the doctor at the treatment site. Those who have been stabilized on treatment are referred back to the assessment site for further follow-up. *Combined treatment-assessment sites* have nurses and doctors at these sites and perform a combination of tasks usually done at assessment and treatments sites respectively (South Africa, 2004:31; Van Rensburg, 2006:57-58; and Oosthuizen, 2009: personal communication). The explained referral required within facilities to facilitate health care services to HIV exposed and HIV positive children has been identified as an Achilles heel by participants as can be seen from the following statements:

"Strengthen and improve referral system <u>within</u> PHC facilities"

"No misunderstanding in coding and de-coding system ***various programmes do not know how to interpret the codes used eg TB****"*

Referral of these children is not confined to referral of clients between professional nurses and doctors. Community Health Workers (CHW) forms an important link in the referral chain. CHW refer to people who "*carry out functions related to health care delivery, trained in some context of the intervention; and having no formal or professional or paraprofessional certificated or degreed tertiary education*". These CHW may be working as a generalist or specialist within a facility or could be community based. They could also be rendering either/or a combination of preventative and curative care (Schneider *et al.*, 2008b: 24). CHW are also sometimes referred to as Home Based Carers. In the Free State these CHW are affiliated to Non-Governmental Organisations (NGO's) who are in turn funded provincially (Van Rensburg, 2004:310).

Within the paediatric HIV programme these CHW are supposed to visit the child identified to be placed on ART and assess the home circumstances, correctness of contact details, support structures including disclosure and drug storage facilities. Their report to the multi-disciplinary team would assist the team in deciding whether the child meets the treatment readiness criteria (South Africa, 2004:32). They further assist in routine follow-up of patients, thus enhancing adherence to ARV drugs (South Africa, 2005a: 98; Booysen, Anderson & Meyer, 2006:328).

One of the guiding principles of the NSP 2007 to 2011 is to promote effective partnerships and so strengthen health care systems (Young *et al.*, 2003: 202; South Africa, 2007a: 55-56). The recruitment of even more CHW is envisaged (South Africa, 2007a: 97). According to the FS DoH, home based care is provided in all towns in the FS, whilst partnering with 137 civil organizations to render this service to the majority of AIDS patients (South Africa, 2006:31). However, it is mostly adult patients who are targeted for care. These good intentions of the National and Provincial Departments of Health to promote partnerships have unfortunately not had the desired impact, as can be seen in the following statements:

*"Willingness of health care workers to work with **NGO's Home Based Carers**"*

"Link ART site with NGO for compliance support"

The reason for this being that the role and links to facility management has not been clearly explored in the FS. This leads to a loose involvement, lacking in control and unfortunately not supplementing the professional workforce to the degree it could (Steyn *et al.*, 2006:130; Van Rensburg, 2006:65). HIV exposed and HIV positive children have therefore also not benefited from CHW in the way they could have. One may ask oneself whether identified gaps in utilizing CHW, could not be addressed by the implementation of guidelines addressing this issue.

Implementation of guidelines

The "*Implementation of guidelines"* theme refers to specific South African guidelines to be used by health professionals caring for HIV exposed and HIV positive children. These guidelines provide comprehensive guidance when identifying and assessing these children, as well as specific recommendations regarding the treatment and follow-up of them. The content of some of these guidelines overlap, but thankfully do not contradict each other. Guidelines under discussion are the:

- Guidelines for the management of HIV infected children (South Africa, 2005a);
- South African National Tuberculosis guideline (South Africa, 2007b);
- Policy and guidelines for the implementation of the PMTCT programme (South Africa, 2008);
- HIV and AIDS and STI Strategic Plan for South Africa 2007-2011 (South Africa, 2007a); and
- Integrated Management of Childhood Illnesses, including aspects of the management of HIV infected children (South Africa, 2008c).

Participants highlighted the following facets when identifying and assessing HIV exposed and HIV infected children that clearly need to be acted upon:

"Screen children for clinical signs of AIDS and not only CD4 ***and WHO-staging****"*

"Test all HIV exposed children at 6 weeks"

"Screen for TB ***and HIV*** *at each visit"*

The benefit of identifying symptomatic children and then testing them for HIV has been recognized by the National DoH (South Africa, 2007a: 91). It is therefore recommended that a clinical examination to assess for symptoms and signs of HIV infection should be performed on children during all visits to PHC facilities or hospitals (South Africa, 2005a: 13, 16). The HIV component of the IMCI strategy, guides health professionals in determining whether there is clinical evidence of HIV infection before establishing the HIV status of the child via testing (South Africa, 2008c: 57). It seems as if the majority of professional nurses working in primary health care and community health care services in the FS do make use of these IMCI guidelines (Spies, 2008: conference paper).

In order to determine the HIV status of infants as early as possible, the DoH aims to have all health facilities in SA, able to offer HIV Polymerase Chain Reaction (PCR) tests by 2011 (South Africa, 2007a: 81). The national HIV testing guidelines for children advise above mentioned testing to be performed at six weeks of age to all HIV exposed infants. This highly sensitive test allows for the testing of the presence of intracellular HIV DNA material (South Africa, 2005a: 12; South Africa, 2008:21). The informed consent of a person legally capable of doing so is needed, before HIV testing may be performed on the child. In SA this refers to the parent or legal guardian of the child who is under the age of fourteen (South Africa, 2005a: 109).

As part of providing a comprehensive package of services to children, the DoH plans to reach a 100% target by 2011, thus ensuring that all HIV exposed and HIV positive children receives Cotrimoxazole (South Africa, 2005a: 14-15; South Africa, 2007a: 92; South Africa, 2007b: 67; and South Africa, 2008:21). Overwhelming scientific evidence exists proving that Cotrimoxazole prevents Pneumocystis jiroveci pneumonia (PCP), protects against invasive bacterial disease and other opportunistic infections (South Africa, 2005a: 40; South Africa, 2007b: 67; and World Health Organisation *et al.*, 2008:96). The majority of professional nurses working in primary health care and community health care clinics in the FS indicated that they do provide Cotrimoxazole as prophylactic treatment (Spies, 2008: conference paper).

All TB positive children should therefore be screened for HIV, and all HIV infected children for possible TB infection (South Africa, 2007a: 87; South Africa, 2007b: 69, 73; and South Africa, 2008c: 61). In spite of this policy only 74% of professional nurses working in primary health care and community health care clinics in the FS indicated that they screen for TB in these children (Spies, 2008: conference paper). Apart from the need identified for existing guidelines to be implemented, a human resource need was also identified within health care in the FS.

Human resources

More than a decade ago Pick (1995:103) came to the following conclusion: "*In SA, human resources for health care have developed in an ad hoc and fragmented manner. The ideology of apartheid not only compounded the inherent inequality in the provision of health care along race, gender and class lines, but also entrenched the development of human resources along these lines. This has resulted in an inequitable distribution of human resources in SA. The only way in which these historical inequities can be addressed is through deliberative, goal-directed human resource policy and planning.*" It is sad to observe that a very similar situation still exists within the health care services rendered to HIV exposed and HIV positive children, therefore proclaiming a less-than-effective human resource policy and planning.

The Comprehensive Plan estimated that approximately 14,000 additional staff were required to reach set targets, of which 6,000 would be doctors and nurses (Schneider, 2006:26). The 43% and 44% vacancy rate for professional nurses and doctors respectively in the FS (as was the case in 2008), do not better the situation. The situation is further compounded by a vacancy rate of 55% amongst enrolled nurses, placing further strain on professional nurses who have to perform this category's work as well. The HIV programme in the Free State filled professional nurses' posts through lateral transfers. This meant the transfer of professional nurses from within the same district, inter-district or from the same facility would manage the HIV programme, thus creating vacant posts and potentially weakening

the rest of the health system (Steyn & van Rensburg in Schneider *et al.*, 2008b: 23; Burbidge, 2009: personal communication).

Various factors affect the availability of health professionals for rendering health care to HIV exposed and HIV positive children in the FS province. These include unequal geographical distribution, unequal public-private distribution, insufficient production of nurses, and emigration to other countries, HIV positive health professionals and vacant posts. This multifaceted problem clearly has no easy answer (Steyn *et al.*, 2006:101). The DoH intends to expand the human resource pool through increased production, retention strategies and partnerships with private providers. Furthermore compulsory community service by newly graduated health professionals and the recruitment and preferential registration of foreign workers who are willing to serve in under-resourced areas are ways they plan to address the shortage of doctors and nurses (Steyn *et al.*, 2006:107; South Africa, 2007a: 88). It is also envisaged that task shifting/sharing could assist in the shortage of professional nurses and doctors. This could imply that CHW render traditional nursing tasks (South Africa, 2007a: 147; World Health Organisation *et al.*, 2008:104). Taken all of the above into consideration, one can understand participants *"cry for help"* and then almost immediate cancellation of their own proposed strategy namely:

"Appoint more PN's and drs - ***Not realistic****"*

It is therefore quite understandable that nurses become de-motivated. As participants stated:

"Keep RN motivated to render the best service patients deserve"

Nurses within the public health system are demoralized and de - motivated. This leads towards them not focusing on organizational goals and experiencing difficulty in showing clients sympathy (Schneider, 2006:28). Studies in the FS's adult HIV programme proved this to be true, with recommendations being made to address levels of frustration and discontent among staff in order to better professional nurse's motivation (Steyn *et al.*, 2006:130). The position of nurses caring for HIV positive children is unknown. Deming (in Booyens, 2005:603) emphasizes that management

should not focus on individual motivation only, but that group motivation would promote productivity and quality service rendered.

The absence of management support further leads to poor motivation (Penn-Kekana in Schneider, 2006:27). This has been the case in the FS's HIV programme (Steyn *et al.*, 2006:128). Apart from management support, Van den Berg *et. al*. (2006: iii) recommended the provision of human resource management in close proximity to health care centres in order to attend to the occupational health and well-being, as well as the human resource needs of professional nurses within this programme. The health care system is strengthened when support is provided to health care providers (South Africa, 2007a: 88).

3.10.2 Training

Training is aimed at gaining a skill (Kurtus, 1999: online). The DoH refers to paediatric HIV related courses professional nurses attend, as training courses. The content of many of these courses encompasses more than only gaining specific skills. Knowledge, attitude and problem solving skills are addressed in some of these courses. Such courses could therefore be seen as education and not training programmes. This study will refer to training in order to be in line with terminology used by the DoH. Such training plays an important role in the expansion of paediatric HIV services. Adequate training further enables good service rendering. This requires management to focus on the training needs of personnel (Booyens, 2005:603). Establishing an effective HIV programme requires more than just drugs. Without well-trained health workers the implementation of health care services for HIV exposed and HIV positive children in the public sector can not be successful (South Africa, 2004: iii; Chopra, 2005:3; Stein, 2005:7; Steward, and Padarath & Milford, 2006: 297). The question remains as to what the training outcomes should be, in order to have these well-trained health workers.

Outcomes

Spady, (in Maree & Fraser, 2004:14) describes an outcome as a learning result obtained after significant learning experiences occurred. It could also be seen as the expectations set for learners once they have completed all these experiences. In the South African context, the concept outcome is used inclusively. It therefore incorporates all that has been learnt, the knowledge and understanding gained, methodologies used and values and attitudes integrated by the learners (Maree & Fraser, 2004:13). Yet, these outcomes are not always clearly stipulated for health care workers who need to render services to the children in mention.

The only available plan to address training outcomes can be derived from the South African Guideline for the Management of HIV infected Children. This guideline acts as national policy in SA, guiding health care workers in their caring practises for HIV exposed and HIV infected children (South Africa, 2005a). See Table 2.2 and 2.3 for an overview of the content of various paediatric HIV related training courses presented in the FS and how the content compares to expectations set out in the national guideline.

In order for the HIV programme to be successful, it is expected of HCW to have a high index of suspicion for conditions associated with HIV. Except for identifying these children, the necessary knowledge and skills to manage these conditions is essential (South Africa, 2005a: 32). It is the unavailability of such trained personnel posing a major threat to the implementation of comprehensive health care (South Africa, 2007a: 146). Therefore the health system can only be strengthened if this capacity is built into health workers (South Africa, 2007a: 88).

One such a training programme aiming to build capacity, is training presented in the Complementary IMCI strategy. It aims to train all health personnel working at the front line of a clinic, community health centre or an out-patient department of a hospital, enabling them to have the necessary knowledge and skills needed to identify and treat HIV exposed and HIV infected children (South Africa, 2005a: 32; South Africa, 2008b: 75; and South Africa, 2008c: 7). No record is being kept as to

how many professional nurses have undergone this training in the FS (Masakala, 2009: personal communication). Participants agreed to the necessity of this training, when proposing the following strategy:

"All personnel trained and refreshed in HIV component of IMCI ***Professional nurses, Auxiliary nurses, Doctors****"*

Since comprehensive HIV care includes the initiation of treatment, the DoH acknowledged the need to train professional nurses to initiate ART. A training course designed to address HIV infected adults needs was compiled by the Lung Institute of the University of Cape Town. The PALSA PLUS is an integration of the National TB Control Programme, ART Programme, as well as elements of the revised Essential Drug List guidelines, VCT and PMTCT (Fairall, 2005:14). The so called STRETCH programme within the PULSA PLUS allows professional nurses at pilot sites to initiate ART to adult clients meeting set criteria. Although this is being phased in for adults, the DoH has not committed themselves into empowering nurses to do the same for children. At this stage action plans only address the enlargement of the proportion of stable children on ART being managed by nurses (South Africa, 2005a: 78; South Africa, 2007a: 93, 147; and South Africa, 2008c: 62). Participants however, felt strongly that this process should also be initiated for children:

"Paediatric trained Professional Nurses empowered to implement "child STRETCH"
Paediatric trained Professional Nurse – long term, short term all Professional Nurses in PHC should be trained"

Although the STRETCH programme permits the initiation of treatment, it still does not deal with another challenge namely the integration of HIV training in all other health programmes. Taking into account that integrated training for HIV in all programmes would improve staffing shortages, better service continuity and strengthen entire facilities, rather than a single programme (Heunis & Schneider, 2006:265; Steyn *et al.*, 2006:129). Participants recognized this need too, proposing a similar strategy:

"To have integrated training for Professional Nurses included (information regarding children) in all programmes"

Integrated training never materialized, due to the numerous programmes created in response to the Millennium Development Goals leading to a lot of money and effort being directed towards short training courses. These *'epidemics'* of in-service training lack comprehensive workforce strategies (World Health Organization, 2006a: 20). This is also the case in the FS where PHC is packaged into vertical programmes. Managers often have to decide who attends which course, as each programme has a number of training courses (Fairall, 2005:15). These managers are lead by norms such as *"every clinic has nurse practitioners able to treat clients according to IMCI principles", "at least one professional nurse will attend an HIV/AIDS/STD/TB workshop or other continuing education event on HIV/AIDS each year"* and *"at least one staff member who has or has had opportunity for continuing education in TB management"* (South Africa, 2001b: 19, 33, 38). The paediatric HIV related training presented in the FS is further complicated due to the fact that various directorates and sub-directorates present these training courses.

It is not only in-service training opportunities complicating the training scene. The majority of HCW in SA did not benefit from HIV/AIDS care training during their basic training (Steyn *et al.*, 2006:115). Due to this, PHC nurses feel they lack appropriate skills to deal effectively with HIV/AIDS clients (Lehmann & Zulu, 2005:45). This was also found to be the case in the FS, where an insufficient number of professional nurses who were required to render care for patients receiving ART, where not trained in Clinical Primary Health Care or IMCI. These untrained nurses would therefore be unable to conduct comprehensive physical assessments and be incapable to identify a child with an IMCI classification of Suspected HIV and AIDS (Botma, 2004:19). Professional nurses rendering health care to HIV exposed and HIV positive children in the FS overwhelmingly echoed this sentiment, indicating that they need further training regarding the care and treatment of HIV positive children (Spies, 2008: conference paper). Participants acknowledged that this was still the state of affairs:

"Have refresher training for doctors in paediatric ART"

"HIV/AIDS management included in pre-service training"

3.10.3 Research

Research is a systematic inquiry that uses orderly, disciplined methods to answer or solve problems (Polit & Beck, 2004:730; Polit & Beck, 2006:509; and Lategan, 2008:4). In the process existing knowledge is refined and new knowledge generated (Burns & Grove, 2005:749). Research therefore has four characteristics namely:

- knowledge investigation;
- critical enquiry;
- discovery of new knowledge; and
- analysis of facts and data (Lategan, 2008:4)

The manner in which the research is conducted can either be as a qualitative study, quantitative study or a combined approach (De Vos *et al.*, 2005:114; Maree, 2007:33). Irrespective of the approach followed, the aim of research stays to solve problems encountered in practice, such as bettering training or communication networks. This type of research is called applied research and its goal is to broaden scientific and technological knowledge through the finding of solutions to specific practical problems (Uys & Basson, 2005:5).

