

THE PSYCHOLOGICAL, SOCIAL AND DEVELOPMENT NEEDS OF BABIES AND YOUNG CHILDREN AND THEIR CAREGIVERS LIVING WITH HIV AND AIDS



HSRC
Human Sciences
Research Council

**Tamsen Rochat,
Carol Mitchell &
Linda Richter**



health

Department:
Health
REPUBLIC OF SOUTH AFRICA

unicef 

Copyright © 2008

Department of Health, South Africa

The opinions expressed herein and any statements represented as fact do not necessarily reflect the views and policies of the Department of Health or UNICEF nor should they be assumed to do so. This report has been prepared with the help of many individuals and agencies and the views expressed in this document are solely the responsibility of the contributors. With an identification of Department of Health as source, the document may, however, be freely reviewed, abstracted, reproduced and translated, in part or in whole, but not for sale nor for use in conjunction with commercial purposes.

Photography: Tamsen RoCHAT/HSRC

Design and typesetting: Handmade Communications

**THE PSYCHOLOGICAL,
SOCIAL AND
DEVELOPMENT NEEDS
OF BABIES AND YOUNG
CHILDREN AND
THEIR CAREGIVERS
LIVING WITH
HIV AND AIDS**

**TAMSEN ROCHAT, CAROL MITCHELL
& LINDA RICHTER**

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	3
EXECUTIVE SUMMARY	4
Introduction	4
Research activities and rationale	4
Summary of key findings	5
Early childhood development	5
HIV and AIDS and the young child	5
Children living with HIV and AIDS	5
Lessons learnt from South Africa	6
Experiences of children and caregivers	6
Recommendations	6
CHAPTER 1: THE RESEARCH FRAMEWORK	8
1.1 Research aims	8
1.2 Research approach	8
1.3 Research methods	9
1.3.1 Review of literature	9
1.3.2 Expert interviews and site visits	10
1.3.3 Research with children and caregivers	12
1.4 Conclusion	17
CHAPTER 2: EARLY CHILDHOOD DEVELOPMENT	18
2.1 The importance of the early years	18
2.2 Normal developmental pathways	18
2.3 Caregiver responsiveness and developmental tasks	19
2.4 Critical developmental tasks	19
2.4.1 Cognitive and neurological development	19
2.4.2 Language development	20
2.4.3 Socio-emotional development	20
2.5 Conclusion	20
CHAPTER 3: HIV AND AIDS AND THE YOUNG CHILD	22
3.1 The status quo of young children	22
3.2 Poverty as a platform for HIV and AIDS	22
3.3 The impact of HIV and AIDS on children	24
3.3.1 The changing face of parenthood	24
3.3.2 The loss of a primary caregiver	25
3.3.3 Living with a chronically ill caregiver	26
3.3.4 Caregiver mental health and quality of care	26
3.4 Conclusion	27

CHAPTER 4: CHILDREN LIVING WITH HIV AND AIDS	28
4.1 HIV and AIDS as a chronic paediatric illness	28
4.2 HIV infection impacts on early childhood development	29
4.3 The impact of antiretroviral treatment	30
4.4 Barriers to treatment and care for children	31
4.5 Rights-based approaches to treatment and care	33
4.6 Conclusions	34
CHAPTER 5: LESSONS LEARNT FROM SOUTH AFRICA	35
5.1 Barriers, opportunities and lessons learnt	35
5.2 Innovative practice and materials development	36
5.3 Conclusion	38
CHAPTER 6: EXPERIENCES OF CHILDREN AND CAREGIVERS	39
6.1 Testing, diagnosis and living with an HIV-positive child	39
6.1.1 Early testing and treatment changes lives	39
6.1.2 Testing – always a tough blow	40
6.1.3 What if prevention fails?	41
6.1.4 Getting testing and treatment is not easy	42
6.2 Antiretroviral treatment, adherence and side-effects	42
6.2.1 “This medicine is a miracle”	42
6.2.2 “Side-effects are not too difficult to manage”	43
6.2.3 “Taking medication is just a way of life for us now”	44
6.2.4 “Children are able to do this”	45
6.3 Disclosure to children, families and communities	47
6.3.1 Telling children	47
6.3.2 Telling families	48
6.3.3 Telling communities	49
6.4 Medical and health-care contact profiles and developmental status	50
6.5 Psychosocial assistance and support required for ART programming	51
6.5.1 The pain in daily activities	52
6.5.2 Coping practices	52
6.5.3 Support systems	53
6.6 Conclusion	54
CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS	55
7.1 Young children and HIV and AIDS	55
7.2 Child and caregiver experiences	56
7.3 Limitations of the research	56
7.4 Recommendations for research, policy and practice	57
7.4.1 Research	57
7.4.2 Policy	57
7.4.3 Practice	57
REFERENCES	65

APPENDICES

Appendix 1: List of databases searched for literature review	59
Appendix 2: Developmental tasks and care strategies age 0 to 12 months	60
Appendix 3: Developmental tasks and care strategies age 12 to 24 months	60
Appendix 4: Developmental milestones ages 3 to 5 years	61
Appendix 5: Studies on the impact of HIV on child development, Sherr (2005)	62
Appendix 6: Studies of impact of HIV on child development conducted in Africa	63
Appendix 7: Intervention opportunities in antenatal and postnatal care	64
Appendix 8: Intervention opportunities in paediatric care	64
Appendix 9: Integration of developmental screening and early referral into health-care service	65

LIST OF FIGURES

Figure 2: Expert interview participants	11
Figure 3: Cut-out figures used to elicit discussion on families and antiretroviral treatment	13
Figure 4: Antiretroviral treatment cues used to elicit children's experiences of treatment	13
Figure 5: Developmental observation chart	14
Figure 6: Examples of drawings at three years of age	15
Figure 7: Examples of drawings at four years of age	15
Figure 8: Example of drawing at five years of age	15
Figure 9: Age of child participants in months	16
Figure 10: Poverty, stunting, childhood development and school achievement	23
Figure 11: Prevalence amongst pregnant women in South Africa	24
Figure 12: Rise in deaths of women of child bearing age	25
Figure 13: Examples of training and support materials	36
Figure 14: Caregiver, child and health-care worker support materials	37
Figure 15: Degree of illness prior to onset of treatment	51

LIST OF TABLES

Table 1: Enrolment by research sites	12
Table 2: Age and gender distribution	16
Table 3: Number of children by time on treatment or treatment stage	16
Table 4: Benefits of paediatric antiretroviral treatment (ART) – summary of existing studies	31
Table 5: Contributing factors to slow roll-out of paediatric ART	32
Table 6: Summary of findings from Michaels, Eley, Ndhlovu & Rutenberg (2006)	33
Table 7: Four principles of rights based programming	34
Table 8: Main themes expert interviews	36
Table 9: Services through which caregivers had learnt of their own or the child's HIV status	39
Table 10: Relationship between testing and early access to treatment	40
Table 11: Reported experience of side-effects	43
Table 12: People who assist the child with medication	44
Table 13: Reasons stated for non-disclosure to children	47
Table 14: Helpful support practices	52
Table 15: Sources of help	52
Table 16: Support needs as ranked by caregivers	54

ACKNOWLEDGEMENTS

*T*his research was commissioned by the National Department of Health (Maternal, Child and Women's Health and Nutrition Cluster) and supported by UNICEF through a grant awarded to the Child, Youth, Family and Social Development Programme (CYFSD) of the Human Sciences Research Council (HSRC).

This research would not have been possible without the support, assistance and encouragement of Andries Viviers at the UNICEF South Africa office, and the assistance of the Maternal, Child and Women's Health and Nutrition Cluster at both national and provincial levels. In particular the support and co-ordination of Michele Bester, Lenore Spies and Dr Nonhlanhla Dlamini is appreciated. We also extend our thanks to the health facility managers, Doctors Haselau, Naidoo and Miss Findlay, and to Doctors McKerrow, Bhengu, Wiseman and Dedicoat and their colleagues and clinic staff for the openness and willingness with which they engaged with the research process. We appreciate and acknowledge the assistance of the public-private and private facilities that allowed us to visit their sites and whose staff participated in the expert interviews. We would like to extend our sincere thanks to the caregivers and their young children who participated and without whom the research would not have been possible.

We would like to acknowledge the contributions made by the research staff working on the project: we thank Merridy Boettiger for her contribution to the preparation of the research and literature searches; Thembelihle Zuma for her contributions to fieldwork; Thandi van Heyningen for assistance with literature searches and report writing; and Christina Mitchell for her assistance with editing and references. We also thank Jane Argall for proofreading and editing assistance.

EXECUTIVE SUMMARY

INTRODUCTION

The early years of a child's life are critical. Over the last few decades, science has significantly enhanced what we know about the needs of infants, toddlers and young children, underscoring the fact that experiences and relationships in the earliest years of life play a critical role in a child's ability to grow up healthy and ready to learn. Research shows that it is during the first three years of life that the brain undergoes its most dramatic growth and developments, more so than at any other time in the child's lifespan. The key to supporting the healthy development of children is to ensure the translation of this research into effective, evidence-based policies and practices.

In their early years, children living in South Africa, along with those living in most parts of sub-Saharan Africa, face tremendous challenges to their survival, development and wellbeing. Most of these challenges arise from poverty and deprivation and are made worse by the impact of HIV and AIDS. Children may be directly impacted through infection, or indirectly through the quality of care they receive from absent or ill caregivers. Further, they may be distally affected through the effects of HIV and AIDS on their social support networks and their access to health-care services.

There is growing recognition that pragmatic and effective solutions for addressing the plight of today's and tomorrow's most vulnerable children in South Africa are urgently needed. Most experts agree that children are best supported within their families and everyday systems of care. Building stronger families goes hand-in-hand with building stronger communities, and strong communities ensure that babies and young children have good health, strong families, and positive early learning experiences which will lay the foundation for a lifetime of success.

RESEARCH ACTIVITIES AND RATIONALE

UNICEF, in support of the National Department of Health (Maternal, Child and Women's Health and Nutrition Cluster), commissioned this research. The research project aimed to better understand the needs of young children affected or infected by HIV and AIDS in South Africa. In order to meet this aim, researchers reviewed the literature on young children and HIV and AIDS; sought the opinions of experts in the field of paediatric HIV and AIDS; and undertook qualitative research with a sample of children and their caregivers receiving antiretroviral treatment at Department of Health facilities.

In undertaking these research activities, the project aimed to address three important issues:

1. While a great deal of information exists on the psychosocial care needs of young children exposed to adversity, this is seldom applied in the field of HIV and AIDS, nor is it readily available to government and policy makers. This report provides a summary of the evidence-base relevant to health-care decision makers and duty bearers.
2. Little documentation is available on lessons learnt and best practices in providing antiretroviral treatment, care and support for young children in South Africa. This report draws attention to useful expert experiences, best practices, and available materials and resources relevant to health-care decision makers and duty bearers.
3. Developing appropriate and sensitive interventions and programmes requires a deep understanding of young children's needs and experiences. However, little research is available on the experiences of young children receiving antiretroviral treatment. This report offers feedback to health-care decision makers and duty bearers on the experience and needs of children and caregivers receiving antiretroviral treatment, highlighted during the qualitative research.

SUMMARY OF KEY FINDINGS

Early childhood development

The most critical period of a young child's physical, cognitive, emotional and social development occurs in the first five years of life. Development is taking place at a rapid rate and is easily disrupted if a child's fundamental needs are not met. Their needs include nutritious food, health care for protection from childhood illnesses, and human interactions that nurture mental and emotional development. The literature demonstrates that what a child most needs during this time is a loving and stable caregiver who plays a role in fulfilling critical developmental functions in the cognitive and neurological development, language development and socio-emotional development of the child.

There is a need to develop co-ordinated systems of services for children that allow us to support the whole child—physically, socially, emotionally, spiritually and cognitively—within the context of the family, the home, the community and health-care settings.

HIV and AIDS and the young child

The known vulnerability of the early years coupled with the probable threat that HIV and AIDS is likely to bring to bear on young children, either through direct illness or through threats to the quality of their care-giving or their access to services, raises many challenges requiring urgent attention. Investing in the first five years of a child's life offers the most significant, cost-effective approach to ensuring success throughout the rest of the lifespan. Interventions which ameliorate the effects of poverty on young children by improving access to basic resources for children, families and systems of care, are likely to reduce the platform of poverty which facilitates and increases the risks of HIV and AIDS impacting on childhood. HIV and AIDS present multiple and serious threats to the early childhood development potential of children in South Africa. These require the urgent attention and intervention of health-care decision makers and other relevant duty bearers.

High quality, effective services are needed for those young children who are competent, yet at risk for compromised development, as a result of the direct or indirect impact of HIV and AIDS or other childhood adversities.

Children living with HIV and AIDS

Children living with HIV and AIDS face a multitude of challenges including: the threats of exposure to childhood illness associated with HIV infection and the subsequent loss of developmental potential; the loss of parents and primary caregivers; the reduced quality of care-giving by chronically ill parents or caregivers; and the direct impact of HIV infection on cognitive, social, emotional and behavioural development in early childhood. Sufficient evidence exists in both the South African and international contexts to demonstrate that antiretroviral treatment can significantly improve childhood developmental outcomes of children who receive treatment. While the challenges and barriers to providing care are vast, it remains a key responsibility of health-care decision makers and other relevant duty bearers to ensure a child's right to treatment. Likewise, beyond receiving antiretroviral treatment, children need opportunities to grow and to learn, to be secure and protected, to be loved and to live to their full potential.

Specific services need to be developed for those children who face particular developmental challenges as a result of living with HIV. It is important that health-care decision makers and other duty bearers address the rights of children living with HIV including accessing the treatment, care and support required to maximise their life potential.