The National DoH supports research, evaluating HIV training requirements within the public health sector (South Africa, 2007a: 110). The emphasis on research has already been sited in 2003 in the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for SA (South Africa, 2003b: 3). Participants however, felt that more research needs to be done within the HIV training field:

"Encourage more research on effective training regimes especially in children"

Another field in which applied research was identified was HIV related communication. This type of communication can be defined as *"any communication activity involving content that is related to HIV and AIDS, using diverse channels"* in the process (Parker, 2007:48). Participants expressed themselves as such on the matter:

"Enhance communication on international, national and inter provincial level ***Research should be made available, Policy development***"

One of the strategic priorities for the National Health System for 2004 to 2009 is to strengthen international relations (South Africa, 2006/07:6). A regional framework established between SADC member states, can therefore assist in co-operative agreements being reached amongst these states (South Africa, 2003b: 13; South Africa, 2007a: 51). Best international methodology could also be used to obtain data, for example data reflecting HIV incidence (South Africa, 2007a: 114). On a National level the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for SA proposed the implementation of a comprehensive communications programme, thus ensuring that all relevant role players are kept informed on requirements of the plan and their respective roles (South Africa, 2003b: 31). Even the PMTCT programme targeted the development of a comprehensive integrated communication strategy, thus ensuring that policy and guidelines information get disseminated (South Africa, 2008:15, 73). From participants input conclusions and recommendations could be made.

3.11 CONCLUSIONS AND RECOMMENDATIONS

Participants of the NGT have already identified strategies to expand health care services for HIV exposed and HIV positive children in the public health sector in the FS. The researcher has taken these strategies a step further by drawing conclusions and constructing recommendations for this phase of the study. These conclusions will be discussed according to categories identified in Table 3.5, namely health care, training and research. The researcher took the intricate manner in which the content

of these categories interact with each other into consideration when making recommendations.

Participants of the NGT clearly placed emphasis on themes resorting under the *Health care* category. Quantitative data analysis of themes forming part of this category indicated that four of the top five statements occurred here (Table 3.4). Health care systems as a theme was co-ranked number one, with again four of the five top five ranking themes originating from the Health care category (Table 3.6). It was further noted that 35 of the total of 46 statements came from this category (Table 3.7). The more statements a specific theme presented with, the more important the theme is to participants (Van Breda, 2005:10). Qualitative analysis of themes in this category echoed this sentiment with participants stressing the importance of utilizing strategies addressing health care in order to expand health services for these children.

Training was also deemed important by participants, as can be seen from data analysis done quantitatively as well as qualitatively. Empowering professional nurses to initiate ART to children was placed as the second most important statement under the top five statements (Table 3.5). Outcomes as a theme within the training category, was co-ranked as the number one ranking theme with the health system theme of the health care category (Table 3.6). It is therefore clear that training activities cannot be separated from whatever happens within a health system. Qualitative analysis of individual statements noticeably demonstrated participants expressed desire to present an integrated training to all health care professionals rendering care to these children.

Although the *research* category did not receive any placement under the top five statements and was ranked lowest when ranks and themes occurring in NGT was calculated, it was deemed important to two participants. These participants felt so strongly about the importance of research activities within the paediatric HIV field, that they prioritized their statements under the top five statements. All these conclusions lead the researcher towards certain recommendations.

The fundamental recommendation derived from proposed strategies, is that of addressing fragmented care that is derived from over verticalisation of programmes. Realistically spoken, vertical programmes will not disappear over night. Although verticalisation is against the SA national health policy, it is entrenched into the policy and health structure of the FS DoH (Van Rensburg, 2004:158; Schneider, 2006:33; and South Africa, 2007a: 50). The political will on managerial level has not transpired as yet to address verticalisation of programmes, with health personnel on service delivery level not being able to conceptualize a holistic and integrated care of either adults nor children (Heunis & Schneider, 2006:271). The question therefore remains as to what can be done to rectify the problem, when the cause cannot be addressed.

A deliberate, conscious effort to break down barriers between directorates and sub-directorates responsible for various health programmes could alleviate fragmentation of services rendered to HIV positive children. This could even have a positive spill-over effect on all PHC services. This functional integration of various programmes would imply that health management and personnel rendering services should actively seek out opportunities to better communication between programmes (Pleaner, 2007:10). This does not refer to a quarterly meeting between a few programmes where programmes managers purely inform others of actions taken by a specific programme. It should include much more. Functional integration should include actions such as:

- combined monitoring and evaluation of programmes;
- merging the planning of projects or outreaches;
- co-ordinating training courses;
- creating an effective referral policy; and
- consolidating guidelines.

Monitoring and evaluation programmes spanning over various programmes rendering care to HIV exposed and HIV positive children would lessen fragmentation of services. Currently each programme rendering care to these children have their own monitoring and evaluation programmes, with duplication occurring between the efforts put in by each programme. A combined effort between the various programmes can only be successful if all affected levels of HCW buy into the

concept and form part of creating such a combined monitoring and evaluation programme. Such a combined programme would act as a binding factor between various programmes, since they would all be working towards the same outcome. Monitoring and evaluation of services are but one example of how programmes can merge efforts.

Instead of each programme planning its own project or community outreach, within its own budgetary and human resource constraints, a joint effort could again break down fragmentation of services. Health care workers would be given the opportunity to work as a team, addressing identified health care needs in a holistic manner and not placing emphasis on pre-identified health needs in a specific health programme. These pre-identified needs are often identified on national and provincial level, therefore not necessarily addressing true health needs of a specific health district. When this take places, the health care system makes itself guilty of ignoring the tripartite relationship between the health care system, the environment and the patients they serve. Uniting projects can only be truly successful, when HCW and in this case professional nurses, have the same theoretical point of departure.

Fragmentation in training presented to professional nurses rendering care to HIV positive children was a natural consequence flowing from fragmentation of the health care services themselves. In order to establish co-ordinated training to professional nurses, clearly stipulated outcomes are needed stipulating what is expected of a professional nurse who is to render care to a HIV exposed and HIV positive child. The clear need expressed by participants of the NGT was for these professional nurses to be able to render comprehensive care and that the training should be integrated into all programmes. The current situation of each programme compiling and rendering training are strengthening fragmentation of services. Investigation into the possibility of extending the scope of professional nurses to initiate ART to children, as is currently happening with adults, should also be pursued. Whilst such an investigation may take some time, it would be advisable to actively support the training of professional nurses in the complimentary IMCI strategy, where the management of children with HIV is targeted. It would be advisable for the FS DoH to keep record of the number of professional nurses trained in this strategy, as well as to set action plans as to address this venture.

The researcher could not find a copy of a referral policy for the FS DoH, even after extensive enquiries within the department. Such a referral policy is needed and would also address the present fragmentation of health services. The policy should clearly state the up and down referral chain between the different levels of care. Participants identified the need for the policy to not only address referral between, but also within health care centres. The policy should further address referrals between HCW and CHW. Specifics as to what is to be done at which level of care by whom, as well as what the referral criteria to the next level of care should be addressed in consolidated guidelines.

Since each programme is currently producing their own guidelines with limited or no input from other programmes, fragmentation is further entrenched in the health care services. Apart from recommending that this practice should be discontinued, a concerted effort should also be put into place to disseminate guidelines to health care workers rendering services. The researcher found the various guidelines from the programmes not to be available freely, as was also stated by participants from the NGT.

None of the mentioned recommendations are however possible without managerial as well as service delivery personnel buying into the concept of functional integration. It might therefore be needed to investigate how to bring about a paradigm shift, especially seen in the light that functional integration is known to decrease fragmentation and duplication and so enhance integrated service delivery (Pillay in Heunis & Schneider, 2006:266). The influence of possible limitations the study was subjected to has to be taken into consideration.

3.12 LIMITATIONS OF STUDY

The participants that formed part of the NGT being part of this phase of the study did not include community members. Participants represented managerial and service delivery levels. Proposed strategies from community members as how to expand health care services for HIV exposed and HIV positive children in the public health sector in the FS could have been triangulated with strategies obtained from the mentioned group. Triangulated data would have enriched findings.

The researcher was further challenged by the fact that most available literature based on the topic was based on adults and not on children. This therefore left the researcher in the predicament of not knowing what the results would have been, should the research have targeted children as well. Due to the nature of the research, the researcher had to relay closely on input from various representatives within the DoH. Unfortunately in many instances limited cooperation was obtained, in spite of written commitment to the study having been obtained (Addendum C). Although this commitment indicated that the outcome of the research would be informing policy within the FS DoH, the concern exists as to whether this would actually happen, seen in the light of lukewarm commitment shown at times during the study.

CHAPTER 4

Framework

4.1 INTRODUCTION

This chapter will explain how preceding chapters contributed towards the development of a framework to expand public health services to children in the FS. Framework development forms part of Phase 2 of the study as depicted in Figure 4.1.

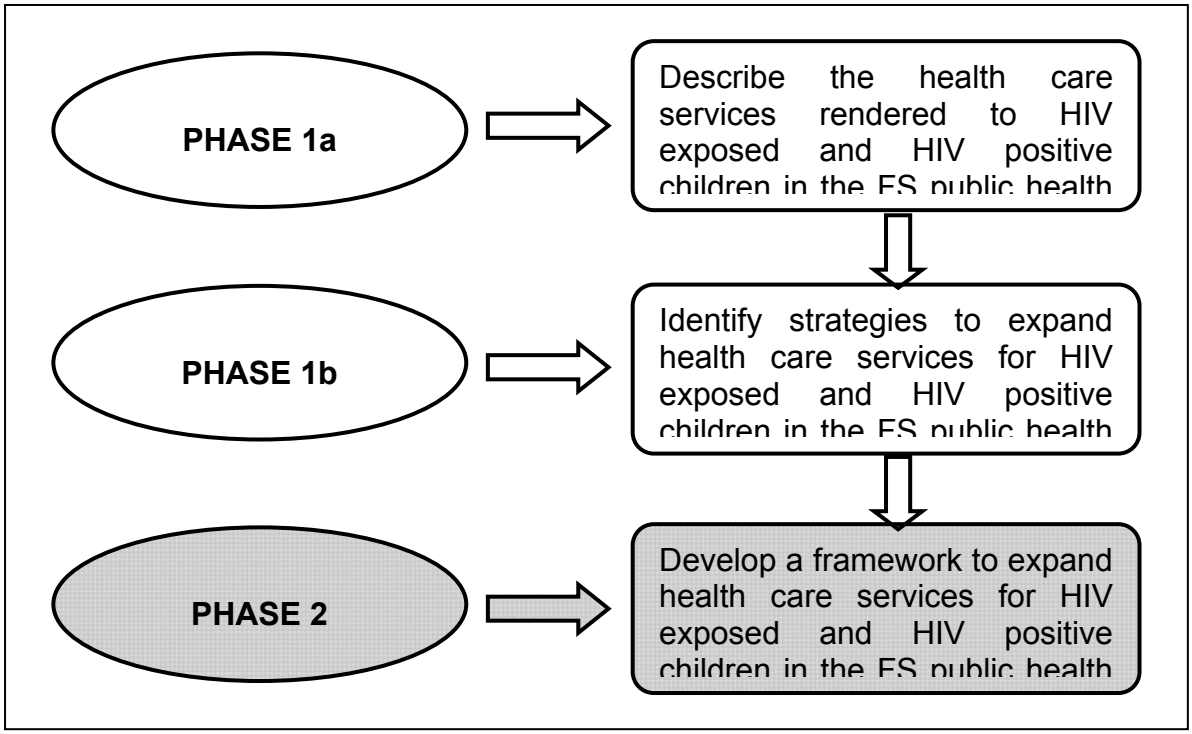

FIGURE 4.1: Placement of content of chapter 4 in the study – Phase 2

During Phase 2 a staggered approach was used to develop the framework. The Theory-of-Change Logic Model formed the theoretical underpinning of the framework with the empirical foundation being based on research findings from Phase 1 of the study. The community[5] needs identified from this research led to formulating desired results for the program[6] reflected in the framework. Factors that could influence change in the program were further identified, as well as strategies that have been successful in similar circumstances. The completed draft framework was validated with the stakeholders, making it possible for the researcher to finalize the framework. The limitations and strengths of the framework were discussed lastly. Before discussing the Theory-of-Change Logic Model, it is important for the reader to take note of certain aspects the researcher had to take into account whilst contemplating the development of the framework.

The aspects referred to include the type of information that had to be reflected in the framework, as well as the manner in which the information had to be reflected. Added to this, literature findings and data gathered during Phase 1 of the research had to be triangulated. Validation of the framework with stakeholders contributed further to the development of the framework. Reilly (cited in McCray, 2003:393) explains that a framework offers a frame of reference and then simultaneously simplifies reality. The only information reflected in a framework is that which the author considers relevant to understanding. However, in this study stakeholders' input necessitated them also understanding information reflected. The researcher was further challenged while developing the framework to integrate information obtained from literature with input collected from stakeholders during their participation in the NGT (Phase 1b of the study). In addition, triangulation of data obtained from Phase 1a and Phase 1b had to be reflected in the framework. As will be discussed further on in the chapter, stakeholders' validation of the framework was essential, posing its own unique challenges. Taking mentioned aspects into consideration, repetition of certain information already reflected in the study was unavoidable. It is necessary to recap on such information, in order to emphasize the

[5] Community referred to is the FS DoH

[6] The program refers to all services rendered to HIV exposed and HIV positive children in the FS public health sector.

need for the development of a framework to expand public health services to children.

4.1.1 The need to develop a framework

It is well known that progress remains disappointing in the prevention, diagnosis and treatment of HIV disease in children, with the WHO promoting a public health approach to expand HIV and AIDS services (World Health Organisation *et al.*, 2007a: 45-46). But, expansion of services can only happen within a strong health care system (Stenberg, Johns, Scherpbier & Tan-Torres Edejer, 2007:305). Within the South African health care system a PHC approach within a DHS is followed. Unfortunately this approach has not been directed to priority needs, such as HIV positive children, and gives a poor account for its performance. The DHS has also not been institutionalized or developed (Schneider & Barron, 2008:ii). This led to a weakened health system where a lack of integrated plans and targets between various programs in the DoH occurs (Travis *et al.*, 2004:900).

The multi-faceted nature of HIV and AIDS necessitates the management thereof in an integrated fashion (Heunis & Schneider, 2006:267). Various SA policies and guidelines emphasize integration, such as the National PMTCT Policy and Guideline, National Strategic Plan, IMCI strategy and The National Antiretroviral Treatment Guidelines, but does not necessarily suggest how this should happen in practice (South Africa, 2004:iii; Loenig in Kibel *et al.*, 2007:198; South Africa, 2007a: 59; and South Africa, 2008:15). One therefore finds PHC packaged into vertical programs in the FS (Fairall, 2005:15). An exaggerated emphasis on verticalization of programs has in turn led to fragmentation and duplication of services. Functional integration has been hailed as a buffer against fragmentation and duplication of services. This type of integration can also enhance integrated service delivery (Pillay in Heunis & Schneider, 2006:266, Pleaner, 2007:10, and Schneider & Barron, 2008:16). Taking the provided background into consideration, one can therefore summarize the problem which framework aims to address as follows:

The SA health care system is weakened by a mediocre PHC approach and poorly developed DHS. The consequence of the DHS not being fully functional is a lack of integration between various programs rendering care to HIV exposed and HIV positive children. The lack of integration in turn, results in fragmented care being offered to the children, due to an over-verticalization of these programs.

The need exists for a framework to be developed to address this problem and so expand public health services to children. The researcher was guided by the Theory-of-Change Logic Model in developing the said framework.

4.2 THEORETICAL UNDERPINNING OF THE FRAMEWORK

Logic models can be divided into three categories, each emphasizing a different approach. An outcome, activity or theory approach can be utilized or even a combination of these. The decision as to which category to use depends on the purpose for using the specific model, as well as where one is in the life of the specific program that is to be addressed by the model (W.K. Kellogg Foundation, 2004:9; Wildschut, 2009:8). Outcome approach models are mainly used when the emphasis is placed on evaluation of programs (W.K. Kellogg Foundation, 2004:10; Wholey, Hatry & Newcomer, 2004:11; McDavid & Hawthorn, 2006:24; and Frechtling, 2007:5). Whereas activities approach models lend prominence to implementation of programs (McDavid & Hawthorn, 2006:43; W.K. Kellogg Foundation, 2004:10; and Wholey *et al.*, 2004:98). The theoretical underpinning for framework development in this study was the Theory-of-Change Logic Model. These models are used to conceptualize program design and planning (Hernandez & Hodges, 2006:167; W.K. Kellogg Foundation, 2004:5; and Wholey *et al.*, 2004:14). It is the appropriate choice, since this model assisted in the conceptualization of the design and planning of integrated health care services to HIV exposed and HIV positive children in the FS public health sector. Theory-of-Change Logic Models have often been applied in health and used by policymakers and program managers for similar purposes (Frechtling, 2007: ix).

As with other logic models, the Theory-of-Change Logic model is a visual representation or a mapping of how a program works (W.K. Kellogg Foundation, 2004: iii; Wholey *et al.*, 2004:11; McDavid & Hawthorn, 2006:41; Taylor-Powell & Henert, 2008:4; and Wildschut, 2009:6). When referring to a program the researcher refers to all services rendered to HIV exposed and HIV positive children in the FS public health sector. The program itself is seen as a theory and therefore has specific theoretical premises on which it is based (Weiss in W.K. Kellogg Foundation, 2004:9; Wildschut, 2009:7). Whenever reference is thus made to *"the program"* within framework development, this wider concept is implied. The reader should not confuse programs rendering services to children in various directorates of the DoH, with what is implied when referring to the program in the framework.

The model provides clarifications as to why a specific idea for a given program is explored. In an effort to explain why a program will work, additional components are added, such as: the problem to be addressed, the reasons for selecting certain types of solution strategies, connections between proven strategies and factors influencing the program and other assumptions the stakeholders have that could influence the effectiveness of the program (W.K. Kellogg Foundation, 2004:9; Taylor-Powell & Henert, 2008:36; and Wildschut, 2009:13-14). It is especially the description of the relationships or causal linkages between these various components that distinguishes the Theory-of-Change Logic Model from other logic models (Wholey *et al.*, 2004:10; Frechtling, 2007:138). The linkage and articulation of the components guide stakeholders in conceptualizing and planning the program, whilst focusing on the problem and reasons for suggesting specific solutions for the program. The emphasis is placed on the big picture or the whole, allowing one to reflect on the function of a system's parts based on their relationships with one another and within the system's larger context (Leonard & Beer in W.K. Kellogg Foundation, 2004:9; Hernandez & Hodges, 2006:166; and Frechtling, 2007:9). In this study the larger context refers to the health care system in which services are rendered to HIV exposed and HIV positive children. The input of stakeholders planning and managing these services is hence essential.

Stakeholders referred to consisted of senior managers of directorates within the Strategic Health Programs Chief Directorate of the FS DoH, as well as representatives of important stakeholders outside this specific Chief Directorate, who are also involved in rendering care to these children. During framework development stakeholders had the opportunity to examine best practice research in order to define the desired results (W.K. Kellogg Foundation, 2004:5). Stakeholders participation were strengthened by logic modeling in itself, as the model facilitates the participation of stakeholders (W.K. Kellogg Foundation, 2004: iii). Participation was of utmost importance in this study, since health system research, as used in this study, is characterized by stakeholder participation (Barron *et al.*, 1997: 6). All stakeholders therefore got the opportunity to examine the program and a common understanding of the program and expectations was thus created (Wholey *et al.*, 2004:11; Frechtling, 2007:11).

Figure 4.2 depicts a template of the model illustrating the various components that assisted in the understanding of the framework, capturing linkages and enabling stakeholders to understand and evaluate hypothesized linkages (Wholey *et al.*, 2004:20).

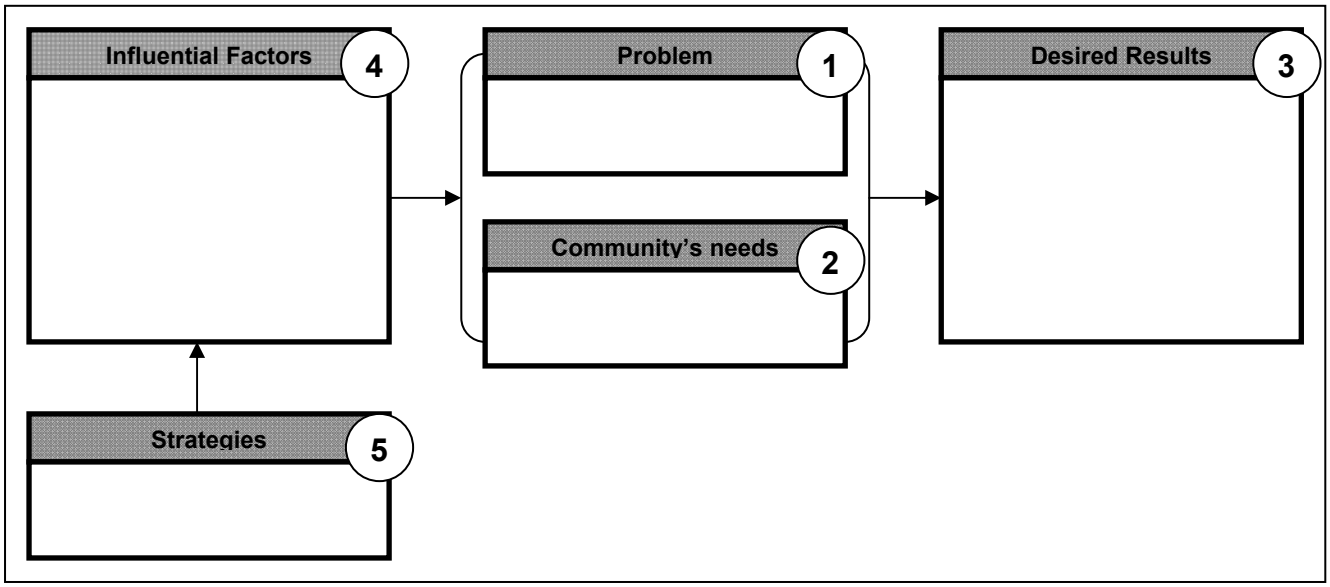

FIGURE 4.2: Theory-of-Change Logic Model template (W.K. Kellogg Foundation, 2004:28)

The problem statement describes the problem the program is attempting to solve, and it is on this statement that the Theory-of-Change Logic Model will be built. It is the problem that actually drives the need for the program. Data reflecting community needs or assets linked to the problem assist one to understand the problem. This data specifies the needs of the community that led the program to address the problem. The identified problem and supporting research assists stakeholders in identifying the desired results of the program and also made stakeholders aware of possible influential factors that could act as barriers or support structures and how it will influence desired results. As the mapping of this model expands, stakeholders are additionally confronted with strategies or *"best practices"* that have proven effective in similar communities (W.K. Kellogg Foundation, 2004:29-31; Wholey *et al.*, 2004:17-24).

Aspects reflected in the model is not elaborated on, but cryptically stated – yet it should still be understandable to stakeholders and reflect how the program works (Wholey *et al.*, 2004:18). Frechtling (2007:91) is of the opinion that in order to prevent becoming lost in complexity the right level at which to describe the program's theory of change has to be identified. Hernandez (2000:31) support Frechtling by stating that a differentiation between program, service or macro level can be made. At program level implementation takes place of strategies generated from the service level. This study described theory of change on macro level, since the design and planning of all services rendered to HIV exposed and HIV positive children within the FS public health sector are conceptualized.

How the conceptualization is presented may vary, but it is usually depicted as a diagram with columns and rows of boxes, with abbreviated text put in a box and causal links shown with connecting one way arrows (Wholey *et al.*, 2004:20). Connections by means of arrows are of utmost importance in articulating the theory of change in a logic model. These arrows show how the various components relate and demonstrate interactions and feedback that are expected to occur (Frechtling, 2007:42). The appropriateness for linking depends on whether a cause effect relationship exists, leading to intended results (McDavid & Hawthorn, 2006:50). However, a problem is created with the depiction of inputs on the far left side and results on the far right side with right pointing arrows that connect the components.

This visual display compels readers to think that the model follows a left-to-right progression. That this is not the case is frequently very difficult, but very important to understand. Central to modelling is that one constantly begins with the results and then work both back and forth and up and down as the model is created (Frechtling, 2007:90).

Having discussed the theoretical background to the Theory-of-Change Logic Model, readers will now be led into the staggered approach followed whilst developing the draft framework, starting with research data obtained during prior phases of the study that confirmed the problem of the program namely:

Fragmented care delivered to HIV exposed and HIV positive children in the public health sector in the FS (due to over-verticalisation of programs)

4.3 EMPIRICAL FOUNDATION OF THE FRAMEWORK – COMMUNITY NEEDS

Phase 1a of the study described the health care services rendered to children in the FS public health sector. Research data obtained from this assessment highlighted community needs. The community referred to in this case being the DoH. The empirical foundation of the framework was further deepened by strategies proposed to expand health care services for these children during a nominal group discussion as part of Phase 1b of the study. Both these sets of findings have been entrenched in extensive literature reviews. The nature of each investigation is briefly discussed.

In order to describe health care services rendered to this group of children, structured interviews were held with professional nurses rendering care to HIV exposed and HIV positive children. The research participants were conveniently selected. The health care facilities where participants worked were selected using proportionate stratified sampling. Referred health care facilities included all public health care facilities rendering care to HIV exposed and HIV positive children in the FS public health sector. The facility population therefore consisted of tertiary-, regional- and district hospitals, as well as community health centrums and primary

health care clinics (Spies, 2008: conference paper). Data obtained from this research made a critical contribution towards the identification of needs within the program and assisted in development of this section of the framework. Apart from the description of the health services, a nominal group was also held.

A Nominal Group Technique (NGT) was used to identify strategies to expand health care services for children in the FS public health sector. This interview technique allowed structured group work to take place, with the group identifying mentioned strategies and reaching consensus on the strategies by following a prescribed sequence of problem solving steps. Participants consisted of representatives on managerial level from three directorates within the Strategic Health Program Chief Directorate of the FS DoH, as well as stakeholders outside the directorate who were also involved in some form of care to these children. This group's participation in the identification of strategies was essential in conducting health policy research by presenting data to be incorporated in the development of the framework.

Data from Phase 1 of the study contributed to a better understanding of the needs experienced by the FS DoH when rendering services to children. Table 4.1 illustrates how the researcher triangulated findings according to the two emerging data categories from Phase 1a and Phase 1b of the study, reflecting fragmented care as the problem leading to the FS DoH experiencing difficulty in expanding services to this group of children. The colour coding used in the table will be replicated in the discussion of the pursuing components of the framework, highlighting to the reader the linkage between the content in the various components of the framework.

In Table 4.1 data obtained from the Health Care category reflected the need for monitoring and evaluation, comprehensive PHC service rendering, strengthening of PMTCT program and referral system, better utilization of guidelines and resources, as well as the effective dissemination of information. The training category indicated a further need for training with addressing fragmentation and duplication, in addition to the need to monitor and evaluate training. Data reflected in Table 4.1 has already been discussed in previous chapters and will be further integrated in discussions of the various components of the draft framework.

TABLE 4.1: Triangulated data from Phase1 reflecting fragmented care delivered to HIV exposed and HIV positive children

DATA CATEGORY	STRUCTURED INTERVIEWS: PHASE 1A	NOMINAL GROUP TECHNIQUE: PHASE 1B	LITERATURE REFERENCES
Health Care	-	Need for *monitoring and evaluation* across programs	(Schneider, 2006:32; South Africa, 2007b: 95; and Magagula, 2009: personal communication)
	Regular referral to "other facility" for counselling, testing, treatment, and follow-up	Move away from *vertical PHC* towards *comprehensive PHC*	(Young *et al.*, 2003:26; Heunis & Schneider, 2006:271; McCoy, 2006:3-4; Schneider *et al.*, 2006:33; Van Rensburg, 2006:61; South Africa, 2007a: 12, 50, 88; and World Health Organisation *et al.*, 2008:115)
	PMTCT one of programs used but not fully implemented	Prioritize *PMTCT* program	(Rabie *et al.*, 2006:13; Schneider *et al.*, 2006:110; South Africa, 2006:37; Chintu, 2007: online; Michaels & Elay, 2007:135; South Africa, 2007a: 76; and Schneider *et al.*, 2008b: 25)
	-	Attend to inadequate *referral* system	(Steyn *et al.*, 2006:130; Van Rensburg, 2006:65)
	Guidelines not fully implemented	Improve utilization of existing *guidelines*	(South Africa, 2005a; South Africa, 2007a; South Africa, 2008; and South Africa, 2008c)
	Doctor driven program in hospitals with health professionals not fully utilized	Address underutilization/shortage of *human resources*	(Steyn & Van Rensburg in Schneider *et al.*, 2008b: 23; and Burbidge, 2009: personal communication).
	Policy/guidelines not widely available, more so in hospital settings	*Disseminate information* effectively	(South Africa, 2003b: 31; Parker, 2007:48; and South Africa, 2008:15, 73)
Training	Need further training and willingness to initiate ART	Need to train *PN to initiate ART*	(South Africa, 2005a: 78; South Africa, 2007a: 93, 147; and South Africa, 2008c: 62).
	Need identified to undergo various training courses	Deal with *fragmentation and duplication* of training	(South Africa, 2001b: 19, 33, 38; World Health Organization, 2006a: 20)Table2.2
	Low training coverage in PHC and programs used to render service to HIV exposed children	*Train* staff *adequately*	(Botma, 2004:19; Lehmann & Zulu, 2005:45; and Steyn *et al.*, 2006:115)
	Need identified for monitoring and evaluation of training due to non-implementation of training received	*Monitor and evaluate* training	

Figure 4.3 portrays the problem statement already identified, as well as a summary of data reflecting community needs, obtained from research conducted during Phase1 of the study.

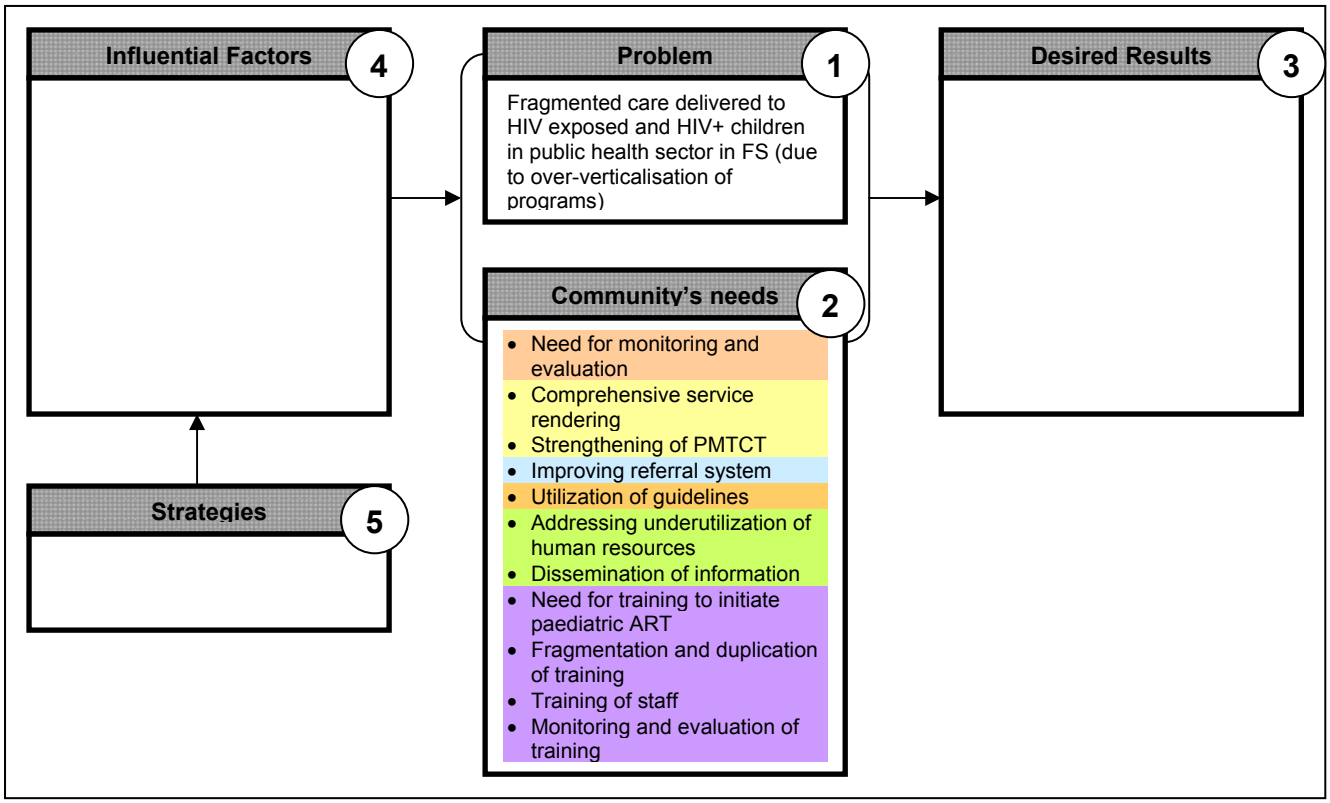

FIGURE 4.3: Draft framework: Problem statement and Community needs

Having mapped the problem statement and community needs of the framework, it was necessary to look at what the desired results of the program could be.

4.4 DESIRED RESULTS

Desired results mapped in the framework can also be referred to as a vision of the future. The short and long term outcomes, planned outputs and possible impact of the program are projected in this way (W.K. Kellogg Foundation, 2004:14, 24). The desired results discussed presently were a purely academic exercise, done without the input of the stakeholders. In order for the stakeholders to later effectively validate the framework, the researcher had to suggest desired results and so assist the

stakeholders to better understand the framework (W.K. Kellogg Foundation, 2004:6; Wholey *et al.*, 2004:10; and Frechtling, 2007:22). The proposed desired results therefore originated from the identified problem and community needs already discussed, with proposals culminating from literature studies that formed part of the study. The researcher aimed to motivate why proposed results would be of benefit to the stakeholders.

Combined monitoring and evaluation across relevant programs

Monitoring and evaluation across programs rendering preventative, curative and rehabilitative services to HIV exposed and HIV positive children are suggested. Figure 2.1 depicted the directorates and sub-directorates providing programs to these children with a successive discussion on the programs. Stakeholders are therefore challenged to identify tangential points across programs in which care to this group of children is addressed. Schneider and Barron (2008: ii) were of the same opinion, strongly suggesting limiting the number of indicators within a specific focus area such as child health. Currently monitoring and evaluation of programs are as fragmented as the programs themselves, in spite of efforts of the Elizabeth Glazier Foundation to combine monitoring and evaluation of two programs (PMTCT and Comprehensive Management and Treatment of ART) (Magagula, 2009: personal communication). The health care system itself would benefit from combined monitoring and evaluation across programs.