Lessons learnt from South Africa

While the provision and delivery of paediatric antiretroviral treatment in South Africa has historically occurred through a blend of private, private-public and public treatment programmes, many similarities were found in both the barriers and the opportunities across the spectrum of service delivery settings. Among the barriers to effective antiretroviral treatment for children are the difficulties in the integration of government sectors and programmes, and of policy and practice. Several examples of innovative practice, materials and intervention development, and support services emerged from the site visits and expert interviews. However, distribution and dissemination of this knowledge, experience and skill is poor. Health-care practitioners require greater access to, and opportunities for, training and development, along with user-friendly tools and guidelines to ensure the developmental appropriateness and quality of the care they deliver to young children. Likewise, local intervention studies have demonstrated that basic home programmes can significantly improve both the cognitive and motor development of young children living with HIV and AIDS, and should be explored further.

The challenges facing both private and public providers of paediatric antiretroviral treatment are similar, suggesting benefits of collaboration between duty bearers and civil society to address these challenges. Examples of developmentally sensitive and appropriate training and programming are available in South Africa, and should be implemented on a wider scale.

Experiences of children and caregivers

Caregivers reported that HIV testing, receiving a diagnosis and living with an HIV-positive child present more significant emotional and social challenges for caregivers than did managing antiretroviral treatment adherence or side-effects. Likewise, children themselves were able to demonstrate antiretroviral treatment competence. The earlier a child was tested and received treatment, the better their developmental outcome, and children who commenced treatment were reported to have made significant developmental recovery within short periods. In terms of support and assistance, caregivers most commonly identified basic resource needs, particularly in nutrition and transport, as being most salient; but reported that psychosocial assistance and support is important for antiretroviral treatment to be sustained over time. Caregivers expressed fewer concerns and difficulties with stigma, disclosure and support within family networks than within their community networks.

Support services, information and counselling need to be provided to assist caregivers to deal with the social and emotional challenges of living with HIV, and the parenting demands of caring for a child who is living with HIV.

RECOMMENDATIONS

Further **research** is required to:

1. Evaluate psychological, social and developmental interventions which improve developmental outcomes in children over the life course.
2. Develop large-scale demonstration studies to test interventions which have shown positive effects in smaller-scale studies; these studies should test usability, acceptability and cost-effectiveness at scale.
3. Conduct a rapid analysis to catalogue existing materials developed to assist children on antiretroviral treatment across age groups, and to develop a framework for wider distribution and use of a set of standardised and reviewed materials.

Increased **advocacy** is required to continue to:

1. Increase children's access to antiretroviral treatment in general, and specifically for access at the earliest possible and most developmentally appropriate time.

2. Mainstream children's psychological and developmental care into health programming.
3. Highlight the urgent need for improved diagnostic tools and formulations for paediatric antiretroviral treatment.
4. Support the National Department of Health by ensuring timely dissemination of evidence to ensure that protocols and policy remain aligned to the best practice evidence emerging from research and practice.

Several opportunities for improving **practice** exist. These are to:

1. Encourage the participation and empowerment of all care providers through developing the knowledge and skills of both caregivers and health professionals on the benefits of compassionate and developmentally appropriate care for young children receiving antiretroviral treatment.
2. Develop, as a matter of urgency, user-friendly psychosocial guidelines for counsellors, nurses and doctors which offer practical mini-interventions based on psychological, social, cultural and developmental aspects of care, which make use of the monthly contact sessions to build the developmental potential of the child.
3. Ensure the rapid implementation of the training programme and manual developed by Cotlands in collaboration with UNICEF and the Department of Health entitled "Psychosocial care of babies and young children living with HIV and AIDS" which addresses several concerns raised in this research.

CHAPTER 1: THE RESEARCH FRAMEWORK

In consultation with UNICEF and the National Department of Health, the research brief was finalised. It included the following three separate research activities to address the issues raised in the terms of reference:

1. **LITERATURE REVIEW:** The first component involved a review of the developmental, psychological and social literature relevant to young children affected by or living with HIV and AIDS.
2. **SITE VISITS AND EXPERT INTERVIEWS:** The second component involved conducting visits and expert interviews at antiretroviral treatment sites to explore best practices in providing care and treatment for young HIV-positive children in South Africa.
3. **QUALITATIVE STUDY:** The third component included a small qualitative study to explore the experiences of caregivers and young children living with HIV and receiving antiretroviral treatment at three Department of Health facilities.

The scope of the research was limited to children under five years of age. Approval for the research to take place at Department of Health facilities was granted by the office of the Director-General in the National Department of Health and by the KwaZulu-Natal Provincial Head of Department and Research Committee, as well as by the relevant hospital authorities. The research protocol was given ethical clearance by the Research Ethics Committee of the HSRC (REC 5/19/07/06).

1.1 RESEARCH AIMS

The research had three specific aims:

- i. Review, synthesise and summarise the literature relevant to understand the psychological, social and developmental needs of young children under the age of five who are affected or infected by HIV and AIDS;
- ii. Conduct site visits and expert interviews at both public and private antiretroviral treatment sites, to collect information on the treatment and care of young children, and to explore lessons learnt and best practices;
- iii. Conduct qualitative research with young children and their caregivers currently receiving antiretroviral treatment at Department of Health facilities to better understand their experiences and psychological, social and developmental needs.

1.2 RESEARCH APPROACH

The theoretical framework of the research followed an interpretive perspective. This meant that it attempted to understand phenomena in their context in an empathetic manner that takes people's subjective experiences seriously (Terre Blanch, Durrheim, & Painter, 2006). The research aimed to seek information-rich cases to provide in-depth data about the experiences of children, caregivers and experts in paediatric antiretroviral treatment programmes. The literature review provided a lens through which these experiences could be understood and interpreted in the data collection and analysis phases of the study.

Children's participation in research is becoming increasingly recognised as important and valuable and can enhance the quality and validity of research. Various authors argue that children are best positioned to comment on the problems they face, and to participate in the generation of solutions to these problems (Black, 2003; Hart, 1997; Johnson & Ivan-Smith, 1998; Miller, 2003). Including children's and caregivers' experiences in health research allows for their active participation in seeking out opportunities to improve care and support and, in doing so, removes barriers to integrating such types of care into treatment programming in a meaningful way (Black, 2003; Hart, 1997).

Children's experiences of being HIV positive and receiving antiretroviral treatment, especially young children, is not easily elicited or consciously reflected on in a research process. However, as Clacherty & Kushlik (2004) have demonstrated in similar work in South Africa, finding ways to develop an understanding of children's experience allows an approach to interventions with children and families that is both reflective and meaningful.

In this study, the choice of methodology and the use of participatory research techniques aimed at shifting the emphasis from research *on* children to research *with* children. In taking such an approach, research activities were designed to be sensitive, ethical and to take into account the developmental stage of the child. This participatory approach is particularly useful since the nature and extent of children's vulnerability in such circumstances can make direct elicitation of such experiences using traditional research methodologies painful and inappropriate (Clacherty & Kushlik, 2004; Kvalsvig & Richter, 2002).

Research with young children is a more difficult and complex process than with older children or adult participants. Clacherty & Kushlik (2004) propose that research methodology needs to be sensitive to a child's developmental stage because the latter has implications for his/her ability to reflect on experiences, articulate opinions, or have appropriate levels of concentration and comprehension, linked to either age or stage of illness.

Using methods such as projective techniques (for example, drawing or using figures of people) allows children to express themselves in a way which is familiar and developmentally comfortable. It also allows for an emotional distance when the topic is sensitive and emotive. Likewise, play (for example, with a baby doll) is not only a technique for gaining information from a child who is not yet verbally articulate, but is also a way to represent their experiences in the third person. Again, this allows for a measure of emotional distance when talking about difficult issues.

1.3 RESEARCH METHODS

The research methods used in this study included a review of literature, expert interviews and in-depth interviews with caregivers as well as small play groups, and participatory and observational techniques suited to and validated for use with younger children. The procedures and methodology used for each of these are briefly described below.

1.3.1 Review of literature

The review of literature aimed to summarise and synthesise literature related to the psychological, social and developmental needs of young children under the age of five in the context of HIV and AIDS. In examining literature, the review process drew on an ecological approach similar to that of Bronfenbrenner (1979) which situates the development and wellbeing of young children within a biological, familial, social and communal context.

The review examined both published and unpublished material between the period 1990 and 2006, sourced through keyword searches using various combinations of relevant terms including: HIV and AIDS, antiretroviral treatment, young children, mother or caregiver, child or infant, psychological, social, mental health, chronic illness, social support, coping.

A wide range of online databases were searched using the virtual library facilities of the Human Sciences Research Council. A brief description of each of these databases is listed in Appendix 1 at the end of this report. Additional papers were identified through scanning the reference lists of papers identified through keyword searches. Experts in the field of paediatric HIV and AIDS were consulted via email, telephone or in person to assist in identifying key resources. Interview participants at the site visits were asked about materials they found relevant or useful to their paediatric HIV and AIDS efforts.

1.3.2 Expert interviews and site visits

In developing an overview of the existing knowledge, skills and experience present in antiretroviral treatment facilities in South Africa, the researchers conducted a brief search-and-review of operational research and situational analyses undertaken since the roll-out of paediatric antiretroviral treatment in South Africa. Furthermore, several site visits were conducted at existing paediatric antiretroviral treatment sites and interviews were conducted with key stakeholders involved in paediatric antiretroviral treatment delivery.

Using snowballing and convenience sampling techniques, interview participants were drawn from the following two groups:

- i. Selected experts and academics in the areas of antiretroviral treatment research, programme activities and psychosocial support services within non-government sponsored antiretroviral treatment programmes;
- ii. Paediatric antiretroviral treatment programme managers and staff at the participating Department of Health sites, and senior management within the Maternal, Child and Women's Health cluster.

During these site visits the researchers observed treatment programme activities. When conducting interviews with expert participants, the researchers focused on the following key issues:

- i. Context of the site or expert's current involvement in the field of paediatric HIV and AIDS in South Africa;
- ii. Experiences and challenges in delivering paediatric treatment;
- iii. Experiences, practices and programming which focus on the developmental or psychosocial needs of children;
- iv. Examples of 'good practice' or recommendations for improved care of children living with HIV and AIDS.

In this research study, public sector sites were those Department of Health sites which are entirely publicly funded. In line with the terms of reference, available resources and government permissions, these were restricted to three hospital sites. The public-private partnership sites included research sites where clinical trials were being conducted through public facilities or where donor funding was being utilised to run a public antiretroviral service. Private sector sites were those sites funded privately and accredited by government, but run separately from public health facilities. The sites visited are mapped in Figure 1. Visits involved an observation of facilities and interviews with various levels of staff.

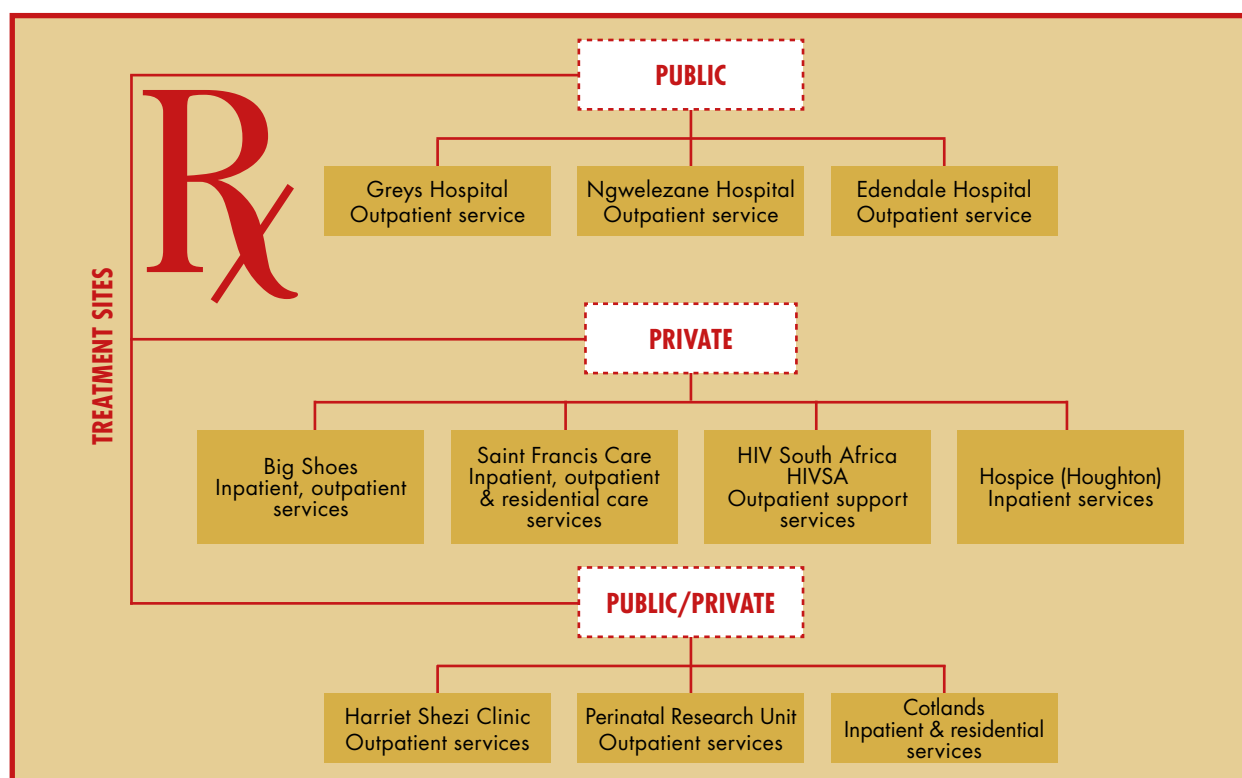


Figure 1: Antiretroviral treatment sites visited

The individual expert interviews sought to explore multidisciplinary perspectives on the experience of paediatric antiretroviral treatment and, in particular, to investigate the expert's experiences with young children on antiretroviral treatment. Interviews were conducted with participants from civil society, government services and academia, as listed in Figure 2 below.