Quality of service rendering can only be guaranteed within a health care program when formal monitoring and evaluation exist, enabling management to identify opportunities to improve services (Booyens, 2005:597, 605; South Africa, 2007b: 90; and South Africa, 2008b: 77-78). Should the monitoring and evaluation stretch across programs quality assurance would be further strengthened. The same standard would be set across various programs and it would be easier to co-ordinate aspects identified that need further attention.

Comprehensive and integrated care

In order for comprehensive and integrated care to be delivered to the children, a paradigm shift regarding integration of care needs to take place. Decentralization in delivery of care would only be possible when screening, treatment and follow up of children takes place at the lowest health care level possible. A further movement towards merging projects across relevant programs and using the PMTCT program as vehicle towards integrated service delivery could strengthen comprehensive and integrated care being delivered to children.

Paradigm shift regarding integrated care

Decentralized delivery of care

Screening, treatment and follow-up of child at lowest health care level possible

Merging of projects across relevant programs

Use PMTCT program as vehicle towards integrated comprehensive service delivery

To facilitate integrated care delivered to children in the public health sector, stakeholders would need to make a paradigm shift, away from the current verticalization of programs (and as a consequence fragmentation of services), towards the integrated comprehensive approach as proposed by the Alma Ata Declaration (Young *et al.*, 2003:26; Heunis & Schneider, 2006:271; McCoy, 2006:3; South Africa, 2007a: 12, 50, 88; and World Health Organisation *et al.*, 2008:115). In order to revitalize the PHC approach originating from Alma Ata, health care needs need to be addressed in a comprehensive manner, as well as in an integrated fashion through district and sub-district processes. Horizontal integration of all functions at sub-district and district levels and vertical integration of roles and responsibilities could act as the vehicle to accomplish the desired integrated comprehensive service delivery (Schneider & Barron, 2008: ii). Such an approach is in line with the Kopanong Declaration adopted by government in August 2003 as well as the Birchwood Declaration in April 2008 (National Primary Health Care Conference, 2003; Birchwood Declaration, 2008). The rest of the proposed desired results would automatically follow in the wake of this required paradigm shift.

Decentralization of services to these children would then be a *"natural progression"* within service delivery, making it possible for children to be screened, treated and followed-up at any PHC facility. As has been previously highlighted, this is not the case at present (Steyn *et al.*, 2006:99; Van Turha, 2008a: personal communication; and Tshegare, 2009: correspondence). A paradigm shift would further not make the suggestion of Schneider and Barron (2008:21) to the National and Provincial Department of Health sound foreign. They strongly urged government not to engage in any ad hoc initiatives or campaigns, thus creating the opportunity to critically assess the possible merging of projects across relevant programs. Additionally it is well known that PMTCT programs can strengthen existing health systems, even though poor links currently exist between the PMTCT program and other programs (Chersich & Gray, 2005:397; Michaels *et al.*, 2006:52; and Population Council and Health Systems Trust, 2006:8). Putting the strengthening of the PMTCT program as a desired result, is aligned to recent data obtained from a situational analysis conducted locally. The study explored current practices in paediatric Antiretroviral (ARV) rollout in SA and recommended the creation of a comprehensive PMTCT program and the encouragement of early identification of HIV infected children. This approach has also been endorsed by the WHO which promotes an integrated delivery of interventions for PMTCT and child health services (WHO 2006b: 11; Michaels *et al.*, 2006). The advantages of actually implementing a PHC approach to its full extent are eminent.

It would lead to a common vision and priorities for PHC to which all role players are held accountable, resulting in decentralization of authority and responsibility (Schneider & Barron, 2008: ii). The DHS will act as the decentralized structure and so a strengthened DHS will in turn strengthen the health care system (Travis *et al.*, 2004:900). A break down of barriers between programs will prevent isolated functioning and better quality care (Booyens, 2005:603). It would also make it possible to change the adult orientation in the program towards a family oriented approach which would include children.

Attend to functionality of referral system

Another desired result could be to strive towards a functional referral system. The National Antiretroviral Treatment Guidelines proposes an approach of continuum of care, with a holistic patient focus in an integrated health system. This care is rendered within the context of the DHS and should integrate primary to tertiary levels of care (South Africa, 2004: iii). The proposed continuum of care is only possible in a well functioning referral system. Unfortunately the National DoH's standards set regarding the public health referral system is not adhered to on provincial level. The FS DoH could not provide the researcher with a copy of a referral policy for the FS. This led to HCW having to integrate the various guidelines to be followed regarding referrals and feedback on referrals for themselves. This uncertain situation again led to a further breakdown in the referral chain and so undermined the approach of rendering a continuum of care further (South Africa, 2000:12-13; Dor *et al.*, 2002:103). A functional referral system will have definite benefits.

In the utilization of a Referral Policy communication between assessment, treatment and combined sites, as well as referrals within a health facility will improve. Management would then also be in a position to evaluate whether the policies/guidelines are being followed and act accordingly (McCoy, 2005: 19).

Improving impact of policies/guidelines

Dissemination and implementation of policies/guidelines

Consolidating policies/guidelines between relevant programs

The impact of existing policies/guidelines can be improved should serious attention to the dissemination and implementation of these policies/guidelines be given. Consolidating them between programs rendering services to children is further suggested, with the added guarantee that these policies/guidelines would then be disseminated and implemented. The policies in mention have already been discussed in chapter two. They provide comprehensive guidance when identifying a

nd assessing HIV exposed and HIV infected children, as well as specific recommendations regarding the treatment and follow-up of these children. The content of some of these guidelines overlap, but fortunately do not contradict each other (South Africa, 2005a; South Africa, 2007a; South Africa, 2007b; South Africa, 2008; and South Africa, 2008c). Action needs to be taken in this regard, with the health care system again benefiting from such an action. Consolidating these documents would send a uniform and unambiguous message to all health care workers in the field, assisting them in implementing the policies/guidelines.

Optimal utilization of human resources

Address underutilization /shortage of human resources

Community participation in rendering health care services in a structured/organized manner

Professional and non-professional personnel needs to be optimally utilized. In order to attend to the ripple effect caused by fragmented service delivery, underutilization of human resources and poorly structured community participation needs to be addressed. A nearly 40% vacancy rate of professional nurses in the FS's public health sector and underutilization of professional nurses and doctors rendering care to children necessitates action (Spies, 2008: conference paper). Apart from professional nurses, a large number (65 000 in SA), of CHW forms part of the cadre of PHC providers, with this group being poorly regulated and managed. This is also reflected in the FS where their role and links to facility management has not been clearly explored (Steyn *et al.*, 2006:130; Van Rensburg, 2006:65; and Schneider & Barron, 2008:4). Should these human resource issues be addressed, positive results could transpire.

Maximal utilization of health care staff at tertiary level could already alleviate human shortages experienced at lower levels of care (Spies, 2008: conference paper). Structuring community participation would assist community members in being held accountable for their actions. This being possible in the light of international evidence suggesting that CHW who are well supervised and supported would be able to take responsibility for a number of tasks (Schneider & Barron, 2008: iv, 19).

Evaluate current indicators used to describe services rendered to HIV exposed and HIV positive children

An evaluation of current indicators used to describe services rendered to children is recommended. Presently facilities submit data on a monthly basis where it is then computerized and combined at sub-district, district, provincial and national levels (Schneider & Barron, 2008:4). Most data elements captured in the health facility have their own specified indicator, which can be used to reflect change over time (Giese, 2009:8). Presently data indicators used as part of the FS District Health Information System (DHIS) mainly consist of coverage indicators. Examples of these types of indicators are the number of HIV testing performed during the ante-natal period or, on children of various age groups and the number of clients referred to ART service points for assessment (South Africa, 2007f; South Africa, 2008d). The need exists to have indicators reflecting quality of care being rendered to the group of children in mention. Examples of such indicators would be the measurement of the increase in the percentage of children on ART or those receiving follow-up care. Unfortunately the situation is aggravated by an absence of a culture of information use by managers in planning and management, which in turn leads to a non-critical approach towards current indicators in use (Schneider & Barron, 2008:11).

A strong information system that provides usable information for management creates the basis for management to formulate decisions on (Travis *et al.*, 2004:900; Chopra, 2005:4-5). Should quality indicators be present it would be possible to evaluate aspects such as the retention in care for paediatric ART (Schneider & Barron, 2008:15).

Consolidated paediatric HIV training across all programs

Consolidated paediatric HIV training across programs is needed. Figure 2.3 depicts a sample of the FS DoH organogram illustrating paediatric HIV related training courses presented by various directorates. The need for consolidation of training is further highlighted in Table 2.2 where an overview of topics currently covered by these courses is given, and attention is drawn to the overlap as well as gaps of topics. Matters are further complicated due to the fact that content covered by each topic varies from training course to training course. To make issues worse the expansion of SA's HIV and AIDS services within the public sector, pose a further challenge, since additional personnel needs to be trained and those in the health care system retained. Those already part of the health care system need training themselves (World Health Organisation *et al.*, 2007a: 60). Positive results can be anticipated from consolidating training.

Duplication of training will be ruled out, having a direct effect on trainers and trainees alike. Except for scarce workforce being utilized more effectively, definite budgetary savings would occur. Consolidated training would ensure that health personnel would all have received training on the same content and therefore be able to render standardized care to children. Integration of a number of programs in the health care system, would strengthen service continuity and the facilities itself (Steyn *et al.*, 2006:129).

A summary of the proposed results are reflected in Figure 4.4 where the further development of the draft framework is depicted.

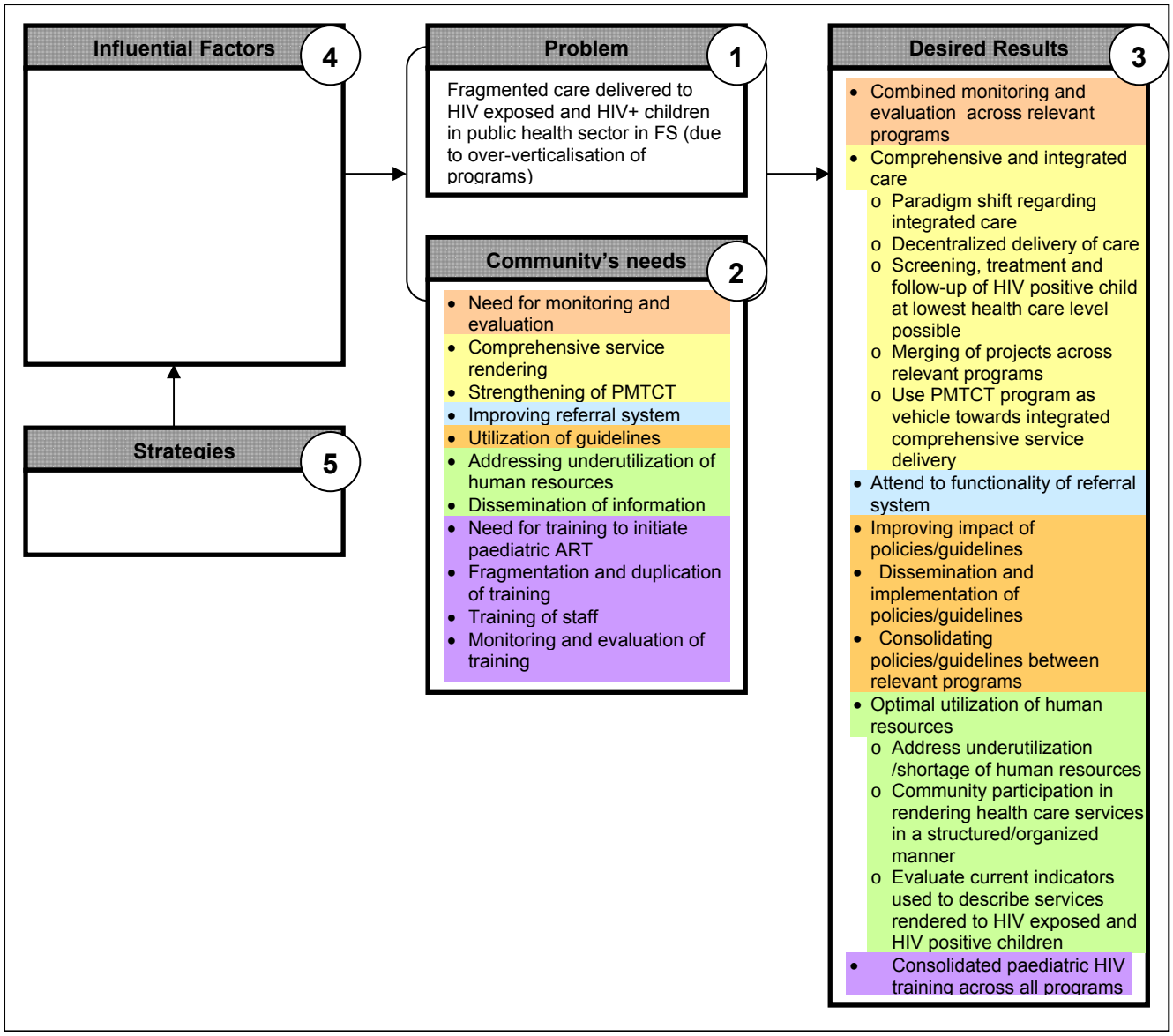

FIGURE 4.4: Draft framework: Problem statement, Community needs and Desired results

In the draft framework thus far the problem statement, community needs and desired results have been discussed. It is however, important to take note of factors that could potentially have an influence on the program reflected in the framework.

4.5 INFLUENTIAL FACTORS

In building a framework according to the Theory-of-Change Logic Model, factors that could act as potential barriers or support mechanisms in a program must be acknowledged. This is important since such factors could influence change in the program (W.K. Kellogg Foundation, 2004:14,30; McDavid & Hawthorn, 2006:50). Stakeholders should not feel discouraged when identified influencing factors falls outside the domain of the program, but they should rather then develop performance partnerships with other programs whose mission is to solve the same problem, being influenced by the same factors (Wholey *et al.*, 2004:18). Most of the influential factors identified in the framework development of this program, do indeed originate from the health care system in which services are rendered to children, thus necessitating partnerships with other programs. The identified factors are the absence of combined monitoring and evaluation projects, the political will to change, health care workers conceptualization of comprehensive and integrated care, the need for clarity regarding referral practices, the fact that guidelines/policies of various programs are not being consolidated, the underutilization of resources, a lack of structured community participation, the absence of coordinated/integrated training, budgetary constraints within the DoH and paediatric HIV care competing with an adult focused program. A brief discussion of what these factors entails follows.

Policy constraint: No combined monitoring and evaluation projects

At present no combined monitoring and evaluation projects stretch across the program reflected in the framework. This policy constraint limits the collaboration between services and strengthens fragmented service delivery, in spite of the WHO endorsing a collaborative approach between services (WHO 2006b: 11; Michaels *et al.*, 2006). A collaborative approach forms part of a health systems approach in which combined monitoring and evaluation fits. Root causes of problems would be identified in this manner and challenges addressed. In the same process combined monitoring and evaluation projects would lead to building upon and strengthening other programs (Chopra, 2005:4-5). Consequently quality improvement would be

achieved which is a core competency for long-term patient care, as is the case with children infected with HIV (World Health Organization, 2006a: 25).

Political will

Political will is a strong influential factor. In spite of documents such as the National Strategic Plan and the PHC approach and DHS being accepted to form the cornerstone of health services in SA, integrated service delivery still does not take place (South Africa, 2000:3; South Africa, 2007a; and Schneider & Barron, 2008: ii). Since children make up almost half of all people in SA, this sector can play a leading role in strengthening the national response to HIV and AIDS (Giese, 2009:20). Political will is needed to implement a reorientation towards these accepted roots of health care delivery in SA and therefore in the FS. This change needs to be embraced and seen as an opportunity for further development (World Health Organization, 2006a: 26; Schneider & Barron, 2008: ii). With results of the 2009 national elections been announced, it is possible that the newly elected national and provincial health government could give new impetus to the surge towards integrated service delivery.

Health care workers conceptualization of comprehensive and integrated care

As have been noted the terms *"comprehensive"* and *"integrated"* are used interchangeably, since comprehensiveness of services necessitates an increased need for integration (World Health Organisation, 2005:108). A study conducted in the FS indicated that health care managers as well as providers were incapable of conceptualizing comprehensive and integrated care. Their concept of seeing services rendered as a collection of health programs, strengthens the delivery of fragmented health care (Heunis & Schneider, 2006:271). The reason for the poor understanding of the concepts in mention could be laid in front of the door of the dysfunctional DHS in SA (Schneider & Barron, 2008:9). This in spite of the WHO and the White Paper on the Transformation of the Health System in SA's view, that the

DHS is to be used to ensure integrated health care delivery (South Africa, 1997:14, 28).

Policy constraint: referral policy

In the absence of a referral policy, such as the case in the FS, health services have to suffice without this important support system. The referral guidelines stipulated in the various guidelines/policies of the FS DoH seems not to be sufficient in rendering the needed support. Should these guidelines/policies not be known to health care workers, as have been seen in a study conducted in the FS, referrals would be further negatively impacted on nurses settings (Dor *et al.*, 2002:103; Spies, 2008: conference paper). A clear referral system assists the services to be more effective, efficient and equitable to the public (Siddiqi *et al.*, 2001:197). The breakdown in the follow-up of exposed children and those who are already seriously ill are examples of the consequences of an inefficient referral system (Rochat *et al.*, 2008:33).

Policy constraint: Guidelines/policies of various programs not being consolidated

The poor outcomes for ART on national level can be ascribed to fragmented planning (Schneider & Barron, 2008:8). The fact that guidelines/policies of various programs are not consolidated directly links to fragmented planning, which in turn leads to fragmented implementation. This policy constraint can therefore have a negative impact on possible program change (Travis *et al.*, 2004:901; Rochat *et al.*, 2008:6). Typically health program policies would only address issues within what it considers to be its own domain, often referring to services rendered by the program as being *"comprehensive".* However, the *"comprehensiveness"* referred to only address issues of the specific program. Examples being the South African National Tuberculosis Guideline, Policy and Guidelines for the implementation of the PMTCT programme, South African National Guidelines on Nutrition for People Living with HIV, AIDS, TB and other Chronic Debilitating Conditions and the Integrated

Management of Childhood Illness policy (South Africa, 2005a; South Africa, 2007b; South Africa, 2007c; South Africa, 2008; and South Africa, 2008b).

Underutilization of resources

The DHS's aim is to ensure that all resources available to a specific area are fully utilized. In this way an integrated, inter-sectoral and collaborative approach to service delivery is facilitated (McCoy *et al.*, 2000:10; McCoy, 2006:8; and World Health Organization, 2006a: 26). Unfortunately, a poorly functioning DHS leads to underutilization of available resources, as have been found in SA and also in the FS. The description of health services provided to children in the FS conducted as part of Phase 1a of this study, confirmed the underutilization of human resources. Professional nurses and medical doctors caring for these children within a hospital setting missed out on multiple treatment opportunities for the children. Their limited involvement led to a heavier burden being placed on medical personnel rendering care to the children in PHC and Community Health Care (CHC) settings (Spies, 2008: conference paper). It is thus clear that the poorly functioning DHS, place health care services under severe strain, since resources are not optimally utilized (Stein, 2005:10).

Lack of structured community participation

Since health care does not occur in isolation, community participation is needed to assist in identifying community needs (Magnussen *et al.*, 2004:172). The community participation can occur in various forms, such as clinic committee's or CHW assisting nursing personnel. With a faltering DHS, clinic committee's are not functioning on the level they could and the policy regulating CHW in the FS need urgent attention to ensure the implementation there-of (Hlope, 2006:199). It is possible that the governments' current revision of the community health worker policy framework could address the present lack of structured community participation (Schneider & Barron, 2008:4). In the mean time HIV positive children will miss out on the opportunity of receiving follow-up care from CHW that would have a positive impact on those who need adherence support (Hlope, 2006:191). Although structured

community participation will benefit a large portion of services, the need for CHW to become actively involved in adherence support to children in the FS has been identified. Only 38% and 57% of hospital and PHC nursing staff respectively indicated that they check drug adherence in children who are on ART. This implies that children would benefit from adherence support offered by CHW, since they do not receive this specific care appropriately from professional nurses settings (Spies, 2008: conference paper).

Policy constraints: Absence of coordinated/integrated training

Health policies governing the various health programs do not necessarily directly address the training content to be covered by each specific training course (South Africa, 2003b; South Africa, 2004; South Africa, 2005b; South Africa, 2007b; South Africa, 2007c; and South Africa, 2008). Due to deductions made from these policy documents national and provincial health managers created various training courses. As a result limited integration of comprehensive paediatric HIV related training occurs within the FS DoH, as a number of short courses are being presented by various directorates. The need for working towards an integrated comprehensive paediatric HIV related training has not been widely recognized. This in spite of the identified need for coordinated and integrated training that is part of the health system, equipping health care personnel to render comprehensive care to HIV exposed and infected individuals (World Health Organisation and UNAIDS, 2004:19; McCoy, 2005:19; South Africa, 2005a: 32; World Health Organisation, 2007c: 1; and Rochat *et al.*, 2008:6, 33). However, the need for coordinated and integrated training can only be addressed once policies are created that enable such training to take place.

Budgetary constraints within DoH

A health care system needs adequate funding to ensure a strong workforce, supplies and equipment (Travis *et al.*, 2004:900; McCoy, 2005:19). Currently the FS DoH experiences serious budgetary constraints. The previous Minister of Health, Barbara Hogan, acknowledged the financial shortfalls of the DoH and identified it as a critical

shortcoming that needed urgent attention so as to ensure the effective management of the public health system (Heyns, 2008:15). The result of the DoH budgetary constraints is that medical services to all public health patients in the FS have been severely compromised. This being so due to unavailability of goods and services at every level of care (OFM news, 2009: Broadcast). The budgetary constraints have a direct impact on HIV positive clients in the FS who can not be placed on ART and have to wait for monetary relief before starting lifesaving treatment (Cloete, 2009:1). These budgetary constraints are further aggravated by poor communication among vertical programs, leading to redundancy, overlap and additional waste (Magnussen *et al.*, 2004:170-171).

Competing with adult focused program

Children's access to treatment and care in SA are limited because the available services are designed for adults (UNAIDS, 2009:13). The children further have to compete with the demands of adult care (Eley & Nuttal, 2007:2-3). This is understandable when the sheer numbers at stake is taken into consideration, being treated by a limited workforce. Children have as a result been left behind in much of the scale-up efforts to date (Gilks *et al.*, 2006:509).

A summary of the factors that could influence change in the program are reflected in Figure 4.5. The reader is again brought up to date with the progress of developing the framework.

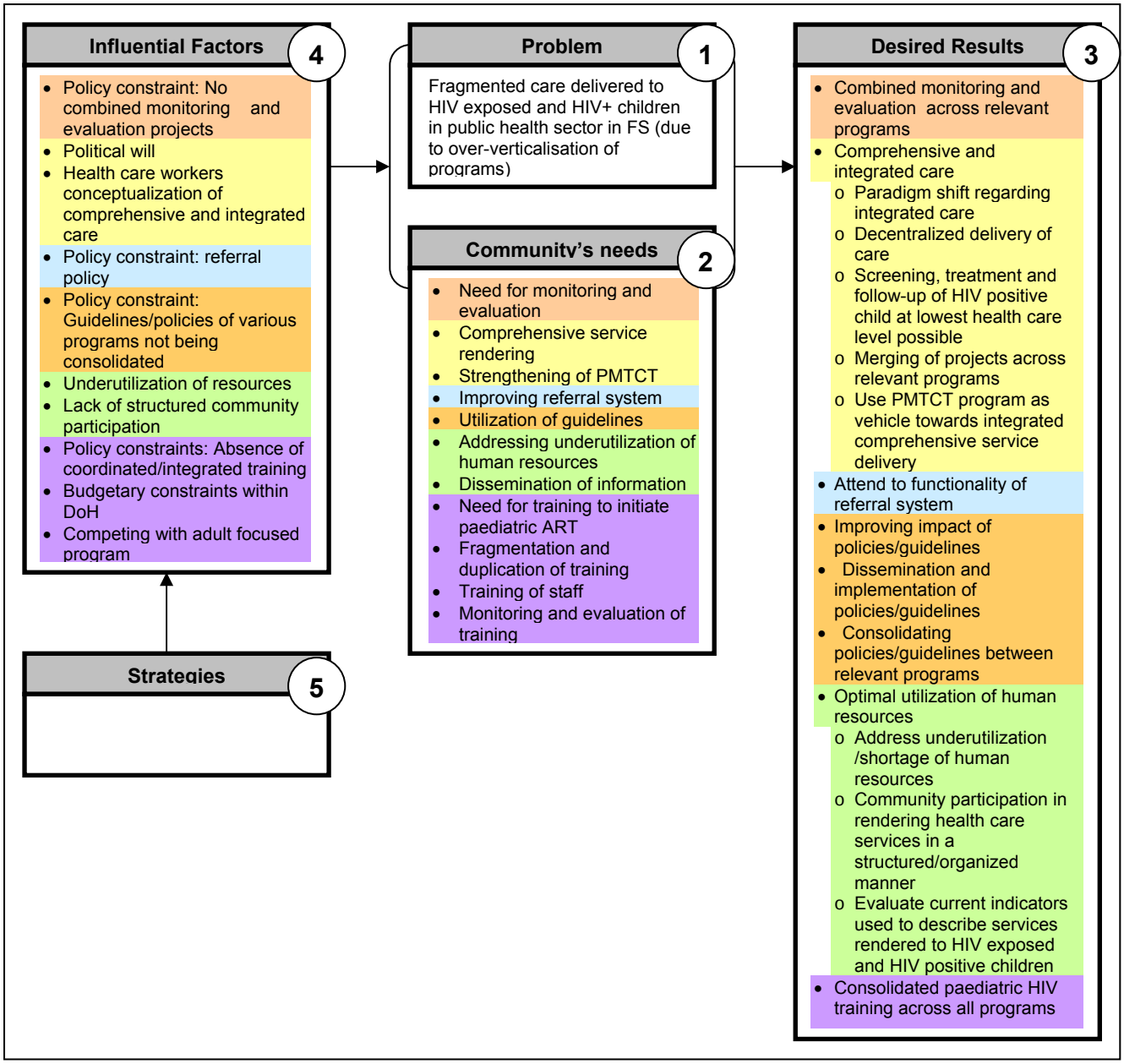

FIGURE 4.5: Draft framework: Problem statement, Community needs, Desired results and Influential factors

In the draft framework so far the problem statement, community needs, desired results and influential factors have been discussed. Taking all this information into consideration, strategies that have been used by others in similar circumstances will now be discussed.

4.6 STRATEGIES

Strategies used to address fragmented care delivered to HIV exposed and HIV positive children in the public health sector in the FS, need to follow a comprehensive and integrated approach with a strong family focus. In generalized epidemics, as we experience with HIV and AIDS, preventative and curative activities lend themselves to a family focus. By targeting only individuals, many HIV interventions and services are missing out on critical opportunities to reach out to family and community members. Comprehensive approaches to children's wellbeing offer vital opportunities to reinforce key components of PHC delivery for all. The health sector further gets the opportunity to integrate actions with child-focused work into other sectors (Horizons Program, 2006:9; Richter, 2008:10; and Irwin, Adams & Winter, 2009:21). This sentiment was echoed by an analysis of service delivery models conducted by the Joint Learning Initiative on Children and HIV/AIDS (JLIC). They found that programs obtain the best results for children when they adopt integrated intervention strategies providing a range of services to the whole family. Systems that integrate HIV and AIDS services with family-centred PHC and providing social services through community–based models were found to be the most effective (Irwin *et al.*, 2009:48). A literature review reflecting strategies or *"best practices"* with a family focus approach, assisted the researcher to gather evidence used to substantiate that the correct program approach has been selected for the development of the framework for this study (W.K. Kellogg Foundation, 2004:14; Wholey *et al.*, 2004:16).

The two categories identified in Table 4.1 namely health care and training have also been used in dividing the literature based strategies. The reason for highlighting strategies that address comprehensive and integrated care is that in the presence of such care, other problems identified in this study become redundant. The integration of monitoring and evaluation, as well as policies/guidelines would be addressed within an integrated approach. Referral would no longer be an issue, with a human resource plan ensuring the effective utilization of health care personnel within comprehensive delivery of care. Other strategies to be discussed are those addressing training and how consolidation of training is proposed.

4.6.1 Comprehensive and integrated care

As has previously been stated, comprehensive care can only be delivered when this care is rendered in an integrated manner. Different meanings have been allocated to the concept integration. Firstly an integrated PHC as an overall approach to all health sectors emphasizes inter-sectoral collaboration and community participation and development. Here the health system is seen as an integrated whole, collaborating with different levels through the DHS. Secondly integrated PHC packages refer to the incorporation of key PHC programs. Thirdly, reference to integrated PHC programs, refers to the integration of two or more programs that were previously separated (Heunis & Schneider, 2006:263). Strategies to be discussed promote functional integration where services seek out opportunities for integration through improved cross referral systems, better communication and greater flexibility (Pleaner, 2007:10). Functional integration decreases fragmentation and duplication, thus enhancing integrated service provision (Pillay in Heunis & Schneider, 2006:266). However, the strategies vary in the way and level integration takes place, therefore influencing the comprehensiveness of service delivery. Examples of these strategies that promote comprehensive and integrated service delivery with a family focus to HIV exposed and HIV affected children, are the IMCI strategy, PMTCT package, using clinical teams and task shifting/sharing to render care and the implementation of integrated home based care.

IMCI

The IMCI strategy was developed by the WHO and UNICEF as a response to the high mortality rate of children under five. According to this strategy an integrated approach to common childhood illnesses is followed. IMCI Case Management provides guidance in the assessment, classification and treatment of acute respiratory infections, diarrhoeal disease, measles, malaria, malnutrition and other infections. Possible HIV identification is also conducted on each child. (Loenig in Kibel *et al.*, 2007:196; World Health Organisation, 2008a: online). The subsequent Comprehensive IMCI added a more comprehensive HIV component of assessment,

classification and treatment for common HIV related skin and mouth conditions, antiretroviral dosages, ART side effects and drug dosages for opportunistic infections to the IMCI Case Management protocol (Qazi & Muhe, 2006:11). Immunization services and nutritional care are further delivered as part of integrated mother- and -child health care intervention (South Africa, 2005a: 31; World Health Organisation, 2007c: 24; and Spencer *et al.*, 2008:35). This strategy is therefore rather successful in integrating comprehensive care to the child itself, as was highlighted in Table 2.2 (World Health Organization, 2006a: 23). A strong emphasis is also placed on involving the primary care giver and the community at large in the care of the child. However, should other family members need health care; they would be referred to appropriate services. The further significance of IMCI is that it facilitates decentralized implementation and that it is integrated within existing health systems. The simplified operational guidelines enable health care workers on different levels of care to deliver HIV prevention, care and ART, as well as to use standardized referral criteria (Gilks *et al.*, 2006:505).

PMTCT

PMTCT plays an important role in paediatric HIV related services, for the reason that primary prevention of HIV infection among women of childbearing age is the most effective and sustainable intervention for PMTCT. Antenatal Care services act as entry point to all PMTCT activities (South Africa, 2008:71). This approach has also been endorsed by the WHO which promotes an integrated delivery of interventions for PMTCT and child health services (WHO 2006b: 11; Michaels *et al.*, 2006). The PMTCT package currently consists of primary HIV prevention programs for women of child-bearing age, routine offer of voluntary HIV counselling and testing to pregnant women, safe infant feeding counselling and support, safe obstetric practices, Nevirapine and Zidovudine to the mother and infant, as well as the provision of infant formula to women choosing this option (South Africa, 2008:18, 23). The Joint United Nations Program of Support on AIDS for SA assists in increasing access to women and children to a comprehensive package of PMTCT – Plus services. These services place emphasis on ensuring that mothers receive the necessary ART treatment (UNAIDS, 2009:18). The PMTCT program aims to

integrate care of HIV exposed infants and their mothers. The Achilles' heel being that in order to render a more comprehensive family focused service, the integration of follow-up of infants born to HIV positive women into the IMCI strategy is needed (South Africa, 2008:15). Effective integration with other paediatric HIV related services would thus lead to more comprehensive health care delivered to these children. A family centerd approach would minimize the necessity for multiple visits to health centres (Giese, 2009:49). Apart from using the IMCI and PMTCT program as strategies, the way in which care is provided can be explored as possible strategies to follow.

Clinical teams and task shifting/sharing

Research has proven that a nurse driven clinical team can deliver a substantial proportion of clinical care and that this type of care is potentially more affordable and acceptable to clients. At the centre of such a team would be a nurse who is adequately trained in PHC, who provides support and supervision to enrolled and assistant nurses, as well as to CHW. The nurse in turn receives clinical support from a generalist doctor. Administrative and pharmacy staff would complete the team (Pienaar *et al.*, 2006b: 7; Schneider & Barron, 2008:19). These clinical teams should function at primary care level and be able to treat non-severe opportunistic infections, manage ART and promote PMTCT, as is found within the IMCI strategy. They would identify complex clinical problems and refer these cases appropriately (Gilks *et al.*, 2006:508). In the absence of having clinical teams functioning at all PHC facilities, it is foreseen that larger better resourced health centres take on a mentoring and supportive role to assist smaller, less resourced centres with implementation of services (Eley & Nuttal, 2007:4; South Africa, 2008:15). Following a clinical team strategy allows for comprehensive care with a family focused approach to take place, with functional integration being facilitated by the clinical team. The expected output from the clinical team and the dynamics of the workforce necessitates task shifting/sharing.