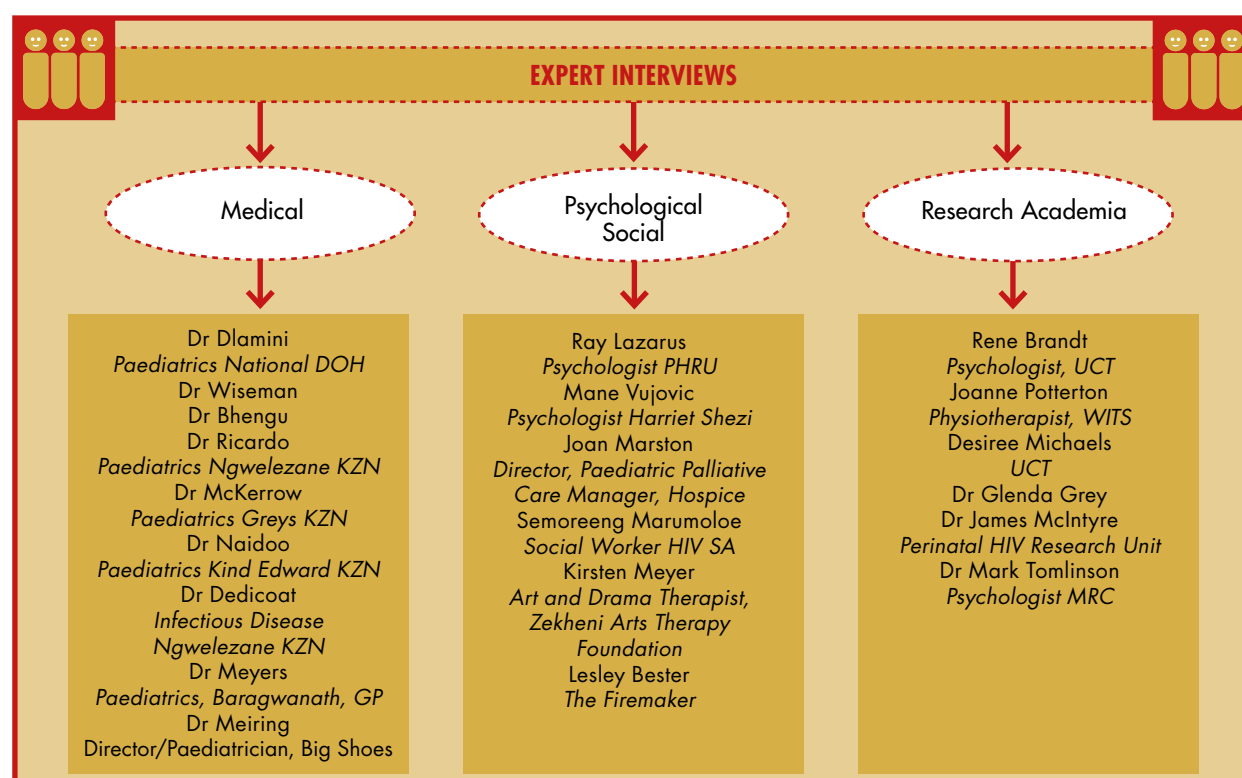


Figure 2: Expert interview participants

The findings from the site visits and expert interviews are discussed in Chapter 5 of this report.

1.3.3 Research with children and caregivers

The observations, interviews, focus groups and children's play groups were conducted by a clinical and a counselling psychologist with assistance from isiZulu-speaking psychology trainees. The interviews and play groups were tape-recorded and transcribed, and a thematic analysis was conducted. The research procedures allowed for the collection of data at three levels (caregiver, child and clinical observation) using appropriately selected research techniques for each level. Each level of data collection is briefly outlined below.

a. Research sites

Together with the Department of Health and UNICEF, three sites with diverse patient catchments patterns were selected in KwaZulu-Natal. The qualitative research was restricted to one province owing to the time and resource constraints of the grant. The research took place at three hospitals during February and March 2007 and a total of 48 caregiver child dyads were enrolled.

	GREY'S HOSPITAL	EDENDALE HOSPITAL	NGWELEZANE HOSPITAL
Total number of patients on ARV at clinic (N=1 623)	200	1005	418
Number of participants enrolled in research (N=48)	13 (27%)	7 (15%)	28 (58%)

Table 1: Enrolment by research sites

b. Research procedure

Participants were recruited in outpatient settings at all the sites, and children were only approached and enrolled through their caregivers or guardians. Efforts were made to establish whether the caregiver was the legal guardian of the child. Caregivers were informed about the study and invited to participate by the nurse who conducted their standard check-up upon their arrival at the hospitals' antiretroviral clinics.

Interested participants were then briefed on the purpose and nature of their participation by an isiZulu-speaking fieldworker. Informed consent was obtained. The research was scheduled so that it would not delay or interfere with appointments with medical staff.

c. Data collection with caregivers

Researchers conducted brief individual intake interviews with all participating caregivers in order to collect important biographical and historical medical information on the child. These preliminary interviews with caregivers took approximately 20 minutes.

Caregivers were then invited to participate in a small focus group with other caregivers. The focus groups took between 45 and 60 minutes and explored the following areas.

- The caregiver's experiences on learning about the child's status; initiating antiretroviral treatment and managing the child's antiretroviral treatment; side-effects and adherence.
- The caregiver's experiences of disclosure; psychosocial support; and health-care services.

d. Data collection with children

The researchers used child-centred participatory play groups, each comprising three or four children in the presence of their caregivers. These play groups were used to elicit discussion of children's experiences of their illness and their antiretroviral treatment. The groups took approximately 30 minutes, and were guided by and sensitive to the children's needs and responses. In cases where children were not yet verbal (because of their developmental stage and age), structured observations were used to

assess the child's experience and coping in the treatment setting, as well as their responses to treatment cues. In the play groups with verbal children, two specific techniques were used:

- i. Cut-out figures of people were introduced. Children were asked to participate in a game of identifying figures representing people with whom they lived, people who cared for them and people who were involved in their antiretroviral treatment. Examples of the cut-out figures used in the fieldwork are included in Figure 3 below.
- ii. Treatment stimuli including a doll, syringes and measurement spoons were presented to children. Their responses to cues were recorded and explored. Researchers used the play activity to probe experiences and perceptions of medication. Children were encouraged to demonstrate antiretroviral treatment competence and engagement with medication cues. Examples of antiretroviral treatment cues used in groups are included in Figure 4.



Figure 3: Cut-out figures used to elicit discussion on families and antiretroviral treatment



Figure 4: Antiretroviral treatment cues used to elicit children's experiences of treatment

e. Developmental observations with children

Full developmental assessments, while ideal, were not possible within the scope and resources of the study or within the constraints of the treatment clinic environment. However, since so much of the data collection, analysis and interpretation needed to be framed within an understanding of the child's current developmental level and status, a brief screening of children's current developmental status was undertaken. This took place during participatory group activities, using the observational guide in Figure 5 to assess for physical, mental and social developmentally-appropriate tasks (Werner & Smith, 1992).

Name: _____

Birth date: _____

Date: _____

EVALUATION OF A CHILD'S LEVEL OF PHYSICAL DEVELOPMENT

Note: Although on these guides physical and mental skills are separated, the two are often closely interrelated.

These charts show roughly the average age that a normal child develops different skills. But there is great variation within what is normal.

RECORD SHEET (page 1)

PHYSICAL DEVELOPMENT	Average age skills begin	3 months	6 months	9 months	1 year	2 years	3 years	5 years	What to do if a child is behind
Head and trunk control	lifts head part way up	holds head up briefly	holds head up high and well	turns head and shifts weight	holds head up well when lifted	moves and holds head easily in all directions			Activities to improve head and trunk control (see p. 302).
Rolling		rolls belly to back	rolls back to belly	rolls over and over easily in play					Activities to develop rolling and twisting (see p. 304).
Sitting	sits only with full support	sits with some support	sits with hand support	begins to sit without support	sits well without support	twists and moves easily while sitting			Work on sitting. Special seating if needed (p. 306).
Crawling and walking		begins to creep	creeps or crawls	pulls to standing	takes steps	walks	can walk on steps and on heels	hops on one foot	Activities to improve balance (see p. 306).
Arm and hand control	grasps finger and puts in hand	follows shape object with eyes	reaches and grasps with whole hand	passes object from one hand to other	grasps with thumb and forefinger	uses small objects (e.g., blocks)	uses small objects (e.g., blocks)		Eye-hand activities. Use toys and games to develop hand and finger control (see p. 305).
Seeing		follows shape object with eyes	reaches and grasps with whole hand	passes object from one hand to other	grasps with thumb and forefinger	uses small objects (e.g., blocks)	uses small objects (e.g., blocks)		Have eyes checked (see p. 412). If poor, see Chapter 30.
Hearing	moves or cries at a loud noise	turns head to sounds	responds to mother's voice	enjoys rhythmic music	understands simple words	hears clearly and understands most simple language			Have hearing checked (if poor, see Chapter 31).

Name: _____

Birth date: _____

Date: _____

EVALUATION OF A CHILD'S LEVEL OF MENTAL AND SOCIAL DEVELOPMENT

RECORD SHEET (page 2)

MENTAL DEVELOPMENT	Average age skills begin	3 months	6 months	9 months	1 year	2 years	3 years	5 years	What to do if a child is behind
Communication and language	cries when wet or hungry	coos when comfortable	makes simple sounds	uses certain sounds for different things	begins to use simple words	begins to use words together	uses simple sentences		Speak and sing often to child. If needed, develop alternative to speech (p. 313).
Social Behavior	smiles when smiled at	smiles when smiled at	begins to understand and respond to "no"	begins to do simple things when asked	likes to be praised after completing simple tasks	likes to be praised after completing simple tasks	interacts with both adults and children		Consider using behavioral approach to social behavior (see p. 349).
Self-care	holds breast	takes everything to mouth	chews solid food	begins to feed self	dresses alone	takes off simple clothes	helps with simple work		Encourage child to help self if possible. Use behavioral approach to learning (see p. 356).
Attention and interest	smiles when smiled at	smiles when smiled at	shows interest in toys and sounds	develops strong attachments to caretakers	likes to be praised after completing simple tasks	likes to be praised after completing simple tasks	likes to be praised after completing simple tasks		Early stimulation activities (see Chapter 32). Provide toys and fun objects.
Play	grasps things placed in hand	plays with own body	plays with simple objects	begins to enjoy first social games (peek-a-boo)	imitates and copies people	begins to play with other children	plays independently with children and toys		Guided play, lots of stimulation and interaction with other children.
Intelligence and learning	cries when hungry or uncomfortable	recognizes mother	recognizes several people	looks for toys that fall out of sight	copies simple actions	points to things when asked	follows simple instructions		Early stimulation (p. 315). Lots of toys, talk, and step-by-step training.

Put a **circle** around the level of development that the child is now at in each area.

Put a **square** around the skill to the right of the one you circled, and focus training on that skill.

If the child has reached an age and has not mastered the corresponding level of skill, special training may be needed.

Figure 5: Developmental observation chart

Werner and Smith (1992)

To complement this data, where a child's developmental age allowed for it, children were also encouraged to engage in a draw-a-person test. This is a technique to infer children's cognitive developmental levels (Abell, Wood & Liebman, 2001) and was undertaken while children were waiting for caregiver interviews to be completed. The aim was to give the child an activity which could occupy them during the caregiver interview, and could supplement the observations made to determine current developmental staging. Examples of typical drawings by age are included in Figures 6, 7 and 8.



Figure 6: Examples of drawings at three years of age



Figure 7: Examples of drawings at four years of age



Figure 8: Example of drawing at five years of age

f. Sample

A sample of 48 children and caregivers were recruited and was considered sufficient to reach saturation for an exploratory study. Reaching saturation implies that the sample size should be large enough to ensure that all salient themes have the opportunity to emerge; after saturation is reached new themes are unlikely to emerge. There were 25 male and 23 female child participants, aged from six months (0.5 years) to 66 months (5y 6mo) with a mean age of 43 months (3y 7mo).

	AGE 0–12 1 YEAR	AGE 13–24 2 YEARS	AGE 25–36 3 YEARS	AGE 37–48 4 YEARS	AGE 49–66 5 YEARS	TOTAL
Male	0	4	5	6	10	25
Female	2	0	7	8	6	23
TOTAL	2	4	12	14	16	48

Table 2: Age and gender distribution

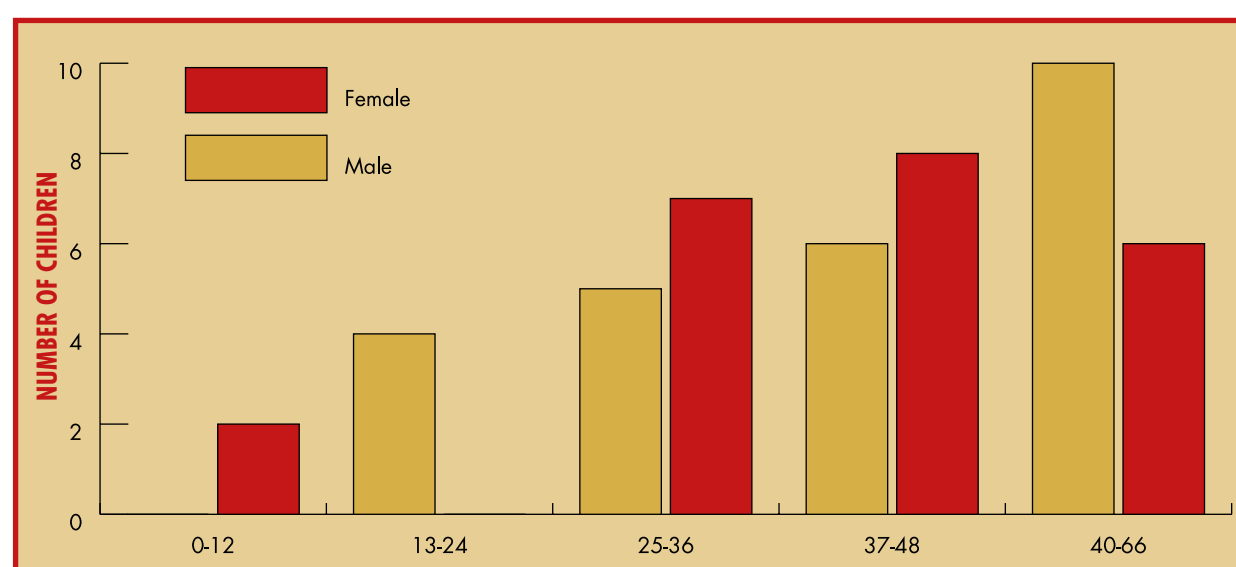


Figure 9: Age of child participants in months

For the purposes of this research, a caregiver was considered to be the person who had brought the child to the clinic that day. In some cases, participants were excluded because of their distant relationship to the child (for example, as a neighbour or friend) and where they were not familiar with the daily routines in the home. During informed consent procedures, efforts were made to establish whether the person was a legal guardian to the child. During preliminary interviews researchers explored the role of presenting caregivers in the child's life, treatment and care in greater depth. Most children were brought to the clinic by their mothers (63% N=29); or grandmothers (23.9% N=11); and the balance were brought by aunts (6.5% N=3), fathers (4.3% N=2) or other family members (2.2% N=1).