The efficiency of workforce performance can be improved by simplifying services and delegating appropriately. Simplification often improves staff productivity by allowing more to be done, with greater consistency, and often by less skilled colleagues. Task shifting/sharing that flows from simplification, is especially important in resource-constrained settings where skilled staff are short in supply (World Health Organization, 2006a: 23; World Health Organisation *et al.*, 2008:104). The WHO and other health leaders propose to use task sharing to use CHW to form part of the workforce to combat AIDS (World Health Organization, 2006a: 23; Michaels & Elay, 2007:139; and Schneider *et al.*, 2008b: 31). The clinical team can also make use of the client (in the case of paediatric client, the care giver), to render support. The involvement can consist of management of the illness, adhering to treatment, responding to side-effects and preventing transmission to others (Gilks *et al.*, 2006:508). It is especially in delegating traditional nurse based care to lay cadres that comprehensive integrated care can be rendered to clients. Should the use of clinical teams and task shifting/sharing be combined with an integrated home based care model as strategy, even more focus can be placed on a family approach when caring for children (Richter, 2008:8).

Integrated home based care

When integrated home based care is followed as strategy, all service providers aim to render a continuum of care to clients and their families. The strategy endeavours to enhance mutual support and collaboration between different components: families, community care givers, clinics, hospitals, support groups, non-governmental organizations and community-based organizations. It allows for referral between all partners, builds trust and develops capacity in partners. CHW are trained and then supervised and supported (South Africa, 2001a; Van Dyk, 2008:338). Within a family-centred approach, home health visiting involving CHW visiting pregnant and new mothers at home is a promising strategy that could be followed to build capacity within a family-centred approach (Irwin *et al.*, 2009:22). The South African Department of Social Development produced a guideline as how to go about to render/establish home community based care support programs (South Africa, n.d.-a: 10). One such a success story is that of Inkwanca Home Community Based Care

Centre in Molteno in the Eastern Cape, S.A. This centre has been able to combine a number of strategies already discussed. The integrated multi-sectoral approach with a strong family and community focus, allows multi-disciplinary teamwork to take place. Home based care support is provided to children and their families and referrals to necessary services made (Chomba, Eghtessadi, Chingandu & Page, 2008:25). HCW at this centre also receive required training to be an effective member of the team caring for children. Training strategies for professional nurses will now be discussed.

4.6.2 Consolidated training

In a health care environment where comprehensive and integrated care is rendered to children, it is imperative to have multi-skilled health care professionals (Pruitt & Epping-Jordan, 2005:638; Heunis & Schneider, 2006:275). Accessibility to care would be improved, since clients would be attended to at all levels of health care (South Africa, 2005a: 76). The present verticalization of programs has led to fragmentation of health services and also of training of professional nurses rendering paediatric HIV related care. A need therefore developed to consolidate this training and so ensure that training for these health professionals become as integrated and comprehensive as possible. The training must further be coordinated and integrated with the health system (World Health Organisation, 2007c: 1). Specific recommendations regarding such training are found in literature.

Integrated and comprehensive training programs should consist of initial training, regular refresher training, on-the-job mentoring and coaching as well as systematic and regular supervision. Capacity would only be developed if theory and practice are integrated and reflection on practice is allowed (Lehmann & Zulu, 2005:45). The South African Guideline for the Management of HIV infected Children clearly states what should be done at PHC level for HIV exposed children, as well as care needed for HIV positive children (South Africa, 2005a: 23, 24). These expectations can be used as a standard to identify paediatric training content for professional nurses. The African Network for Care of Children Affected by HIV and AIDS (ANECCA) produced the ANECCA Comprehensive Paediatric HIV Care Curriculum. This generic

paediatric HIV Care Training Curriculum is used to train various categories of health workers in several countries in Africa. The training aims to build capacity for comprehensive paediatric HIV care and treatment on the continent (ANECCA, 2006). It might therefore not be necessary to reinvent the wheel, but training could be consolidated taken existing training courses, South African Guidelines and those of ANECCA into consideration when consolidating training content. The positive outcome of such training being that integrated service rendering in health facilities is strengthened (Steyn *et al.*, 2006:129).

Figure 4.6 reflects the completed draft framework. Strategies that could be utilized by stakeholders to address fragmented care delivered to HIV exposed and HIV positive children have been added to the figure.

The completed draft framework was then ready to be validated by the stakeholders in order to finalize the framework.

4.7 VALIDATION OF FRAMEWORK

The validation of the framework was a natural progression of the health policy research used in this study. Since this type of research informs health managers of policy choices, their input in validating the framework was of vital importance, as the framework could be used by them. The health managers have been identified as stakeholders and played an important part right through the study. Their assistance in gathering data during Phase 1a of the study was invaluable and the opportunity was created to give feedback to them on data gathered during that phase of the study. Their important input during Phase 1b made this group part of establishing community needs in the development of the framework.

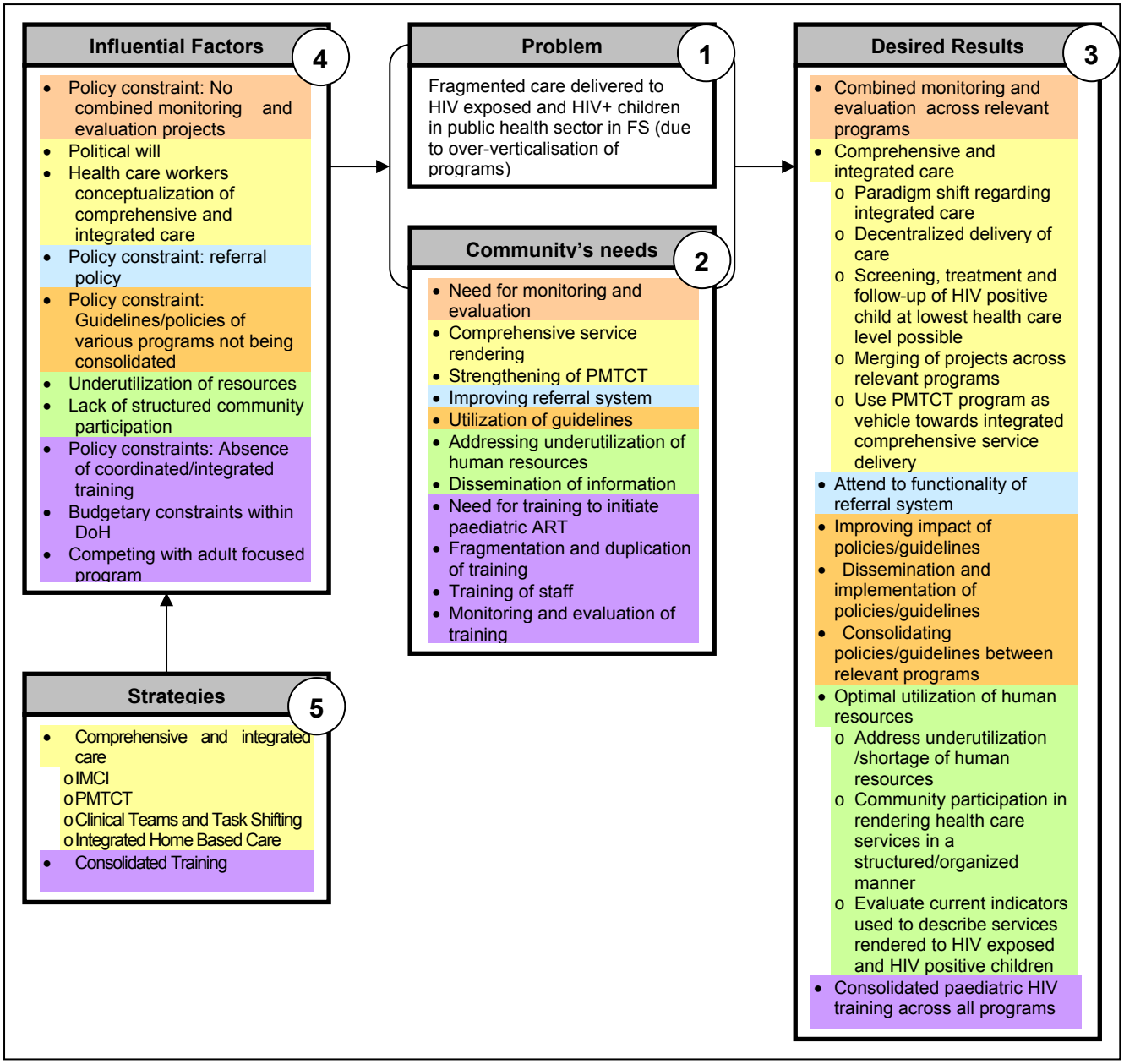

FIGURE 4.6: Completed draft framework

Managerial representatives of the three directorates from the FS DoH (HIV and AIDS/STI & CDC directorate, TB Management directorate and Health Programs & Non-Communicable Disease Directorate) that formed part of Phase 1b of the study again assisted in the validation of the framework. Whereas managers of sub-directorates who resorted under the mentioned directorates also attended Phase 1b, the DoH requested only senior managers of the directorates to take part in the validation of the framework. As during Phase1b, the stakeholder group who validated

the framework further consisted of other stakeholders outside the DoH, who were also involved in rendering care to these children. Due to work commitments only two of the four other stakeholders that formed part of data gathered during Phase 1b could attend the validation of the framework.

Five stakeholders consequently participated in the validation workshop where they were given the opportunity to add their expert advice to the information obtained from literature and research conducted during Phase 1 of the study. Input from the stakeholders directed the researcher in planning a venue and date for the validation workshop that suited those involved. Structured questions, which will be discussed later on in the chapter, formatted the validation of the framework further (Barron *et al.*, 1997:5). In this way the draft framework could be finalized, becoming a workable framework depicting the processes and outcomes of the program (McDavid & Hawthorn, 2006:58). The researcher was further guided by literature on Theory-of-Change Logic modelling as to the process to be followed during the validation of the framework (W.K. Kellogg Foundation, 2004:33; Wholey *et al.*, 2004:19; McDavid & Hawthorn, 2006:58; and Frechtling, 2007:42).

4.7.1 Process followed

The validation process can be seen as a checking process, since one endeavours that stakeholders understand the logical flow of the program from problem identification to proposed strategies. It is not good enough to only specify and discuss the various components. The theory of change would remain vague if verification of hypothesized connections is not made. It was counteracted in this study by using checking questions such as *"how did we get here?"* or *"why is there a connection between these components?"* Since one can use any component as an entry point when asking these checking questions, the process is also known as forward and backward mapping (Wholey *et al.*, 2004:19; Frechtling, 2007:42).

Although stakeholders were given the opportunity during the validation workshop to do forward and backward mapping, the discussions were structured according to the various components of the framework, in the same order of the staggered approach followed in this study. In order to refresh participants' minds, a brief summary of data obtained during Phase 1 of the study was given. (A six month period had lapsed since the last contact session between researcher and stakeholders). Each component was consequently discussed within the group, with the researcher acting as facilitator. These discussions were guided by questions put to the group, allowing them to add their expert advice to a component and clarify the linkage between the various components. (See Addendum F - Validation workshop program). With the assistance of a colleague, the feedback of the group was immediately captured on a computer attached to a data projector with screen, enabling stakeholders to follow proceedings. Input from stakeholders was then also combined with information already captured by the researcher in the draft framework. According to the Theory-of-Change Logic Model, the framework now had a fully fledged scientific base. It no longer only consisted of literature reviews and need assessments that were mainly spearheaded by the researcher, but stakeholders' expert advice were added to scientific data already gathered (W.K. Kellogg Foundation, 2004:33).

The questions put to stakeholders and the specific component of the framework these questions addressed is depicted in Table 4.2. Questions were not only answered in a yes/no fashion, but stakeholders had the opportunity to make comments or propose revisions to the content reflected in the various components of the framework.

TABLE 4.2: Questions posed to validate the framework (W.K. Kellogg Foundation, 2004; Wholey *et al.*, 2004:24; and Taylor-Powell & Henert, 2008:51)

QUESTION	COMPONENT OF FRAMEWORK
1. Is the problem to be addressed in the framework clearly stated?	Problem
2. Are all the community needs identified?	Community needs
3. Is there a specific, clear connection between the identified community needs and the problem to be addressed?	Community needs
4. Are the desired results appropriate?	Desired results
5. Is a clear connection between the problem and community needs identified and desired results visible?	Problem, Community needs and desired results
6. Are all the influential factors identified?	Influential factors
7. Is it clear why identified factors could influence the problem and community needs identified?	Influential factors, problem and community needs
8. Are all the strategies identified?	Strategies
9. Are the proposed strategies viable within the FS DoH?	Strategies
10. Is a clear connection between influential factors and proposed strategies visible?	Influential factors and Strategies

The questions posed to stakeholders in Table 4.2 had been formulated to evaluate the validity of the framework. By answering these questions stakeholders were given the opportunity to add their expert advice to all components of the framework and clarify the linkages between the components. Validating the framework in this way also implied that they were satisfied with the research data used and the manner in which it was used and then reflected in the framework. A discussion of how methodological integrity was pursued in developing the framework to expand public health services to HIV exposed and HIV positive children in the FS follows.

4.7.1.1 Methodological integrity

The touchstones of methodological integrity forming part of the development of the framework were the *credibility* of the framework, various types of *validity* tested by questions depicted in Table 4.2, *transferability* of the framework to the health setting and a range of *triangulations* that strengthened the development of the framework.

- **Credibility**

Anything is deemed credible when it is worthy of belief and comes across as convincing (Anderson *et al.*, 2006:191) The credibility of the framework was ensured by involving stakeholders with the development of the framework (Wholey *et al.*, 2004:549). Them being part of phase 1 of the study, having input in the content reflected in the various components of the framework and validating the framework strengthened the credibility of the framework.

- **Face validity**

Face validity refers to the extent an instrument appears to be measuring what it is supposed to measure (Burns & Grove, 2005:737; Uys & Basson, 2005:81; and Maree, 2007:217). In this case the instrument is the framework being mirrored on the Theory-of-Change Logic Model. Since the development of the framework followed the staggered approach proposed by this model, as well as the guideline as to what the content of each component should be and how the content of each component of the framework should be reflected, face validity of the instrument can be claimed (McDavid & Hawthorn, 2006:140).

- **Internal validity**

Internal validity refers to the extent to which there are no plausible rival hypotheses that could explain the linkages between the various variables and so distort the true reflection of reality (McDavid & Hawthorn, 2006:442; Polit & Beck, 2006:502; Babbie, 2007:G5; and Burns & Grove, 2009:704). The variables in this framework can be seen as the components the framework consists of. During the validation of the framework stakeholders had the opportunity through forward and backward mapping to clarify the causal relationships between the various components and so strengthen the internal validity of the framework.

- **Construct validity**

Since construct validity is concerned with the meaning of an instrument (what it is measuring and why and how it operates the way it does), it involves both the validation of the instrument and the theory underlying it (De Vos *et al.*, 2005:162). Whilst validating the framework with the stakeholders, emphasis was placed on what each construct, in this case each component the framework is compiled of, consists of. This was done by the researcher in her facilitator's role, subsequent to stakeholders adding their expert advice to each component of the framework (McDavid & Hawthorn, 2006:437). The description of these constructs and the further development of the framework were guided by the Theory-of-Change Logic Model. The proof of this being the recording of the development of the framework in a meticulous fashion. Construct validity was thus ensured.

- **Content validity**

Content validity occurs when an instrument covers the complete content of a particular construct. Evidence to ensure content validity can be obtained from literature and experts on the content (Burns & Grove, 2009:693). In this case the construct is again referring to each component of the framework. Content validity of the framework was confirmed given that literature findings and triangulation of data obtained from Phase 1 was reflected in the framework. Stakeholders also had the opportunity during validation to verify that the intended content was captured in each construct. Due to the contextualization of the framework it was not possible to weigh the content up against what is reflected in other programs.

- **Transferability**

Transferability is seen as the extent to which study findings have meanings to others in similar settings (Polit & Beck, 2006:511; Speziale & Carpenter, 2007:49). It differs from external validity or generalisability in that demonstrating the applicability of one set of findings to another weighs heavier with the party who would make the transfer, than with the person(s) who originated the findings (De Vos *et al.*, 2005:346).

However, it is also important to take note that context is extremely important in theory-of-change models. What is true in one context might not be so in another (McDavid & Hawthorn, 2006:440; Frechtling, 2007:9). This in spite of methodological and data triangulation, that is to be discussed shortly, that was used during assimilation of information reflected in the framework. Triangulation strengthened the usefulness of this framework in other settings (De Vos *et al.*, 2005:346). The question thus to be asked regarding transferability of data reflected in the framework is: "*Does it make good sense to implement the framework in the FS DoH*?" (Polit & Beck, 2006:475). Although health system policy research does not address implementation, but aims to inform management of health policy choices, it would be nonsensical to develop a framework that would not eventually lead to implementation (Barron *et al.*, 1997:5). The implementation potential was addressed during the validation workshop with stakeholders (see Table 4.2). All stakeholders were in agreement that strategies proposed were viable to implement within the FS DoH. The developed framework can therefore be transferred to the health care setting identified in this study.

- **Methodological triangulation**

Methodological triangulations refer to combining qualitative and quantitative research designs and consequently the combination of research methods (Burns & Grove, 2005:225; Berg, 2007:7; Speziale & Carpenter, 2007:384; and Burns & Grove, 2009:231). In order to develop the framework, quantitative data was obtained from structured interviews conducted during Phase 1a, an extensive literature review and a validation workshop in Phase 2 of the study. Qualitative data was obtained from a nominal group discussion as part of Phase 1b of the study. Although the data collection was done at a sequential level, since Phase1a was followed by Phase1b, which was followed by Phase 2, the standards of rigor was met for each method used. Even though all the data collection process of Phase 1a is not described in this study, the researcher who acted as co-study leader of the study describing public health services to HIV exposed and HIV positive children in public health services in the FS, could verify the authenticity of the data. Data and analysis of data of Phase

1b and Phase 2 has been discussed in depth. Methodological triangulation therefore strengthened the development of the framework.

- **Data triangulation**

Data triangulation involves the collection of data from multiple sources for the same study, with all having the same focal point (Burns & Grove, 2005:225; Speziale & Carpenter, 2007:381). As has been stated in the previous paragraph data reflected in the final framework was the result of data obtained from structured interviews, literature reviews, a nominal group discussion and validation workshop. These data all addressed aspects of public health services rendered to children in the FS. The manner in which the data was triangulated has followed the staggered approach proposed by the Theory-of-Change Logic Model as the framework was developed. Table 4.1 portrays triangulated data from Phase 1 reflecting fragmented care delivered to HIV exposed and HIV positive children as the problem to be addressed by the framework. The subsequent discussion of each of the components forming the framework namely: community needs, desired results, influential factors and strategies, integrated the mentioned data sources. Data triangulation was thus inherent to framework development.

- **Person triangulation**

Person triangulation refers to the collection of data from more than one level of person that could include either a group or individual or a community (Speziale & Carpenter, 2007:383). In the development of the framework different informants were used in data that was collected to be reflected in the framework. Interviews were held with professional nurses during Phase 1a, whereas health management gave their input during Phase 1b and Phase 2 of the study. Stakeholders outside the FS DoH who were also involved in services rendered to the children, further joined management in providing data used in the development of the framework. According to Dick (1999: conference), deeper involvement of stakeholders increase the diversity of data and therefore eventually their understanding of the framework. Apart from person triangulation contributing to the rigor of the study this triangulation

further more established data trustworthiness (Maree, 2007:3; Speziale & Carpenter, 2007:383). In having validated the framework in the way discussed, it is now possible for the researcher to present the finalized framework to the reader.

4.7.2 Framework

Figure 4.7 presents the final framework developed in the study, to be used by management of the FS DoH to expand public health services to HIV exposed and HIV positive children. Stakeholders' expert advice that did not appear in the completed draft framework has been highlighted in this framework.

Stakeholders' expert advices that did not appear in the draft framework and have therefore not been discussed as yet are now discussed according to the various components of the framework.

- **Community needs**

Stakeholders identified additional needs within the FS DoH that confirmed the necessity to develop a framework that addresses fragmented care delivered to children. The needs identified included the call for a policy addressing donor funding, attending to brain drain experienced by the department and handling the confidential nature of HIV and AIDS in such a way that it does not strengthen fragmentation of services further.

Stakeholders identified *donor funding* as a community need that contributed towards fragmentation of services, although the researcher perceived it rather to be an influential factor that could be seen as another policy constraint to be addressed by the FS DoH. Since stakeholders identified this issue as a community need, it has been reflected as such in the framework. Stakeholders' concern that donor funding entrenched fragmentation of services was based on the fact that money allocated may only be used within a specific program, within preset parameters prescribed by the donor organization. Each donor further prescribed specific data elements to be collected. A study conducted by Mugyeni and colleagues found this concern of FS management to be true. Donor agencies would target specific programs

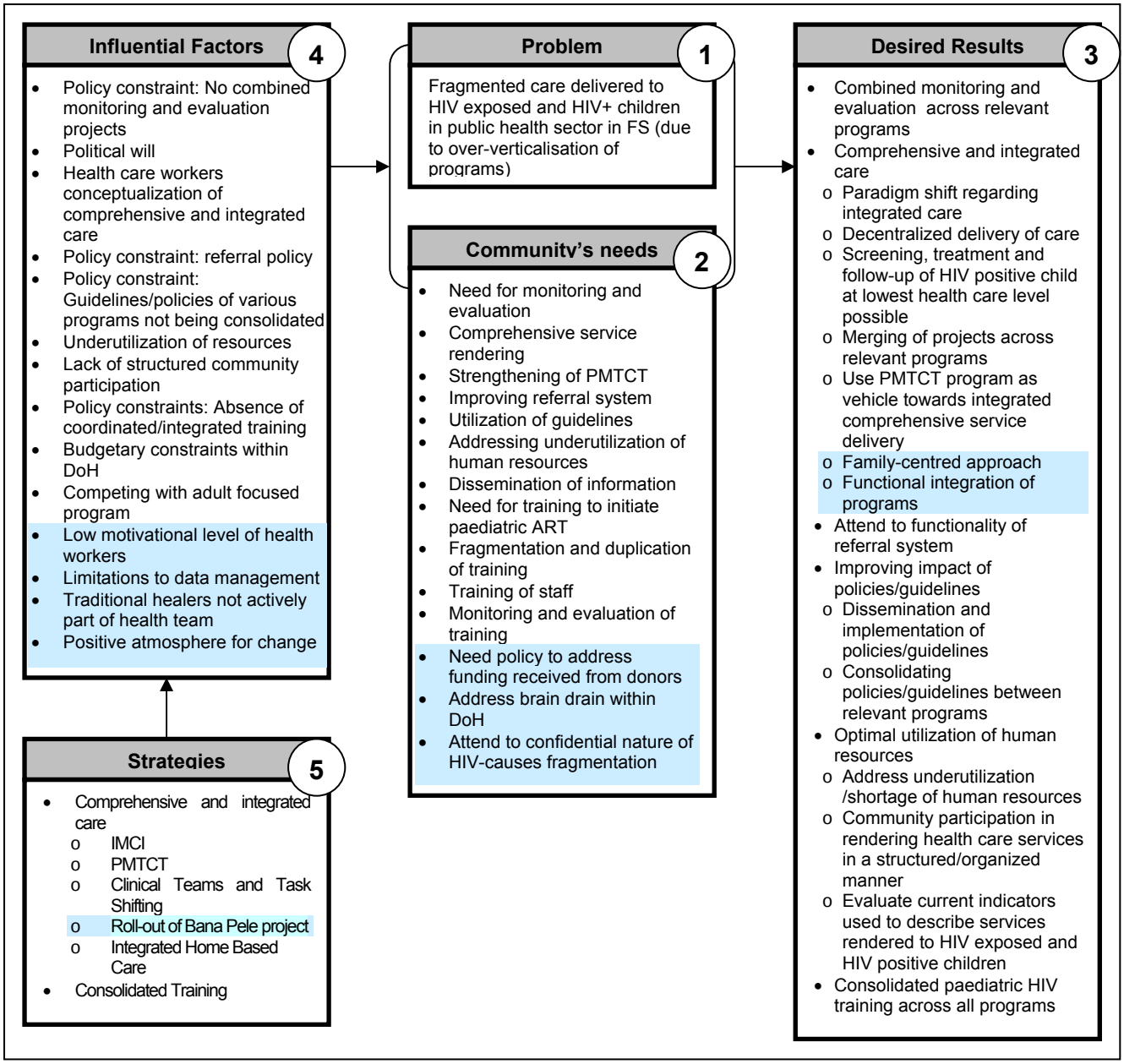

FIGURE 4.7: Framework

within the health system and set targets to be reached by personnel within the program. In order for them to justify the funds provided to the programs, regular report writing is required, which often cause health workers to divert from crucial life-saving services in order to meet deadlines set by these donor organizations (Mugyenyi, Kityo, Kibende, Ssali, Kabuye, Otim, Tugeme, Byaruhanga & Kabugu, 2006:233). The reason why donors opt to generate their own data needed for the structured reports could be due to the weak monitoring and evaluation systems within the DoH, necessitating the donors to generate their own data to

secure future funding for a project (World Health Organisation *et al.*, 2007a: 10). Fortunately donor organizations have become sensitized towards aligning their activities with services already provided within health systems. An example of this being the decision taken at the 2006 High Level Meeting on AIDS, where the United Nations Member States requested that UNAIDS strengthen the harmonization and alignment to national priorities (UNAIDS, 2007a: 56).

The need to retain public health personnel and so prevent *brain drain* was a cause for concern for senior management. This concern is understandable seen in the light that human resource shortage is the greatest challenge faced by the DoH in order to expand health services to children (Population Council and Health Systems Trust, 2006:6; Steward *et al.*, 2006:300; and Steyn *et al.*, 2006:95). Retaining of public health personnel is a worldwide phenomenon, with the WHO also identifying the migration of health workers to the private sector as an aspect to be addressed in order to attend to the workforce crisis being experienced (World Health Organisation *et al.*, 2008:104). The need to stem the outflow of public health sector personnel in the FS is also not a newly identified problem. Doherty (in Steward *et al.*, 2006:301) has already identified it as a critical area of human resource management that needs to be addressed on national level. It therefore seems as if the FS DoH has not been in a position to address this longstanding concern of theirs.

Another aspect highlighted by stakeholders was that the very confidential nature of AIDS, sparked fragmentation of services. Human rights principles protect HIV infected persons in the Charter of Rights on AIDS. This charter address various non-discriminatory actions of which HIV positive people are protected from (Van Dyk, 2008:430). In an effort to adhere to these prescribed actions, HCW tend to refer these clients from one “specialist” to another and often feel uncomfortable in providing a comprehensive service themselves.

- **Desired results**

Stakeholders included two desired results that were not part of the results portrayed in the draft framework, but the concepts were well-established and as such discussed in the strategies of the draft framework. Their proposal to state a *family-centred approach* as a goal they would like to work towards has thus been added to this component of the framework.

Following this type of approach to care and treatment will improve follow-up care for HIV exposed and HIV positive children (Horizons Program, 2006:9; Population Council and Health Systems Trust, 2006:13). Stakeholders further included *functional integration of programs* as an additional result that they would like to have reflected in the framework. They therefore again proclaimed their desire to work towards integration, as they had done in 2005 (Steyn *et al.*, 2006:126). This commitment is heading to the call made in Bloemfontein, SA, at the Round-Table Conference addressing health systems and ART access, to address care and prevention strategies in an integrated manner (Schneider *et al.*, 2008b: 30). The positive outcome being that when HIV services are integrated with other health services, the impact of the investment in HIV interventions are maximized (World Health Organisation *et al.*, 2008:107).

- **Influential factors**

Stakeholders further identified additional factors that could potentially influence change in the community. Potential barriers to change they identified is the low motivational level of health workers, present limitations in data management and traditional healers not actively included in the health team caring for clients. The current positive atmosphere for change experienced within training professional nurses to initiate adult ART was identified as another factor that could influence change.

Stakeholders stated that the *low motivational level of health workers* could most probably be linked to the working conditions of personnel, as well as them having to render a service while lacking basic necessities. This is also not a new phenomenon. Health workers rendering care to HIV affected persons in the FS DoH have felt discontentment as early as 2006 (Steyn *et al.*, 2006:130). In a separate FS study, professional nurses also stated that they were in need of emotional support (Du Plooy, 2006:160). The reason for health workers presenting with low motivational levels can be ascribed to them suffering from burnout and compassion fatigue (Van den Berg *et al.*, 2006: i). Recommendations directed to the FS health management in 2006 included the development of a human resource strategy that would support

health personnel in their work environment and on a personal level (Van den Berg *et al.*, 2006: iii). The fact that senior management still identified this as a possible factor that could influence the implementation of the framework, suggests that these recommendations have not been (fully) implemented.

Three aspects of *data management* concerned stakeholders. Data elements captured did not necessarily capture the information they needed and they were concerned about the quality of data capturing. Furthermore they felt that the management of data could be improved on. Their concern is echoed on a national and international level. McCoy and others (McCoy, 2006:5; Steward *et al.*, 2006:288) agrees that SA is plagued by a weak monitoring system. In addition the WHO pleaded for more progress in order to ensure the availability of high-quality information and to make the best use of information in developing national programs. Emphasis was placed on the challenge faced to collect high quality data (World Health Organisation *et al.*, 2008:108).

Stakeholders stated that no formal communication channels existed between the FS DoH and *traditional healers* practicing in the FS. The absence of such a forum was seen to have a negative impact on the treatment of children. They felt that a formalized structure was needed to regulate referral of clients between the parties. This seen in the light of traditional healers playing an important part in the physical and spiritual health of the majority of people in SA (Population Council and Health Systems Trust, 2006:5; Vermeer & Tempelman, 2006:26, 95). Such a structure could benefit all affected by HIV and AIDS as has been proven in Kwa Zulu Natal and Limpopo provinces. At some health sites in these provinces cooperation between the two parallel systems existed, with traditional healers referring clients to health centres when an HIV diagnosis was suspected and then providing home based care for the HIV patients (Population Council and Health Systems Trust, 2006:5). However, dialogue on national level between the traditional healers and medical groups is still in its infancy (Vermeer & Tempelman, 2006:26).

Stakeholders identified a possible support to change in the program as the current *positive atmosphere* for change. An aspect they identified that attributed to this positive atmosphere was the implementation of the STRETCH program within the PALSA PLUS. The PALSA PLUS being an integration of the National TB Control Program, ARV Treatment Program, as well as elements of the revised Essential Drug List guidelines, VCT and PMTCT (Fairall, 2005:14). The STRETCH program allows professional nurses at pilot sites in the FS to initiate ART to adult clients meeting set criteria. Having given professional nurses the opportunity to initiate ART to adults, stakeholders felt that this could create the opportunity to expand ART initiation to children as well. Professional nurses could be empowered to treat children more comprehensively and in an integrated manner using a "child STRETCH model". Another aspect stakeholders identified that supported a positive atmosphere for change is the current comprehensive training, undergraduate nursing students undergo. They felt that it revolutionized the way people were skilled and that it would have a direct impact in the clinical field where it would be expected of nurses to render a comprehensive service.

- **Strategies**

The possible roll-out of the St Nicholas Bana Pele Network to other districts in the FS was a strategy added to the framework by stakeholders. This network aims to render palliative care for all children in the Motheo District of the FS. Their mission statement is: "*to provide a collaborative network of organizations caring for life-limited children with an effective referral system to ensure quality of life, dignity in death and support into bereavement for children and families*" (St Nicholas Bana Pele Network, n.d.). In order to achieve this mission they have set certain objectives for themselves. They want to develop a strong network of services for vulnerable children. Within the network they aim to identify gaps in the services and close these gaps by building an effective referral system. Children in need of palliative care need to be identified, and those in need of ART's progress need to be monitored. The creation of community wellness centres would act as a community resource for children and their families. Specific attention will also be given to orphans and vulnerable children within the district. A Children's Palliative Care Resource Centre

in collaboration with the University of the Free State will be developed to assist in the expansion of knowledge. The network further aims to act as a resource to strengthen non-governmental, community and faith based organizations to build their capacity to provide care to these children. It is also envisaged that a data base of children within the St Nicholas Bana Pele Network would be created, ensuring that these children are kept within a safety net of services (Basson, 2009: personal communication; Brits, 2009: personal communication; and St Nicholas Bana Pele Network, n.d.)

Having had the opportunity to present and discuss the finalized framework, it is to all those concerned's advantage to scrutinize the strengths and limitations of the framework.

4.8 STRENGTHS AND LIMITATIONS OF FRAMEWORK

The framework has certain strengths built into it. These strengths will be highlighted. As a follow-up discussion possible limitations of the framework and how these limitations were addressed in the development of the framework will be discussed.

Strengths of the framework lie in the fact that:

- The framework *focuses on a priority problem*, namely that fragmented care is being delivered to HIV exposed and HIV positive children in the public health sector in the FS. This focus in the framework is further strengthened by using the Theory-of-Change Logic Model that guided the reader to understand why and how the priority problem was identified (W.K. Kellogg Foundation, 2004:9). The health system research conducted in this study also focus on priority problems and therefore reinforced the focus of the problem identified in the framework (Barron *et al.*, 1997:6);

- *Stakeholders participated* actively in the development of the framework, making the framework to be a more useful tool in which program concepts and plans were clear to all involved (Barron *et al.*, 1997:6; Varkevisser *et al.*, 2003:26; W.K. Kellogg Foundation, 2004:7; and Wildschut, 2009:20). Although implementation

of the framework is not the aim of this study, it has been found that if stakeholders are associated with the implementation of the framework, as is the case in this study, it strengthens the possible implementation and evaluation of the framework at a later stage (Wholey *et al.*, 2004:15);

- The framework can be used to *explore more complex structures* in the DoH, e.g. including adult HIV positive clients or even all PHC clients. The framework can thus be used as guide in other directorates and sub-directorates of the FS and other provinces;

- *Improved health care* is anticipated should senior management of the FS DoH use the information reflected in the framework to inform their policies. Since the framework is aimed at developing solutions for the problem identified and management was part of the generation of the solutions, this would be possible. Solutions need to be affordable and effective and has been validated by the stakeholders to be as such (Barron *et al.*, 1997:6; Varkevisser *et al.*, 2003:26; and Wholey *et al.*, 2004:11);

- The framework offers a *coherent way of thinking about processes*. Fundamental to these processes is a common understanding of the program, which the framework facilitates (Wholey *et al.*, 2004:11). According to McDavid and Hawthorn (2006:67) a visual model is worth *"a thousand words".* The framework outlines cause and effect linkages, defines the problem attempted to be addressed by the framework and quantifies the scope of needs that explains why the problem exists. The framework further acknowledges factors that may influence the ability to change and applies best practice research in proposed strategies to address the identified problem (W.K. Kellogg Foundation, 2004:27; McDavid & Hawthorn, 2006:68; and Frechtling, 2007:11); and

- The *timely development* of the framework strengthened the importance of the framework further (Barron *et al.*, 1997:6; Varkevisser *et al.*, 2003:26). The framework was finalized soon after a new political dispensation started in SA and the FS. This created the opportunity for health managers to propose further

investigation of the framework, which could lead to the implementation and resultant evaluation of the implemented actions.