In this sample, children had been on treatment for between one and 48 months with a mean time on treatment of 11.85 months.

TIME ON TREATMENT	0–6 MONTHS	7–12 MONTHS	13–24 MONTHS	25–36 MONTHS	37–48 MONTHS	TOTAL
Number of children	17 (37%)	13 (28.3%)	13 (28.3%)	2 (4.3%)	1 (2.1%)	46 (100%)

Table 3: Number of children by time on treatment

*Missing N=2 (time on treatment data was missing for two participants)

The findings of the qualitative research undertaken with children and caregivers are discussed further in Chapter 6 of this report.

1.4 CONCLUSION

In summary, this research project aimed to better understand the needs of young children, both those affected by HIV and AIDS, through a review of literature, or infected by HIV and AIDS through a small exploratory qualitative study.

The research framework outlined above in brief shows that in order to meet this aim, researchers reviewed the literature on young children and HIV and AIDS, sought the opinions of experts in the field of paediatric HIV and AIDS, and reached children at selected public and private antiretroviral treatment facilities where they were exposed to structured activities with their caregivers and with other children.

Information drawn from caregiver interviews and from the children themselves, provided a picture of the treatment and care of young children currently receiving antiretroviral treatment at Department of Health facilities.

Before these findings are presented, we will discuss some of the principles of early childhood development which were fundamental to the theoretical framing of this research.

CHAPTER 2: EARLY CHILDHOOD DEVELOPMENT

2.1 THE IMPORTANCE OF THE EARLY YEARS

Between the ages of zero and five years, critical aspects of children's physical, cognitive, emotional, social and spiritual development take place. The events which take place in a child's early life can impact upon their development over the rest of their lifespan. Ensuring that children have an opportunity for normal and healthy development in the early years has been shown to be an effective strategy for building resilience for the adolescent years and later life, and of reducing poverty among disadvantaged populations (Grantham-McGregor et al, 2007).

As a child reaches milestones at different ages, the child's specific needs for each age are unique and should be understood and addressed appropriately. For example, the needs of the infant child differ to those of a three-year-old, and that of a five-year-old. This needs to be factored into any type of early intervention targeting specific age groups. Furthermore, it should be recognised that early childhood development occurs at a relatively rapid rate and that its course and timing is easily disrupted (Dunn, 2005; Shelov & Hannemann, 2006; ZERO TO THREE Foundation, 2007).

To transition well through this critical period, very young children need nutritious food, health care and protection from childhood illnesses, as well as human interactions that make them feel secure and that nurture mental and emotional development. The developing brain at this age is more sensitive to their nutrition and stimulation than at any other time over their life course (Grantham-McGregor et al, 2007; Walker et al, 2007; ZERO TO THREE Foundation, 2007).

In these first five years, the foundations of language, which in later years is a strong predictor of school performance, are laid. So too are values and antecedents of social behaviour. Early socialisation and regulation equips children to become full participants in their community by helping them acquire the behaviours and moral values expected of people in their society (Richter, 2004b).

There is a vast literature to support the knowledge that during this time, what children need most is a loving and stable caregiver. In order for children to reach their full potential and grow up healthy, happy and strong, they require affection, protection and nurturance from a consistent caregiver. These caregivers are the facilitators of early childhood development in that they support the development of psychological and social capacities, and the development of language and cognition through ongoing interaction and responsiveness (Sameroff & Fiese, 2000).

The interaction between caregiver and child during this period plays a profound role in the development of self-regulation, cognition, language acquisition, and socio-emotional adjustment. What children experience, including how their primary caregivers respond to them, shapes their development as they adapt to the world (Garbarino & Ganzel, 2000; Richter, 2004b). Dunn (2005) argues that the early care children receive determines to a large extent the ingredients of their emotional intelligence.

These include childhood confidence, curiosity, intentionality, self-control, relatedness and a capacity to communicate and be co-operative. These, in turn, determine how well a child learns and how he or she will relate to others in school and in life in general.

2.2 NORMAL DEVELOPMENTAL PATHWAYS

Appendices 2 and 3 summarise in detail for the interested reader how children develop in the first five years of life and describe briefly how the primary care-giving relationship can assist in promoting this early development. Appendix 4 describes the normal developmental milestones of children aged three to five years. When addressing early childhood development, it is important to note that the child is an active agent in their own development, seeking opportunities to grow and gain mas-

tery through their relationships with others and through their environment. A responsive caregiver facilitates optimal development.

From the age of three, development continues to occur at an exponential rate, and there is a continual explosion of new physical, cognitive, social and language skills (Shelov & Hannemann, 2006; Richter, 2004b; ZERO TO THREE Foundation, 2007).

2.3 CAREGIVER RESPONSIVENESS AND DEVELOPMENTAL TASKS

One of the key facilitators of these early childhood developmental processes is responsiveness by a consistent and responsive caregiver. As Krebs et al (2005) outline, there are a number of specific ways in which early caregiving experiences can influence childhood development, and in which a lack of caregiver responsiveness is detrimental to the process of development.

Firstly, one of the main functions of caregiver responsiveness is to facilitate learning; the child is able to learn through observing their caregivers' consistent responses to certain cues and by developing learned associations between stimulus and responses within their environment. If a caregiver response is not 'in tune' with the child's, then learning is reduced and subsequent performance in learning tasks is adversely affected (Papousek & Papousek, 1997).

Secondly, caregivers facilitate the development of sustained attention. Sensitive caregivers watch their children closely and follow a child's cues, changing activities when the child's attention is failing; in this way sustained attention is taught. These sensitive interactions have been found to be predictive of the child's capacity to sustain their attention independently and persist in problem-solving tasks (Yarrow et al, 1984).

Thirdly, children also need to learn an awareness of a caregiver's attention and to follow the direction of an adult's attention or pointing; this is known as joint attention (Butterworth, 1991, in Krebs et al, 2005). Joint attention is important to ensure that regulation of attention and affect occurs, and the child learns from the caregiver's affective responses to other people and objects in a process which is called social referencing. Social referencing means that the child will look at the adult when unsure, and will gauge how to respond by looking at how the adult is responding; learning these social references helps the child to maximise their learning. In addition to this, joint attention also provides a framework for language acquisition (Krebs et al, 2005).

Lastly, a key role of caregiver responsiveness is regulating the child's emotional state and this is achieved through the caregiver responding appropriately to the child's cues of distress and pleasure (Richter, 2004b). This capacity for emotional regulation is important in the development of interpersonal relationships, integrating into society and managing the demands of many of our daily experiences, for example learning in school (Krebs et al, 2005).

2.4 CRITICAL DEVELOPMENTAL TASKS

The developmental literature defines three critical developmental tasks that need to be successfully completed during these important early years in order for children to develop and grow normally and to fulfil their developmental potential.

2.4.1 Cognitive and neurological development

Children's cognitive development during these early years is rapid and vast, and the child's developing brain is very sensitive to the environment. During this time, the emotional and social qualities of early experiences are so significant that they have permanent effects on the child's brain. Childhood illness and disease can have a marked effect on brain development and cognitive functioning. Children at this age are especially vulnerable to infections that can disrupt brain development (Blanchette, 2000; Potterton 2001, 2006a, 2006b; Brown & Lourie, 2000).

Social interaction plays a key role in this neurological development. The infant's brain has been described as being both experience-expectant and experience-dependent. As the child has new ex-

periences, new synaptic connections and the maintenance of existing connections occur. Infants' neurological development and differentiation depend on meaningful forms of sensory and motor stimulation from caregivers. This stimulation includes the kind of patterned activation that occurs during affective interactions with responsive caregivers (Richter, 2004b, Sherr, 2005).

COGNITIVE, LANGUAGE & SOCIAL DEVELOPMENT CAN BE PREDICTED BY THE FOLLOWING FACTORS:

- A parent's level of education
- The level of family income
- Single-parenting
- The caregiver's psychological adjustment & sensitivity
- The social and cognitive quality of the home environment

2.4.2 Language development

The neurological sensitivity described above directly impacts on the development of young children's communication skills and language ability. Increasingly, evidence suggests that there are 'critical periods' for speech and language development in infants and young children, and one in which exposure to speech and language is vitally important. The ability to learn language will be more difficult if there are social or developmental arrests in this critical period (Dunn, 2005; Sherr, 2005).

Language development is one of the crucial developmental tasks for the very young child. The acquisition of language skills is a complex phenomenon as it involves a variety of facets including: learning about sounds and the rules for combining sounds (phonemic development); how to form meaningful words from sounds (morphology); the meaning of words and sentences (semantics); the structure of language (syntax); and the use of language in different contexts (pragmatics) (Coplan et al, 1998).

The development of language therefore involves skills in a variety of domains: sensory, motor control, cognitive and conceptual and social, and, given this, language development is also sensitive to damage and deprivation in any of the domains.

As Coplan et al (1998) explain: "Speech and language acquisition are sensitive to a variety of neuro-developmental insults ... thus, language acquisition in young children is a good barometer of central nervous system integrity in general" (p.3). HIV and AIDS research findings indicate that abnormal speech and language assessment can serve as an early warning mechanism to identify children with clinically significant deterioration in neuro-developmental status. Likewise, language function may be useful as an early indicator of the beneficial effects of antiretroviral drug therapy (Blanchette, 2000; Potterton, 2006b).

2.4.3 Socio-emotional development

Relationships between caregivers and young children exert a strong effect on the survival and healthy emotional development of young children. During this early developmental period, children need to master self-regulation and develop social skills, most of which occur through modelling activities between a sensitive caregiver and a child.

Sensitive and responsive early care is essential for the child to develop into an emotionally secure and confident individual. If the infant is treated with love and kindness, he or she feels worthy of love and becomes capable of feeling and expressing love and kindness towards others (Hough, Brumitt, Templin, Saltz & Mood, 2003; Richter, 2004b).

2.5 CONCLUSION

In summary, the most critical period of a young child's physical, cognitive, emotional, social and spiritual development occurs in the first five years of life. Development is taking place at a rapid rate and is easily disrupted if a child's most fundamental needs are not met: nutritious food, health care and

protection from childhood illnesses, as well as human interactions that nurture mental and emotional development.

What a child most needs during this time is a loving and stable caregiver who plays a role in fulfilling critical developmental functions in the cognitive and neurological development, the language development and the socio-emotional development of the child.

The challenge of HIV and AIDS affects the lives of millions of children living in sub-Saharan Africa, many of whom already face the enormous burden of poverty and deprivation in their survival, development and growth. These challenges are discussed more fully in the next two chapters.

CHAPTER 3: HIV AND AIDS AND THE YOUNG CHILD

Young children living in South Africa, along with those living in most parts of sub-Saharan Africa, face tremendous challenges to their survival, development, growth and wellbeing. Most of these challenges arise from poverty and deprivation and the resultant lack of adequate resources. This is made worse by the impact of HIV and AIDS and other disasters such as civil conflict, war and famine. In the context of such multiple challenges and competing interests, ensuring that young children receive sufficient resources and attention has been a long-standing challenge for child advocates.

3.1 THE STATUS QUO OF YOUNG CHILDREN

The mortality rates of young children represent a fairly robust indicator of the status quo of young children in a society. A brief examination of child mortality rates, both nationally and internationally, sheds light on the threats facing young children living in a world of HIV and AIDS.

Internationally, the mortality of young children continues to be of concern with 10.6 million children under the age of five dying annually, mostly in developing countries. Experts argue that this number could be reduced by 63% with the implementation of existing low-cost interventions. This in itself speaks volumes, not only about the vulnerability of young children, but also about the inadequate levels of attention, response and progress on the issues of survival and wellbeing of young children (Black, Morris & Bryce, 2003).

In Africa, while there have been continued attempts to draw attention to the plight of young children, little progress was made, and then reversed in reducing high infant and child mortality rates. Simple and robust indicators (for example, 35% of one-year-old children not fully immunised; 28% of children older than five years moderately or severely underweight; 17% mortality rate for children less than five years of age) all point to the pervasiveness of vulnerability among young children on the continent (UNICEF State of the World's Children, 2006).

In South Africa, Bradshaw, Groenewald, Laubscher, Nannan, Nojilana (2003) report that nearly 100 000 children under the age of five die each year and that the overall infant mortality rate has risen over the last decade. The overall mortality rate of 59 per 1 000 live births masks variations across the country, with some districts experiencing rates as high as 68 per 1 000 live births. Evidence suggests that HIV and AIDS is now a leading cause of death with under five deaths at 40.3%. Diarrhoeal disease, lower respiratory tract infections and malnutrition, when adjusted for HIV and AIDS co-morbidity, account for 20.3% of all under-five deaths.