Limitations that could have a negative influence on the framework are the possibility that:

- The *framework could fail to be sensitive* to factors outside the framework (Frechtling, 2007:93). This has not been the case in this study, as factors that could influence the program were identified. The researcher and stakeholders alike were aware of the fact that care rendered to children is rendered within the bigger public health care system. Any aspect influencing the health care system would therefore also influence the framework;

- A complete *multidisciplinary team* did not partake in the development of the framework (Barron *et al.*, 1997:6). The fact that stakeholders mainly consisted of management within the FS DoH did not act as a limitation at this stage of the framework development, due to the emphasis being placed on informing management on policy issues. Should an implementation and evaluation phase of the framework commence, which falls outside this study, the input of a multidisciplinary team would be valuable. Wholey and colleagues (Wholey *et al.*, 2004:16) have the same opinion. They state that it is correct to identify stakeholders closely associated with the program and then later to move to others who are either affected by the program or who have a stake in its results. It is also the preferable route to follow when working with complex programs as was the case in this study;

- The development of the framework could take up so much *time and resources* that not enough energy and resources remain to address the actual problem initially identified (Wholey *et al.*, 2004:25; Frechtling, 2007:91; and Wildschut, 2009:20). Since the development of the framework was part of a PhD study, the development did not have any negative impact on stakeholders and the framework as such. The development of the framework was budgeted for as part

of the research and structured time periods were negotiated with the stakeholders to purposefully address the problem;

- The *framework* can be criticized as being *too linear* with people tending to assume a chronological sequence that may not be the case (Wholey *et al.*, 2004:26; Taylor-Powell & Henert, 2008:6). Taking stakeholders through forward and backward mapping of the framework, the influence of linear thinking was counteracted. In this way this possible limitation on the framework was reduced;

- The *framework* can be seen to be *rigid* rather than dynamic and unable to capture the change inherent to the program and its circumstances (Wholey *et al.*, 2004:26; McDavid & Hawthorn, 2006:69; and Wildschut, 2009:20). Since stakeholders were involved in the development and validation of the framework, it gave them the insight to be able to update changes and so keep the framework relevant;

- Instead of seeing the *framework* as a means to understand the program, it may *become an end in itself* and so prevent stakeholders from recognising the need for change (McDavid & Hawthorn, 2006:68; Wildschut, 2009:20). The framework and its "future" are in the hands of FS DoH stakeholders. Every effort has been made to involve them as much as possible, for them to be part of the process and understand the benefit of the framework, in order to prevent the framework being seen as the end product.

4.9 CONCLUSION

The framework to expand public health services to HIV exposed and HIV positive children in the FS has been presented. The need to develop a framework has been necessitated by the current fragmented service delivery to these children. With the Theory-of-Change Logic Model acting as the theoretical underpinning of the framework, the platform was created for the staggered approach followed in the development of the framework. Most of the data reflected in the framework is not new and well described in literature. The value of the framework lies in the careful

integration of the various components of the framework that represents a plausible approach to extend services to the children in mention. The further significance lies in the fact that the developed framework became available at a time when key decisions need to be made.

The timeliness of the framework echoing the sentiment that the Alma Ata principles should be revitalized, leading to a revitalization of PHC and a strengthened DHS should not be underestimated (Magnussen *et al.*, 2004: online; Schneider & Barron, 2008). These principles emphasize the rendering of integrated care that acts as a buffer against fragmented care. Even though this study highlights the pledge of HIV exposed and HIV positive children, in many ways the response to HIV and AIDS in young children is a microcosm of the challenges for an effective response overall (PANOS Southern Africa, n.d.). Taking this into consideration, the question can rightfully be asked what this framework can achieve.

When one examines what the framework can and can not accomplish, one has to take into account that health policy research, as used in this study, aims to inform higher levels on health policy choices. Participation of stakeholders was increased as a spirit of collaboration between the parties prevailed. A willingness to learn from and to incorporate the experience and knowledge originating from both parties laid the foundation for this participation. But, even though the FS DoH participated in the development of the framework, the extent to which the framework will actually inform policy is in the hands of the DoH.

Borrowing from the Indian myth of Indra's net, one can only hope that a sensitivity and urgency towards rendering comprehensive and integrated care would prevail amongst all role players rendering care within this intricate net to children.

"*At the beginning of the world the great god Indra tied strands to everything. Earth, sky, clouds, stars, sea, land, mountains, fish, animals, birds, plants, trees, men and women, all were connected. The connecting strands formed Indra's net. Therefore, the movement in any one place caused movement in others. Also, the strands were hard to see, almost invisible in some places, invisible to others. At the intersection of the crossing strands, Indra placed a bell. Thus, one movement effects other movements and the bells ring*" (Davidson, MacIntosh, McCormick & Morrison, 2002:71)

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ADDENDUM A

Permission to conduct study granted by the Ethics Committee, University of the Free State[7]

[7] The title of the study has been amended at the Ethics Committee. UFS

UNIVERSITEIT VAN DIE VRYSTAAT
UNIVERSITY OF THE FREE STATE
YUNIVESITHI YA FREISTATA

Direkteur: Fakulteitsadministrasie / Director: Faculty Administration
Fakulteit Gesondheidswetenskappe / Faculty of Health Sciences

Research Division
Internal Post Box G40
☎(051) 4052812
Fax nr (051) 4444359

E-mail address: gndkhs.md@mail.uovs.ac.za

Ms H Strauss

2007-07-26

MS M REID
SCHOOL OF NURSING
UFS

Dear Ms Reid

ETOVS NR 103/07
PROJECT TITLE: DEVELOPMENT AND IMPLEMENTATION OF STRATEGIES TO EXPAND PUBLIC SECTOR PAEDIATRIC ANTIRETROVIRAL THERAPY SERVICES IN THE FREE STATE.

- You are hereby informed that the above-mentioned study has been approved by the Ethics Committee at the meeting held on 24 July 2007 on condition that it is mentioned in the Informed Consent that the results may be published.
- The following documents are used by the Ethics Committee as guidance documents: Declaration of Helsinki, ICH, GCP and MRC guidelines on bio medical research. Clinical trial guidelines 2000 Department of Health RSA; Ethics in Health Research: Principles structure and processes Department of Health RSA 2004, the Constitution of the Ethics Committee of the Faculty of Health Sciences and the guidelines of the S.A. Medicines Control Council as well as laws and regulations with regard to the Control of Medicines.
- Any amendment, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.
- The Committee must be informed of any serious adverse event and/or termination of the study.
- A progress report should be submitted within one year of approval of longterm studies and a final report at completion of both short term and long term studies.
- Please refer to the ETOVS reference number in correspondence to the Ethics Committee secretariat.

Yours faithfully

.....

for **PROF BB HOEK**
CHAIR: ETHICS COMMITTEE

339, Bloemfontein 9300,RSA ☎ (051) 405 2812
Republiek van Suid-Afrika / Republic of South Africa
gndkhs.md@mail.uovs.ac.za

ADDENDUM B

Consent Form for partaking in Nominal Group Technique

INFORMED CONSENT – NOMINAL GROUP

Dear Colleague,

This letter is to ask you to participate in a collaborative research project of the University of the Free State and the Free State Department of Health. The researchers are trying to establish strategies to improve health care services rendered to HIV exposed and HIV positive children in the public health sector in the Free State. A group discussion, using the nominal group technique, will be held. The discussion will last approximately two hours. During this group discussion you will be asked to propose the mentioned strategies. Thereafter the opinions will be clustered and prioritized according to the group's consent. All information will be handled confidentially and will only be used for research purpose. The results of the study may be published and you will also not receive any remuneration. Participation is voluntary with no retribution should you refuse to participate or want to withdraw.

Your participation will be much appreciated and valued. You may contact Ms M Reid, Cel 0844614634, with further enquiries. If you are willing to participate, will you please complete the form below?

I,……am willing to participate in the group discussion dealing with strategies to improve health care services rendered to HIV exposed and HIV positive children in the public health sector in the Free State.

.....	.....
Signature of participant	**Signature of witness**
.....	.....
Date permission given	**Date permission witnessed**

ADDENDUM C

Permission to conduct research granted by Free State Department of Health

health

Department of
Health
FREE STATE PROVINCE

Prof. Y Botma

RE: Permission to conduct research on Peadiatric ART access.

28 July 2008.

Prof. Botma

Your letter dated 7th April 2008 followed with a meeting held on the 6th June 2008 with Me P. Shai-Mhatu to request approval to conduct research on Peadiatric ART access refers

Kindly be advised that the Executive Management has granted approval to conduct this research at the Free State Department of Health Institutions.

The following conditions should be observed:

- The participants should be informed of the research purpose.
- Facilities where the research will be conducted should be informed on time.
- The study should not interfere with patient care.
- The Free State Department of Health Management will be informed of the findings.
- The issues of how research will inform policy for the Department will be clearly stated in the recommendations.

Kind regards

Prof. P.L. Ramela
HOD: FREE STATE DEPARTMENT OF HEALTH

UNIVERSITEIT VAN DIE VRYSTAAT
SKOOL VIR VERPLEGING
2008 -07- 30
SCHOOL OF NURSING
UNIVERSITY OF THE FREE STATE

KOMMISARIS VAN EDE
DS. C. CROWLEY

Head: Health
PO Box 227, Bloemfontein, 9300
4th Floor, Executive Suite, Bophelo House, cnr Maitland and, Harvey Road, Bloemfotein
Tel: (051) 408 1107/8 Fax: (051) 408 1055, e-mail: hodpa&fshealth.gov.za@fshealth.gov.za

ADDENDUM D

Van Breda's guideline to calculate Nominal Group Technique ranks

VAN BREDA'S GUIDELINE 6 CALCULATE NOMINAL GROUP TECHNIQUE RANKS

Step 5: Calculating Combined Ranks

> In step five you will follow a number of substeps to determine the relative importance of each theme to all the groups combined. This will result in a consolidated and prioritized list of themes/categories.

Having completed the qualitative analysis of the data (ie the content analysis), you are now ready to do the quantitative analysis. This involves calculating the relative importance of the themes you have generated for the entire sample.

Select all the data on the spreadsheet and sort it as follows:

- By Column B (Theme) first, in *ascending* order,
- and by Column F (Top5) second, in *descending* order.

Save the file and print it. Refer to this printed list of statements during the following steps. It is helpful to draw a line between the groups/themes of statements.

Now create a second spreadsheet and type the following headings into the top row:

Column A	Theme
Column B	Top5 1
Column C	Top5 2
Column D	Number 1
Column E	Number 2
Column F	Average 1
Column G	Average 2
Column H	Final Rank

Column A (Theme). In Column A type the themes that you created in the previous two steps. Type in both the theme number and the theme name, eg '1: Support Systems'.

Column B (Top5 1). Add up how many times you typed an 'x' in Column F (Top5) of the printed list of statements, per theme. All of the x's should appear at the top of the list of statements for each theme. Type these totals into Column B for each theme.

Column D (Number 1). Add up the number of statements that fall into each theme on your printed list. Type these totals into Column D for each theme.

Column F (Average 1). Calculate the average score for the statements in each theme, by adding up all of the average scores in Column F of the printout and dividing it by the number of statements as you calculated in the previous paragraph. Type these averages into Column F for each theme.

Now select all the information in this file and sort it according to Column B (Top5 1) in *ascending* order. Check to ensure that the table has sorted correctly. In Column C (Top5 2) type the numbers 1, 2, 3, etc to the end of the list of themes. Now covert these numbers into ranks, following the procedures described below:

- Compare the numbers in Column B (Top5 1) with the numbers you have entered in Column C (Top5 2). If some adjacent statements received the same score in Column B, you will need to adjust the scores in Column C for those statements. If two or more statements got the same Column B score, calculate the average of the Column C scores for these statements and change the Column C scores for these statements to this average score. For example, if statements 3 and 4 in Column C both got a Column B score of 18, calculate the average of 3+4, which is 3.5. So both of these statements would get a Column C score of 3.5. Now Column C would be numbered: 1, 2, 3.5, 3.5, 5, 6… Follow this same procedure if there are two or more statements with the same Column B scores.

- *A shortcut for Odd Numbers of Statements.* If there is an *odd* number of statements which all have the same Column B score, take the value of the middle Column C score, and give this value to the Column C scores for all of these statements.

- *For example.* If the Column C scores 4, 5 and 6 all have the same Column B score, make the Column C scores for all three statements equal 5, which is the middle of the three scores. Note that the average of 4+5+6 is 5.

- *Another example.* If the Column C scores 9, 10, 11, 12 and 13 all have the same Column B score, make the Column C scores for all five statements equal 11, which is the middle of the five scores. Note that the average of 9+10+11+12+13 is 11.

- *A shortcut for Even Numbers of Statements.* If there is an *even* number of statements which all have the same Column B score, work out where the mid point is between the Column C scores, take the smaller of the numbers on either side of that point and add .5 to it. Give this value to the Column C scores for all of these statements.

- *For example.* If the Column C scores 2 and 3 have the same Column B score, the midpoint is between 2 and 3. The smaller number is 2. Add .5 to 2 and you get 2.5. Make the Column C scores for both statements equal 2.5. Note that the average of 2+3 is 2.5.

- *Another example.* If the Column C scores 5, 6, 7 and 8 all have the same Column B score, the midpoint is between 6 and 7.maller number is 6. Add .5 to 6 and you get 6.5 Make the Column C scores for tall these statements equal 6.5. Note that the average of 5+6+7+8 is 6.5.

- Check that everything is correct; if so, save the file before you continue.

Now select all the information in this file and sort it according to Column D in *ascending* order. Repeat the ranking process described above in Columns D and E.

Sort the file for the third time according to Column F in *ascending* order and repeat the ranking procedure in Columns F and G. You have now converted Columns B, D and F into ranks, with higher numbers being of greater importance. If you have access to a statistical computer programme you should be able to do all of this automatically. Consult textbooks for more information on ranking procedures (eg. Meddis, 1984).

Add up the three sets of ranks you have just created in Columns C, E and G for each theme, and type the result into Column H (Final Rank). Now select and sort all the data according to Column H in *descending* order. Print this table. The theme that appears at the top of the list is the theme that the groups in combination rated as the most important theme. The theme at the bottom of the list is the least important (though not necessarily *unimportant*) to the group as a whole.

It is worth noting that each of the three dimensions (Top5, Number and Average) are important for different reasons. The Top5 score incorporates only the statements that groups feel most strongly about – they may vote for 20 statements but only the first few are of great importance to them. The number score accounts for how often participants refer to a theme or issue – the more often they mention a theme, the more important it is likely to be, even if the statements did not receive many votes. The Average score incorporates all the statements but in a standardized way – the highest and lowest scores are set for all the groups irrespective of group size. The combination of these three scores into the Final Ranks provides a holistic and multidimensional consolidation of the many statements generated and ranked by the participants.

ADDENDUM E

Programme of Validation workshop

WORKSHOP: Validation of framework to expand public health services to HIV affected and HIV positive children in the Free State – 27 May 2009

PROGRAM

08h30 – 09h00	Tea & Coffee	
09h00 – 09h05	Welcome	*(Prof. Y. Botma)*
09h05 – 09h25	Results of situational analysis	*(Me. C. Spies)*
09h25 – 09h45	Feedback on nominal group discussion Introduction to Theory-of-Change Logic Model used Problem identified from research	*(Ms. M. Reid)*
09h45 – 10h00	Tea & Coffee	
10h00 – 10h25	Expert advice on organizational needs discussed in small group [10 min] Feedback to larger group [3 min] Research & literature based data re-organizational needs [5 min]	*(Group)* *(Ms. M. Reid)*
10h25 – 10h50	Expert advice on desired outcomes discussed in small groups [10 min] Feedback to larger group [3 min] Research & literature based data re-desired outcomes [5 min]	*(Group)* *(Ms. M. Reid)*

10h50 – 11h15	Expert advice on influential factors discussed in small groups [10 min]	
	Feedback to larger group [3 min]	*(Group)*
	Research & literature based data re-influential factors [5 min]	*(Ms. M. Reid)*
11h15 – 11h40	Expert advice on strategies discussed in small groups [10 min]	
	Feedback to larger group [3 min]	*(Group)*
	Research & literature based data re-strategies [5 min]	*(Ms. M. Reid)*
11h40 – 12h00	Final comments by stakeholders	
12h00 – 12h15	Closure	
	Light lunch served	