For those children who survive the early years, evidence of the severe consequences of early childhood vulnerability, within the context of poverty and HIV and AIDS, is increasing (Richter & Foster, 2005; Richter, Foster, & Sherr, 2006a). Growing attention is being drawn to the importance and benefits of poverty reduction and other early intervention strategies in countries such as South Africa (Heckman, 2006).

3.2 POVERTY AS A PLATFORM FOR HIV AND AIDS

Poverty often serves as a platform by which young children are made vulnerable to HIV and AIDS. Notwithstanding the severe direct impact of HIV and AIDS on the lives of young children and their families, it is important to consider the evidence of the impact that poverty, in and of itself, can have on young children.

A recently published influential Lancet series has demonstrated, using a comprehensive meta-analysis approach, the relationships between poverty, stunting and poor development in young children (Grantham-McGregor et al 2007; Walker et al, 2007). Likewise, experts in South Africa sug-

gest that as a result of poverty, young children become extraordinarily vulnerable to poor health outcomes and that they are unlikely to have adequate access to health, social and educational systems or adequate nutrition (Bradshaw & Nannan, 2006; Hendricks, Eley, & Bourne, 2006; Richter et al 2006a).

Poverty puts children at developmental risk in the early years through the direct physical consequences of deprivation, the indirect consequences of severe stress on the parent-child relationship, and through greater exposure to other risk factors such as HIV and AIDS. Poverty affects not only material resources, but also the quality of caregiving that a young child is likely to receive, because the stressors occasioned by poverty conditions make it difficult to provide sensitive, responsive and stimulating care (Richter, 2004a; Foster, 2005; UNICEF, 2006). Thus poverty increases the chances that a number of risk factors will be present simultaneously with protective factors.

The extent of the impact of poverty is concerning and has implications well beyond the early years of a child's life. Grantham-McGregor et al (2007) found that childhood stunting and the number of people living in absolute poverty are indicators linked to poor cognitive and educational performance in children. Over 200 million children under the age of five, mostly living in sub-Saharan Africa and south Asia, are not fulfilling their developmental potential because of poverty, poor health and nutrition, and deficient care. This estimate represents more than half (61%) of all children under five living in sub-Saharan Africa (Grantham-McGregor et al, 2007; Day & Gray, 2006; Hendricks et al, 2006; Shun King, Mhlana, & De Pinho, 2006).

For many young children in South Africa, the dominant social and economic context is one of poverty, with attendant nutritional deficits, poorly developed health and education services, and distressed care environments. As illustrated in Figure 10 below, Grantham-McGregor et al, (2007) demonstrate that the pathways through which poverty conditions affect children are both direct and indirect and urgently warrant attention since all of these factors result in adverse developmental outcomes.

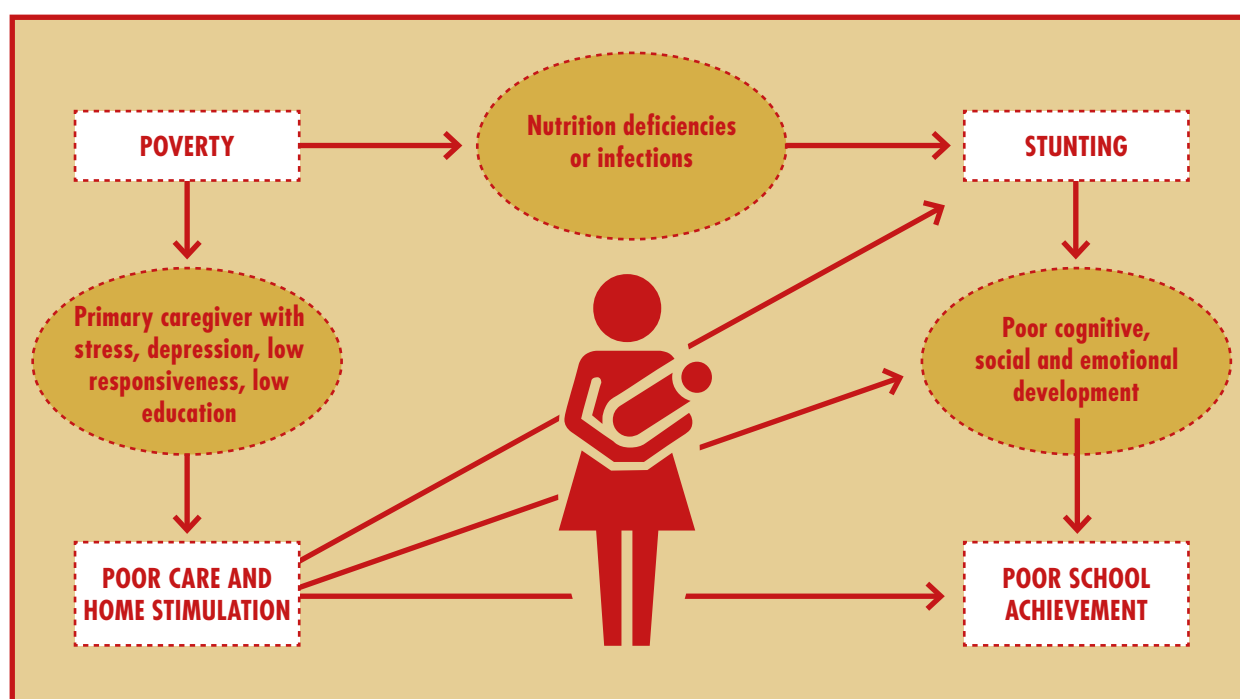


Figure 10: Poverty, stunting, childhood development and school achievement

Adapted from: Grantham-McGregor et al, 2007

3.3 THE IMPACT OF HIV AND AIDS ON CHILDREN

Given the context described above, children are particularly hard hit by HIV and AIDS because of both direct impacts (such as their exposure to infection) and less direct impacts (such as losing access to resources and care). While this report is limited in scope and cannot cover the all ways in which HIV and AIDS impact on children at different ages and stages of the disease, Richter et al, (2006a) provide a good description of the many ways in which children are impacted on by HIV and AIDS, which can be summarised as follows:

- i. Children who are indirectly affected through the pressure that HIV and AIDS brings to bear at a community level, for example by increasing child labour and responsibilities or through decreased access to resources such as health or education.
- ii. Children who reside in households which foster other children may be affected as the family resources are stretched further in an effort to take in additional members, often resulting in the poor helping the destitute.
- iii. Children who are living with chronically ill parents and who, as a result of these living circumstances, may be exposed to a myriad of risk factors including psychological, social or economic risks.
- iv. Children who are orphaned or abandoned and who have suffered the multiple losses of caregivers, parents and other family members.
- v. Children who are living with HIV and AIDS infection and suffer illness and discomfort, possible stigma and discrimination, and lowered life expectancy.

The section below will explore briefly the evidence related to young children who are affected by HIV and AIDS, and how this may impact on their everyday care-giving systems and their early childhood development potential. Chapter 4 explores the impact of direct HIV infection on young children.

3.3.1 The changing face of parenthood

The evidence from research on children's development, HIV and AIDS and poverty all highlight the vital role of the caregivers in the holistic development of the young child. Caregivers' roles are not limited to physical and material care, but incorporate a complex, interactive and reflexive relationship with the child that is vital for healthy development. In South Africa, the ongoing and increasing prevalence of HIV, results in more and more HIV-positive caregivers. These HIV-positive caregivers are infected with a chronic and terminal illness, requiring urgent treatment, care and support. In the absence of adequate prevention and treatment, primary caregivers will succumb to illness and die and their children's access to consistent care will continue to diminish (Save the Children, 2006).

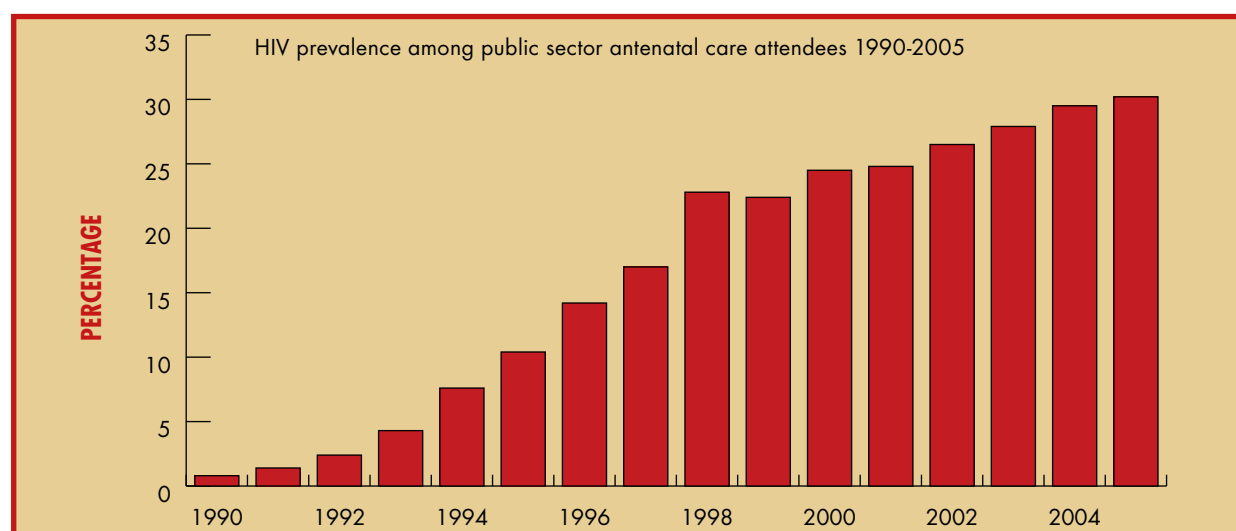


Figure 11: Prevalence amongst pregnant women in South Africa

Sourced from South African Health Review, (Bradshaw et al, 2006)



Figure 12: Rise in deaths of women of child bearing age

Sourced from South African Health Review (Bradshaw et al, 2006)

3.3.2 The loss of a primary caregiver

The death of a primary caregiver (in most cases mothers) can be one of the most devastating events for a young child and can have a dramatic effect on the child's chances of survival, education and a healthy life (Save the Children, 2006). While it is very important to support children who are orphaned and have already lost their caregiver or parent, it is equally important to try to keep caregivers alive and healthy for as long as possible (Meyers, Moultrie, Sherman, Cotton, & Eley, 2006; Richter & Foster, 2005; Richter et al, 2006b; Save the Children, 2006).

In cases where primary caregivers have passed away or migrated for health-care services or work, and where elderly caregivers have become substitutes, some evidence suggests that older caregivers are also more likely to suffer health problems which have an adverse impact on children's development. They are often unable to meet the needs of the children they care for (Juma, Okeyo, & Kibinda, 2004; Linsk & Mason, 2004; Schor et al, 2003).

Children themselves may also experience mental health effects from traumatic experiences such as losing their parents and the related psychosocial distress associated with circumstances of poverty and deprivation. Some children experience post-traumatic stress disorder symptoms, depression and anxiety (Clarke, Hutchinson, & Weiss, 2005). Evidence suggests that children affected by HIV and AIDS are more likely to internalise than to externalise their feelings, making depressive symptoms more common than behavioural problems (Killian, 2004). The emotional impact of bereavement and (multiple) losses are known to disrupt childhood development and parenting. These experiences have effects on all aspects of their development, including (at minimum): cognition, sense of self, identity, moral reasoning, social understanding and perspective taking. Evidence suggests that very young children react to emotional situations such as loss or a death of a caregiver without necessarily understanding the implications (Richter, 2004b; Kvalsig & Richter, 2002; Kvalsig et al, 2006).

While the effect of HIV and AIDS on children is often quantified only through increases in orphaning (Richter & Rama, 2006b), its impact stretches well beyond orphaning. In South Africa for example, while 600 000 children were orphaned in 2001, the HIV-prevalence estimates for the same year would indicate that 2.5 million South African children were living with a mother who was alive, but HIV-infected (Foster, 2005).

3.3.3 Living with a chronically ill caregiver

There is increasing evidence to suggest that adverse outcomes are as likely for children living with infected parents as they are for those who have already lost their parents. The period during which a parent is chronically ill (before succumbing to death) has been found to be highly vulnerable for most children, often more so than the period after their death (World Health Organisation (WHO), 2005; Brookes, Shisana, & Richter, 2004; Black, Nair, & Harrington, 1994; Brown & Lourie, 2000; Richter et al, 2006a).

Although some 80% of children born to HIV-positive mothers are uninfected at birth, studies have found that uninfected children born to HIV-positive mothers have higher mortality rates than other HIV-negative children in the community (Nakiyangi et al, 2003). It is further reported that these children have more attention, social adjustment and behavioural problems than comparison children who have been born to HIV-negative mothers (Dorsey et al, 1999a; Dorsey et al, 1999b; Forehand et al, 1998; Kvalsig, Chagan & Taylor, 2006; Murphy, Marelich, Stritto, Swendeman, & Witkin, 2002). It is frequently hypothesised that the mechanisms for these effects relate to the quality of care-giving which is compromised directly or indirectly by HIV and AIDS.

The effect that HIV has on reducing the quality of caregiving has been described in various local and international studies (Black et al, 1994; Brandt, 2005; Rahman, Bunn, Lovel, & Creed, 2007; Rollins, 2007; Stein et al, 2005). Under conditions of poverty, caregivers are themselves likely to be deprived of basic needs and thus suffer compromised physical health and susceptibility to opportunistic diseases and illnesses. This will compound the physical and developmental risks for themselves and their children.

The evidence suggests that having an HIV-infected caregiver creates many challenges for the health and wellbeing of the young child. The most important of these effects is on the quality of care that the ill caregiver is able to give. Evidence suggests that caregiving is often adversely affected even prior to the caregiver becoming ill, and that this is likely to be as a result of the increased stress and concern created by the HIV-positive diagnosis. Once caregivers become sick, and particularly if they are unable to access treatment and care, they become less physically and mentally able to provide the quality of care necessary for the health and wellbeing of young children, or to meet the children's unique developmental needs.

3.3.4 Caregiver mental health and quality of care

Although studies have reported that asymptomatic HIV does not compromise a caregiver's physical ability to care for children, their mental health may. HIV has been directly linked to maternal depression, and the effects of this on caregiving ability have been well documented (Biggar & Forehand, 1998; Hough, Brummitt, Templin, Saltz, Mood, 2003; Naar-King et al, 2006; Richter et al, 2005a; Richter et al, 2006a; Rochat et al, 2006).

Maternal depression is known to adversely affect healthy mother-child interactions, and women who are poor or suffering chronic or terminal illnesses are more likely to report depressive symptoms (Ickovics et al, 2001; Kvalsig et al, 2006; Rahman, Bunn, Lovel, Creed, 2007; Rochat et al, 2006). Maternal depression has also been found to play a role not only in increasing disease progression in mothers, but also in increasing the risk of infant illness and impaired growth. Mothers who show depressed symptoms are less likely to pay attention to simple health-promoting activities and keep a watchful eye on their child. As such, there is a general consensus that caregiver depression during the early years of children's lives has long-term effects on their development and requires specific and urgent attention (Rahman et al, 2007; Rochat et al, 2006).

Many studies have identified stigma as one of the main concerns facing HIV-infected mothers and their children (Antle, Wells, Goldie, DeMatteo, King, 2001; Hackl, Somlai, Kelly, Kalichman, 1997; Silver, Westbrook, Stein, 1998; Silver, Baumann, Camacho, Hudis, 2003). In two African studies, caregivers reported concerns about stigma; the cost of transport and other difficulties in

accessing care; low levels of education and understanding of their illness; poverty; loneliness; and lack of acknowledgement by health-care workers and non-governmental organisations as major concerns and barriers to support (Katapa, 2004; Orner, 2006). Several authors suggest that caregivers are overwhelmed by their concerns for the child's health and their worries about the future and they doubt their own capacity to care for the child (Reidy, 1991; Weiner, Theut, Steinberg, Riekert, Pizzo, 1994).

3.4 CONCLUSION

The evidence reviewed of the impact of poverty on young children raises two important issues in the context of HIV and AIDS.

- Firstly, there is an urgent need to address and ameliorate the effects of poverty on young children by taking actions which improve access to basic resources for children, their families, and their systems of care. In doing so, the platform of poverty which facilitates and increases the risks of HIV and AIDS impacting on childhood can be reduced.
- Secondly, there is an urgent need to address the direct impact of HIV and AIDS on young children, in particular those living with the disease and those cared for by caregivers living with HIV and AIDS.

The early childhood development literature suggests that a successful transition through the early years for children is highly dependent on the presence of a consistent and stable caregiver to facilitate healthy development. This highlights the need to intervene where HIV and AIDS make young children most vulnerable to poor outcomes, that is, in their everyday systems of care.

The literature provides a strong foundation for understanding the severe impact of HIV and AIDS on communities and families affected by the epidemic. Increasing evidence suggests that the family provides the most direct support and care for children, but that families are under strain and need support. Children affected by HIV and AIDS need interventions which support and strengthen the systems of care around them (Richter et al, 2006a). Children are best protected and assisted through the strengthening of their families and communities, which can then provide a safety net in the event of loss of a parent or other primary caregiver to HIV and AIDS (Killian, 2004; Foster, 2005).

Interventions need to ensure adequate access to health care, including life-saving antiretroviral treatment, education and social protection for families, and to support community development and endogenous responses for children in their everyday lives. Interventions which are aimed at identifiable risk groups, such as orphans, or targeted at single domain outcomes, for example mental illness like depression, while important for a smaller group of children, are unlikely to impact on the vast majority of children affected by HIV and AIDS (Richter et al, 2006a).

While children affected by HIV and AIDS need family care and support, children living with HIV and AIDS have special needs which extend beyond the care that family and communities can provide. The challenges facing young HIV-positive children are pervasive, not only at a individual level in terms of their physical and psychological health, but also at a systemic level in terms of the challenges the scale of HIV and AIDS epidemic presents to an already overburdened public health system. As a result, most public health-care facilities are often ill equipped to provide for these children's special health-care needs. These challenges are explored further in the next chapter.

CHAPTER 4: CHILDREN LIVING WITH HIV AND AIDS

In South Africa, 40.3% of deaths in children under the age of five are attributable to HIV and AIDS (Bradshaw & Nannan, 2006). In sub-Saharan Africa, estimates suggest that less than 10% of women have access to prevention of transmission services during their antenatal care; and that nearly 1 800 children become infected by HIV daily (mostly through vertical transmission). Over 1 000 children die every day as a result of AIDS-related illness (UNAIDS, 2006).

To date, several studies have demonstrated that antiretroviral treatment is effective in reducing morbidity and mortality in paediatric populations. At the same time, only one in ten children needing antiretroviral treatment receive it and at most, one in 25 children born to HIV-infected mothers receive Cotrimoxazole prophylaxis to prevent opportunistic infections.

At the end of 2005, approximately 300 000 children were estimated to be living with HIV in South Africa (UNAIDS, 2006). Approximately 50% of these children required immediate access to antiretroviral treatment. However, access to paediatric care for children living with HIV and AIDS has to date been limited or non-existent. In 2006 only 10 000 to 15 000 children were estimated to be receiving antiretroviral treatment. Of those children receiving treatment, most were in urban centres where paediatric centres exist (Crowley, 2007; Saloojee & Bamford, 2006; Wilfert, 2005).

4.1 HIV AND AIDS AS A CHRONIC PAEDIATRIC ILLNESS

Under epidemic condition such as these, early intervention is vital to prevent infections and rapid deterioration, suffering and death of children. Research in South Africa estimates mortality at 33% in the first 12 months, at 50% by 24 months, and 60% by three years. Some developmental delays of at least 40% of HIV-positive children over 18 months old are seen in clinics. Of these children at least 80% have CD4 counts less than 20%; 82% are at less than 5% weight; and 47% are considered 'stunted' in growth (Potterton, 2006a, 2006b; Wilfred, 2006; Varga, Sherman, Maphosa, & Jones, 2005).

The HIV disease impacts on the young child through a complex interaction of biological, psychological, social, socioeconomic and environmental mechanisms, and there is a large proportion of children under five that are HIV-infected and not currently receiving care or treatment. Most HIV-infected children are diagnosed very late in the course of illness or not at all, often, the first time a child has an HIV test is when the child is already very ill, chronically ill or hospitalised, by which time the detrimental effects of HIV infection are already likely to have manifested (Govender, Ro-chat, Richter, & Rollins, 2006; Domek, 2006; Michaels, Eley, Ndhlovu, Rutenberg, 2006).

Increasing numbers of chronically ill and dying children create challenges for the health-care system (Médecins Sans Frontières (MSF), 2007; Savage & Callery, 2000). There are three important mechanisms by which the burden of HIV and AIDS impacts on the nursing-care system and quality of care delivered to hospitalised children. Firstly, nurses in paediatric settings are confronted with escalating case-loads and greater numbers of acutely and terminally ill children. Their training, support, skills and management seldom matches the demands of care to be delivered (Subedar, 2005). In an effort to cope with the increasing burden and limited resources, care systems tend to become more rigid, and nurses become more burnt out and less compassionate (Sherman, 2000).

Secondly, hospital bureaucracy, constant change of staff, and scarce nursing resources often make it imperative for parents to play a role in the care of their children to ensure the regular feeding, bathing and social and emotional care of the child. This is sometimes difficult because the poorly resourced system has too few staff and, as a result, ward routines become more rigid and rule bound in order to cope with daily activities. For example, times at which parents can visit become less flexible

and this reduces opportunities for parental contact with the child. Furthermore, when health-care staff are stressed and over burdened, they are less willing and/or able to engage with parents about the child's illness and health care while the child is in the health-care system (Algren, 1985; Robinson, 1987). This often results in parents feeling responsible, but having very little opportunity for participation. They frequently experience role conflict and disempowerment in the care, protection and comfort of their children (Ygge & Arnetz, 2004).

Lastly, young children themselves face the physical challenge of a particularly painful and debilitating disease, often compounded by malnutrition (Luo & Coulter, 2002; Puaane et al, 2004). Because of their illness, they have to cope with repeated and distressing separations from parental figures during hospitalisations with little or no psychosocial support and very little access to palliative care (Goldman-Fraser, Fernandez & Marfo, 2005).

Chronically ill children experience developmental delays and regression in milestones because their brain is directly affected by the virus, and because of the psychological and social effects of illness and hospitalisation. While prompt diagnosis of HIV infection in children is vital so that antiretroviral treatment can be started as quickly as possible, there is also need for palliative, psychosocial care and treatment. This is especially important in the absence of antiretroviral treatment programmes, to support young children who are living with HIV as a chronic and terminal illness (Govender et al, 2006; Kvalsig et al, 2006; Médecins Sans Frontières (MSF), 2005; World Health Organisation (WHO), 2007). Likewise, advocating for and encouraging and improving parental participation and skill in the care of children has been shown to be beneficial (Flanagan, 1990).

4.2 HIV INFECTION IMPACTS ON EARLY CHILDHOOD DEVELOPMENT

Given the importance of the early developmental period and the multiple pathways through which HIV and AIDS can impact on them, children are especially vulnerable to various environmental factors that can disturb or arrest their development. Children are extremely vulnerable to the effects of poverty and HIV and AIDS, not only physically, but also socially, emotionally and psychologically. While evidence suggests that even children who are not directly infected with the virus suffer its impact, the child that has been infected with HIV faces the bleakest prospects.

The morbidity and mortality of young children born HIV positive is extensive and pervasive (Brown & Lourie, 2000; Wilfert, 2005), and the rapid progression of HIV in children means that many undiagnosed or untreated young children die in infancy or early childhood from preventable and treatable childhood conditions and opportunistic infections. If they do not die, vertically infected infants are at increased risk of developmental impairments in a number of domains, including mental, motor and emotional. Studies have found motor and cognitive impairments, but the nature of these impairments has also been found to change over time. Delayed milestones, especially in the onset of speech and other language impediments have also been observed in infected children (Aylward, Butz, Hutton, Joyner, & Vohlgut, 1992; Bagenda et al, 2006; Potterton, 2006; Sandison, 2005; Stein et al, 2005; Walker et al, 2007).

Evidence indicates that HIV destroys the neuronal tissues in the central nervous system directly, as well as through viral infections like encephalopathy which leads to a failure to progress developmentally or a regression in developmental milestones (Potterton, 2006; Stein et al, 2005; Wilmschurst, Burgess, Hartely, & Eley, 2006). The impact of HIV and AIDS on children's neurological development has been summarised as follows:

- i. Progressive cognitive impairment may be due to central nervous system (CNS) effects of HIV
- ii. Acquired microcephaly (abnormally small brain)
- iii. Cerebral atrophy (brain tissue wasting), calcifications (calcium deposits) in basal ganglia (nerve structures deep inside the brain) and white matter changes
- iv. Regression in developmental milestones
- v. Declines in intellectual/cognitive functioning

- vi. Delays in speech and language development
- vii. Gross and fine motor deficits
- viii. Short-term memory loss
- ix. Attention deficit disorder, hyperactivity
- x. Emotional withdrawal, depression, apathy

A great deal of research has demonstrated the direct effect of HIV on the physical, cognitive, psychological, social, emotional and behavioural development of young children. Sherr (2005) conducted what is currently the most comprehensive systematic overview of international studies of the impact of HIV on early childhood development. Appendix 5 is adapted from Sherr (2005) and outlines studies with the most significant findings based on the review, and Appendix 6 summarises similar evidence from studies conducted in Africa.

When one considers the current dearth of evidence on poverty and HIV and AIDS and its direct impact on early childhood development, along with the large body of evidence which demonstrates the benefits of intervening with young children, there is no doubt about the value of early intervention, nor about what is required in large-scale intervention. As Tomlinson et al (2007) argue, when resources are limited, guidelines are needed to prioritise health investments. The evidence on poverty, HIV and AIDS and early childhood development suggests that simple low-cost scaled-up interventions to protect health and wellbeing are urgently needed.

4.3 THE IMPACT OF ANTIRETROVIRAL TREATMENT

Despite problems with access to treatment, there is little disputing that antiretroviral treatment has proved to be highly effective in the treatment of children, including those in resource-poor settings. Good practice and operational guidelines have also been published by the SA HIV Clinicians Society in a special issue of their official journal *The Southern African Journal of HIV Medicine* in November 2005. Evidence suggests that rapid initiation of antiretroviral treatment restores and preserves immune functions, promotes normal growth and development, and prolongs life.

Generally, some 80% of children with HIV die by age five years if they do not receive antiretroviral treatment. In high-income countries, where most children with perinatally-acquired HIV infection are treated early with antiretrovirals, such treatment has been shown to reduce mortality by five-fold or more and results in survival rates of 80% and higher (Eley et al, 2004; Koekkoek, Eggermont, De Sonnevile, & Jupimai, 2006; Kvalsig et al, 2006; Meyers, Moultrie, Sherman, Cotton, & Eley, 2006a; Médecins Sans Frontières (MSF), 2007; Perinatal HIV Research Unit, 2006; Saloojee et al, 2006; UNICEF, 2005; World Health Organisation (WHO), 2006; Wilfert, 2005).

In addition, low-cost antibiotics can provide protection against opportunistic and other childhood infections which are potentially life-threatening. But it has been estimated that up to four million children younger than age 15 years could benefit from such combined treatment, while only about one percent of those in need currently receive this.

Research on the impact of antiretroviral treatment in children is on the increase. Brown et al (2000) reviewed several studies which demonstrate the benefits of paediatric antiretroviral treatment. Research in South Africa also demonstrates the effectiveness of antiretroviral treatment in reducing morbidity and mortality in children (Chiriboga, Fleishman, Champion, Gaye-Robinson, & Abrams, 2005; Eley et al, 2004; Kvalsig et al, 2006; Smith et al, 2006).

The literature search identified several studies that examined and demonstrated the benefit of antiretroviral treatment for children, both in South Africa and internationally, and a summary of these findings is presented in Table 4. They provide convincing evidence for the rapid scale-up of paediatric antiretroviral treatment.

STUDY	PLACE	SAMPLE	MEASURES	FINDINGS
Brady <i>et al</i> (1996)	USA	Children 3 months to 12 yrs		Improved cognitive abilities over 36 months. Improved cognitive functioning in 25 %
Butler <i>et al</i> (1991)	USA	43 children age 3 months to 18 yrs	Cognitive battery	Improved cognitive functioning in 25%
Pizzo <i>et al</i> (1988)	USA	N=25 mean age 5 yrs	Vinlands Scales	Significant improvement in communication, socialisation, daily living
Coplan <i>et al</i> (1998)	USA	N=78, age 15-45 months	Various	Improvement in language with initiation of ART
Cowburn <i>et al</i> (1997)	South Africa	68 infants mean age 3 months		Long-term outcome of children on ART is good
Eley <i>et al</i> (2004)	South Africa	N=17, HAART > 6 months		ART benefits children
Rabie, Marais & Cotton (2006)	South Africa	Various	Various	HAART provides the opportunity for desperately ill children to flourish & live a healthy fulfilled life, ART fosters dynamic development of the child both physically & psychologically
Koekkoek <i>et al</i> (2006)	Thailand	34 HIV+ children: 16 ART naive, 11 ART=12 months 7=untreated	Psychomotor tasks evaluated longitudinally over 12 months	At the 12-month evaluation, psychomotor performance was substantially better for those on long-term treatment
McKinney <i>et al</i> (1991)	USA	88 children mean age 4 years	Various indexes	Weight gains & improved cognitive function, clinical, virologic & immunologic improvements
McNeilly (1999)	USA	N=30, age 15–36 months	Preschool Language Scale	Caregiver & psychosocial factors as important as ART
Mitchell (2006)	USA	Perinatally infected infants		Frequency of the most severe forms of encephalopathy decrease dramatically with ART
Potterton (2006)	South Africa	109 on ART age < 2 and a half years	Bayley Scales of Infant Development	Significant improvement in motor development with HAART
Saavedra-Lozano, Fox & Sungkanuparph (2006)	USA	Neurobiological investigations		Significant neuropsychological improvements were shown

Table 4: Benefits of paediatric antiretroviral treatment (ART) – summary of existing studies

4.4 BARRIERS TO TREATMENT AND CARE FOR CHILDREN

Considering the effectiveness of antiretroviral treatment for children, the lack of access to such treatment for young children in South Africa is raising concern. Historically, at an international level, responses to children living with HIV and AIDS were initially very slow and, while it has started to gain some momentum in recent years, most interventions aimed at the treatment, care and support of children have not nearly matched the size of the problem. The UNICEF rapid assessment, analysis, and action planning (RAAAP) analysis of National Plans of Actions for sub-Saharan countries in 2005 demonstrates the need to urgently take steps to scale up and replicate successful interventions for children living with HIV and AIDS (Webb, Gulaid, Ngalazu-Phiri, Rejbrand, 2006).

Specific barriers to the roll-out of antiretroviral treatment for children have been identified in the literature (Foster, 2005; Kegels *et al*, 2005; Marchal *et al*, 2005; Médecins Sans Frontières [MSF], 2007; Michaels *et al*, 2006; Van Damme *et al*, 2006; Wilfert, 2005) and these are summarised in the table below:

CONTRIBUTING FACTORS TO SLOW ROLL-OUT OF PAEDIATRIC ART PROGRAMMES

- Many of the worst-affected countries are struggling with human resource constraints and inefficient health systems.
- There is limited screening for HIV-positive children in many countries.
- Tools for diagnosing HIV in infants tend to be unaffordable or unavailable.
- Misconceptions persist about the effectiveness of antiretroviral treatment for children.
- In many places there is still limited experience with simplified, standardised treatment guidelines.
- Practical paediatric antiretroviral formulations are either absent or unaffordable in many of the countries that need them most.

Table 5: Contributing factors to slow roll-out of paediatric ART

While it appears clear that what is needed is a scaling-up of treatment access, few developing countries are managing to implement treatment effectively or achieving the coverage required to improve the lives and wellbeing of young children (UNICEF/World Health Organisation (WHO), 2007). Several barriers exist to the adequate roll-out of paediatric antiretroviral treatment programmes in developing countries: the formulations have remained expensive in comparison to adult treatment, often costing between four to eight times more; they are difficult to handle, bad-tasting, and administration and management is difficult; diagnostic tools for children under 18 months are generally available, and medical staff report being inadequately trained to treat children.

South Africa launched its national antiretroviral treatment campaign in November 2003 with an operational plan for comprehensive HIV and AIDS care, management and treatment. Critics have argued that paediatric care issues were inadequately addressed in the national plans, protocol and guidelines and were restricted to limited discussions of clinical and technical issues (Médecins Sans Frontières (MSF), 2005; UNICEF/World Health Organisation (WHO), 2007; Wilfert, 2005). Currently political leadership in the fight against HIV and AIDS in South Africa is growing, as is global and national funding allocation. Acknowledgement should be given to significant progress made in increasing the scale of antiretroviral treatment. The current improvements in coverage have been attributed to both the decentralised approach taken to the wide-scale delivery of services and renewed political commitment. The World Health Organisation has argued that improvements in the prevention of transmission and the implementation of comprehensive treatment plans will significantly impact on health in the region (WHO, 2005a, 2005b).

While there have been rapid improvements in the number of people receiving treatment (a three-fold increase in sub-Saharan Africa between 2004 and 2006), it is regrettable that only a very small proportion of these patients have been children. Access to preventative care and treatment is also improving (prevention of mother-to-child transmission (PMTCT) services had improved from 22% to 30% coverage by the end of 2005) and while South Africa showed greater improvement than other developing countries over the last two years, it still fell short of its expected achievements considering its relative resources (Kegels & Marchal, 2005; Marchal, De Brouwere, & Kegels, 2005; Médecins Sans Frontières (MSF), 2007; Van Damme, Kober, & Laga, 2006;).

UNICEF estimates that in South Africa only 30% of HIV-positive pregnant women in need of antiretroviral treatment in PMTCT programmes in 2005 received it, and only 18% of children in need of antiretroviral treatment were receiving it (Bradshaw et al, 2006; Day & Gray, 2006; Mhlanga, & De Pinho, 2006; Ramkissoon et al, 2006; Shun King, 2006). The scale of the epidemic, the cumulative effect of poverty and an increasingly burdened and weakened health system makes progress inadequate, slow and frustrating.

A recent situational analysis explored more specifically the state of paediatric antiretroviral treatment roll-out in South Africa and identified a number of challenges to improve delivery (Michaels et al, 2006). Table 6 below summarises the types of challenges identified in this recent situational analysis.

HUMAN RESOURCE CHALLENGES
In general, there is a shortage of adequately trained staff e.g. nurses, pharmacists and auxiliary staff (social workers, counsellors). Role confusion in management of paediatric HIV exists and the emotionally difficult work is stressful. There is also poor awareness of antiretroviral treatment programming within health systems, contradictory and confusing perceptions of the purpose and process of paediatric antiretroviral treatment roll-out.
SYSTEMIC PROBLEMS
There are physical and structural challenges specifically with regard to lack of space for waiting areas, consulting rooms and confidential counselling at health facilities. Additionally, referral systems between services are inefficient, leading to a breakdown in follow-up of exposed children and late referral of children already seriously ill. This is exacerbated where community knowledge, information and awareness is lacking with respect to services, and in the light of pervading myths and misconceptions about antiretroviral treatment.
POLICY PROBLEMS
Policy and procedure for paediatric antiretroviral treatment is limited. Health facilities are often distant and socioeconomic circumstances in rural areas mean lack of money for transport. Children may have frequent changes in caregivers and lack of social security which adds to the problems.

Table 6: Summary of findings from Michaels, Eley, Ndhlovu & Rutenberg (2006)

The recommendations of the Michaels et al (2006) report attempted to address the issues of human resource shortages and skills development with training to improve the management of paediatric HIV. This and other operational research has recommended that steps be taken to improve the links between prevention, testing and other clinic and antiretroviral treatment services in order to ensure the early identification of children who need antiretroviral treatment; also that support should be extended to include social and financial needs. (Dorsey, Chance, Forehand, Morse, & Morse, 1999a; Médecins Sans Frontières (MSF), 2007; Michaels et al, 2006; World Health Organisation (WHO), 2006).

Less of the operational research to date has focused on the care of young children. Michaels et al (2006), however, draw attention to the special needs and circumstances of infants and very young children. They argue that important factors specific to this group need to be highlighted. Firstly, very few infants and young children are currently receiving antiretroviral treatment and, secondly, that those who are, do so at tertiary care centres. The treatment of children at tertiary sites only, rather than at primary health-care clinics, may explain some of the high mortality rates amongst children not receiving treatment as the needs of young children are often missed or go unmet at primary health-care level. As such, young children are likely to die prior to referral to a tertiary centre. Lastly, the antiretroviral treatment of very young children is seen to be more complex than that of older populations, as are the medical procedures required for treatment and care.

4.5 RIGHTS-BASED APPROACHES TO TREATMENT AND CARE

Current thinking in the field of paediatric HIV and AIDS suggests that a rights-based approach may go a long way to addressing and rectifying many of the distortions that have arisen from the crisis-driven response to children affected by HIV and AIDS (Richter et al, 2006a; Richter & Rama, 2006).

Rights-based approaches aim at enabling the poor, the marginalised and the most vulnerable in society to lay claim to their rights – through empowerment and participation rather than traditional trickle-down approaches. A rights-based framework provides a firm foundation for determining priorities and responses to children (Biersteker & Rudolph, 2003; Richter & Rama, 2006; Viviers, 2005) and, while the state (as primary duty bearer) has the obligation to fulfil children's rights, all actors have responsibilities to protect and care for children. Within a rights-based framework, a collective governmental, civil society and community response is required to strengthen the commitment of caregivers and households to provide for the wellbeing of young children.

The rights of children living with HIV and AIDS to adequate prevention and health-care treatment programmes is exceptionally limited. While government as a duty bearer has the responsibility to provide adequate resources for the actualisation of children's rights, it is inconceivable that the

provision for the care, treatment and support required for children living with HIV and AIDS can be undertaken by government alone.

THE FOUR PRINCIPLES UNDERLYING RIGHTS-BASED PROGRAMMING ARE IDENTIFIED AS:	
Universality	All rights should be accessible to all people, including children.
Indivisibility	Rights are interdependent and interlinked; they cannot be separated from each other.
Responsibility	There is a shared responsibility to ensure that rights are fulfilled and upheld. Duty bearers, especially but not exclusively, and governments should be held accountable for their responsibility.
Participation	Rights holders, including children, must be actively involved in programmes aiming to fulfil their rights.
Sourced in Richter & Rama (2006) Building Resilience: A rights-based approach to children and HIV/AIDS in Africa	

Table 7: Four principles of rights based programming

4.6 CONCLUSIONS

South Africa, like many developing countries, is struggling to provide adequate access to health care, treatment and prevention for young children living with HIV and AIDS. The challenges and barriers to providing such care are vast, and much improvement is needed. A rights-based approach suggests that health-care needs to be mainstreamed and integrated, and that wherever possible a child’s right to treatment, if it is to have any meaning for the child, needs to be enacted through their every-day systems of care, their caregivers, their families and communities. Beyond receiving medication, these children need opportunities to grow and to learn, to be secure and protected, to be loved and to live to their full potential.

In striving toward effective antiretroviral treatment programmes for young children, attention needs to be given to developing adequate systems of care for and within families. Ensuring that the right of children to treatment is fulfilled includes encouraging the participation and empowerment of children and their caregivers in health-care programme experience and development. If children’s rights are to be taken seriously, then their active participation in decisions that affect them needs to be promoted. Likewise, child and caregiver voices need to be given space and opportunity in the development of treatment programmes.

Before exploring the experiences of children and caregivers in Chapter 6, the next chapter, Chapter 5 reports on challenges, experiences and good practice examples explored during interviews and discussions undertaken with experts as part of this research.

CHAPTER 5: LESSONS LEARNT FROM SOUTH AFRICA

Political leadership and funding allocation for the fight against HIV and AIDS is growing and progress is being made in moving toward large-scale prevention and treatment programmes delivered through public services. While the number of people receiving treatment increases daily (currently South Africa has the highest number of patients on antiretroviral treatment in the world), only a very small proportion of these are children (UNICEF, 2006).

Improvements in antiretroviral treatment and prevention coverage have been attributed to both the decentralised approach taken to the wide-scale delivery of services and to recent renewed political commitment. The South African government's National HIV & AIDS Strategic Plan 2007–2011 was launched early in 2007 in an effort to drive the responses to the burgeoning challenges of the HIV pandemic.

The strategy was developed to build on current service delivery achievements and to develop further a comprehensive HIV and AIDS care, management, and treatment approach using multi-sectoral resources. The South African health system's response includes multiple levels such as prevention through programmes such as the prevention of mother-to-child transmission (PMTCT), adult and paediatric antiretroviral treatment services and primary health-care provision and services.

As outlined in Chapter 1, the purpose of the site visits and expert interviews was to develop an overview of existing knowledge, skills and experience within antiretroviral treatment facilities in South Africa. Several visits were conducted to existing paediatric antiretroviral treatment sites and interviews were conducted with key stakeholders involved in paediatric antiretroviral treatment delivery. The findings of these visits and interviews are summarised in the sections below.

5.1 BARRIERS, OPPORTUNITIES AND LESSONS LEARNT

The findings of the expert interview data are organised into four dominant thematic areas including:

- a) Inter-sectoral integration
- b) Technical aspects and challenges to paediatric care
- c) Adherence
- d) Developmental frameworks

INTER-SECTORAL INTEGRATION	<p><i>There are difficulties in the integration between sectors, programmes, policy and practice.</i></p> <ol style="list-style-type: none">1. Early initiation is critical but there are gaps in follow-up and referrals from PMTCT, VCT to ART. Capacity of primary health-care level needs to be developed urgently;2. Sustainability of programmes is difficult where resources are scarce or funding cycles short and insecure; a shift towards public ownership of ART programmes is essential;3. Challenges in diffusing treatment and care from tertiary to primary health facilities require urgent attention if coverage is to improve;4. There is a need to mainstream civil society support programming into public programming to avoid overlap and parallel services.
TECHNICAL ASPECTS	<p><i>Practical difficulties exist within the actual medications, formulations and administration.</i></p> <ol style="list-style-type: none">1. Knowledge and skills on testing and treatment of children still need to be developed and integrated into training;2. Health facilities often face infrastructural problems such as lack of confidential space for treatment and counselling;3. Health-care staff are fearful of testing and treating;4. Difficulties arise in respect to formulations, dosing, decanting and laboratory results.

ADHERENCE	<p><i>Problems with adherence were less evident than expected and most materials are aimed at older children.</i></p> <ol style="list-style-type: none"> 1. Many models of adherence intervention centre on compliance rather than caregiver empowerment; 2. Many programmes focus on older children (6-12 years) using talk therapy, but little attention is given to younger children and to young children's caregivers; 3. Several resources exist but are not generally distributed and are thus not being utilised.
DEVELOPMENTAL FRAMEWORKS	<p><i>Treatment programming and treatment staff in general did not take cognisance of developmental frameworks, risks or opportunities for young children.</i></p> <ol style="list-style-type: none"> 1. While many experts were broadly aware of developmental impact, there was very little evidence of screening or age appropriate referral or intervention as part of programming; 2. Interventions tended to be psychologist or physiotherapist-driven and dependent on external resources; 3. Major barriers to social, psychological and developmental interventions were screening, time constraints and a lack of a 'package' which could be delivered by non-professionals.

Table 8: Main themes expert interviews

ART: Antiretroviral treatment; PMTCT: Prevention of mother-to-child transmission; VCT: Voluntary counselling and testing

The findings are summarised in Table 8 above. In general, many similarities were found in both the barriers and opportunities across the spectrum of service delivery settings. While concerns have been raised regarding the current capacity of public service sites to offer comprehensive services as a result of resource constraints, very similar resource constraints were encountered in public-private partnerships and private settings. In most cases where additional resources were available, they were not usually directed at social or psychological support services.

5.2 INNOVATIVE PRACTICE AND MATERIALS DEVELOPMENT

During site visits and expert interviews, several examples of innovative practice, material and programme development, and support services were found.

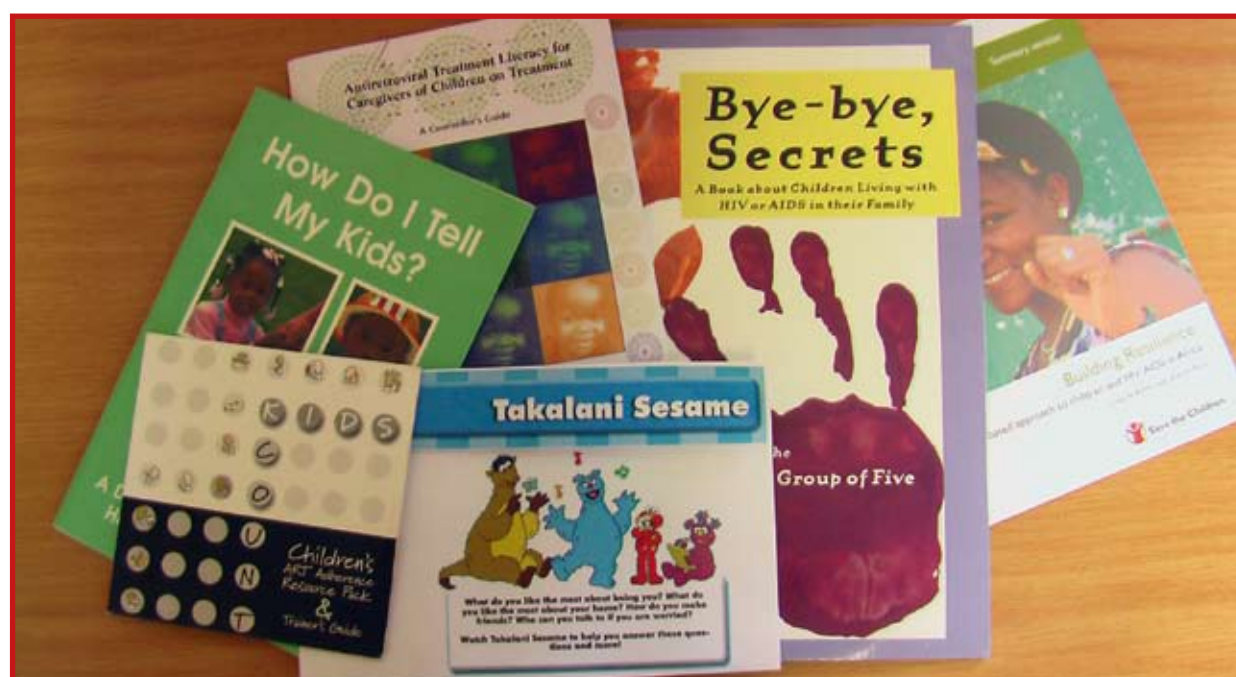


Figure 13: Examples of training and support materials

A comprehensive overview of the pharmacological and medical management of paediatric patients in the South Africa context, with contributions from leading experts in the fields, was pub-

lished in November 2005 by *The Southern Africa Journal of HIV Medicine*, the official journal of the SA HIV Clinicians Society. The journal includes articles covering pragmatic issues related to the management and care of children as well as a discussion of disclosure to children (see for example Naeem-Sheik & Gray, 2005).

A recent PhD study by Potterton (2007) demonstrates that a basic home programme can significantly improve both the cognitive and motor development of young children infected with HIV. This programme was simple and easily implemented and is an example of developmentally appropriate programming which could become standard practice for paediatric HIV clinics in South Africa.

Some examples of resources for disclosure, counselling and adherence are listed in the figures above and below. Furthermore, the Mindset Library, a library of resources which is maintained by a non-profit organisation on behalf of the Department of Health, was found to offer several examples of appropriate materials on early childcare and development which could be used to offer support in antiretroviral treatment settings where caregivers and children spend long periods of time waiting for treatment. Many audiovisual materials have been specifically developed for the Department of Health and are available through the Mindset facility and can be broadcast locally and at primary or tertiary health facilities.

An excellent series on children living with HIV and AIDS has been developed by the Children's Rights Centre in Durban. The development of the series involved wide levels of consultation with health-care providers, children and families. The materials provide practical and age-appropriate guidance and assistance for children, caregivers and health-care providers and are currently available in English and IsiZulu and are well prepared for distribution on a wide scale.



Figure 14: Caregiver, child and health-care worker support materials

5.3 CONCLUSION

There are many challenges to the adequate provision of comprehensive HIV and AIDS treatment for young children including issues of integration and technical support and development. Most psychosocial support focused on adherence and was generally targeted at older children, and little attention was given to developmental frameworks.

Several examples of innovative practice were found across the settings visited. In many cases exemplary practice were seen to be the result of individual initiatives, such as the personality or determination of the health-care staff involved, rather than systemic factors, raising concerns regarding sustainability.

Of great concern regarding the currently available support materials sourced through this research, is the lack of any centralised space/forum for sharing of such resources which could facilitate their wider distribution. In many instances, there appeared to be duplications in materials development, or significant amounts of time and resources had been invested in resource development which subsequently achieved low levels of distribution.

The following chapter will explore how these challenges present themselves in the lived experiences of caregivers and children who are accessing antiretroviral treatment.

CHAPTER 6: EXPERIENCES OF CHILDREN AND CAREGIVERS

In this part of the study, a total sample of 48 caregivers and their children were enrolled to participate in qualitative research to explore their psychological, social and developmental needs in the context of treatment. The ratio of male to female children in the sample was close to equal (25:23), and participants ranged in age from as young as six months to 66 months. Some children had recently started treatment (for example, one month treatment duration), and others had been on treatment long enough to be considered stable (for example, more than 12 months on treatment).

Data consisted of field notes, transcriptions of interviews and group processes, and children's drawings and developmental observations. Initially data was examined on an in-depth individual case-by-case basis and thereafter findings were compared across cases. During data analysis, five clear themes emerged, each offering insight into caregiver and child needs and experiences in antiretroviral programming. The findings are presented according to these categories:

CATEGORY 1	Testing, diagnosis and living with an HIV-positive child
CATEGORY 2	Antiretroviral treatment, adherence and side-effects
CATEGORY 3	Disclosure to children, families and communities
CATEGORY 4	Medical and health-care contact profiles and developmental status
CATEGORY 5	Psychosocial assistance and support required for ART programming

The qualitative research findings demonstrate that early testing, diagnosis and treatment can have a substantial impact on the psychological, social and developmental outcomes for caregivers and young children. Importantly, the data suggests that the complexity of antiretroviral treatment is less of a barrier to treatment than are issues of disclosure and support.

6.1 TESTING, DIAGNOSIS AND LIVING WITH AN HIV-POSITIVE CHILD

6.1.1 Early testing and treatment changes lives

In the category of testing, diagnosis and living with an HIV-positive child, the data illustrates how a child's access to antiretroviral treatment is secondary to and limited by their access to HIV testing, both for themselves and their caregivers. In this sample, most of the caregivers enrolled had not been exposed to prevention of mother-to-child (PMTCT) services during their pregnancy, as shown in Table 9.

TESTING POINT	VALID PERCENTAGE*
Postnatal inpatient hospital services (Child)	70%
Antenatal prevention of mother-to-child services (PMTCT)	15%
Postnatal voluntary counselling and testing clinic services	13%
Postnatal private general practitioner services (Child)	2%
TOTAL N=47	100%

Table 9: Services through which caregivers had learnt of their own or the child's HIV status

Missing data N=1

The lack of access to preventative testing and care in this sample is likely a historical factor and related to the low national coverage in PMTCT at the time of the sample group's pregnancies in 2003, 2004 and 2005. The psychological and social difficulties described by caregivers around testing and

diagnosis highlights the critical importance of increasing the coverage, quality, information and access to preventive and testing services during pregnancy.

“I didn’t know about HIV when I was pregnant; this was a new thing for me when I came to the hospital with my baby so sick. Nowadays they do the testing at the clinic for the pregnancies but when I was pregnant in 2004 they never did this at the clinic. They just check the urine and the pressure and those things. When the doctor told me, it was a shock because I was bringing the child here to get better. I was coming all the time because I thought they could make my child better then they told me this thing and I felt hopeless.”

When a caregiver had received testing and preventative services and was aware of their status during pregnancy or early in the post-partum period, this benefited the child by improving access to health-care services and allowing for the early uptake of antiretroviral treatment. A significant relationship existed between the circumstances under which HIV testing had taken place and the number of serious and frequent hospital admissions the child had been exposed to prior to the commencement of treatment. This is illustrated in Table 10 below.

	ADMISSIONS					TOTAL
	FEW/NO ILLNESSES	FEW/MILD ILLNESSES PRIMARY HEALTH CARE	FREQUENT ILLNESS PRIMARY HEALTH CARE	SERIOUS ILLNESS SELDOM HOSPITALISED	SERIOUS ILLNESS FREQUENTLY HOSPITALISED	
PMTCT	2	1	2	0	2	7
VCT	0	3	2	1	0	6
Hospital	1	2	6	15	9	33
GPs	0	0	0	0	1	1
	3	6	10	16	12	47

Table 10: Relationship between testing and early access to treatment

* Missing data N=1

PMTCT: Prevention of mother-to-child transmission

VCT: Voluntary counselling and testing

GPs: General practitioners

Children who were tested earlier (e.g. during PMTCT programmes) were less likely to have major illnesses and hospitalisations prior to starting treatment.

6.1.2 Testing – always a tough blow

As described above, most caregivers (70% N=33) reported that they had learnt their child’s HIV status during a hospitalisation of the child, and most of those (72% N=24) had learnt about their own status only when their children had been tested at a hospital site on or during an admission for a serious illness. The qualitative data demonstrated that this presents challenging scenarios for both the caregiver and the health-care services. Caregivers are required to cope with the emotional distress of an acutely and chronically ill child, and at the same time assimilate the knowledge and implications of both the child’s and their own HIV status in a stressful and strange environment, lacking familiar support networks.

“It was too hard. That thing when it happened – too hard to accept. My baby was so sick she could not walk any more – and she had sores everywhere. She was crying in the pain. And then they told me about it – that it was me that gave this thing to her (becomes tearful) – when I first heard that I was HIV positive, I just could not believe it, I never thought it

would happen to me. I thought it only happened to promiscuous people. Then there was too much to cope with and I couldn't go home."

Likewise, health-care providers in already overcrowded and over-burdened wards are faced with the extra burden of testing, diagnosis and counselling not only with respect to the child's status and illness, but also that of the caregiver.

6.1.3 What if prevention fails?

Some caregivers in the sample described testing and adhering to preventative regimes in order to prevent transmission – but failing to prevent infection in the child. In most cases, this was a difficult and frustrating experience and highlights the needs of a specific group for whom, regardless of their compliance, vertical transmission will still occur.

"I tested at the hospital outpatient clinic during pregnancy and I tested positive. They gave me counselling and I took the Nevirapine at the time of the birth like they told me. Then we had to attend the clinic for 18 months. They started giving the baby the Bactrium since he was born and I came once every month. The clinic gave me the milk to feed the baby for six months. Then later on the baby tested positive. It was too difficult – they told me this could happen but it was too difficult because I didn't think it would. I don't understand why my child must have this suffering. Everybody treated me as if I had failed."

In several instances where women had tested and knew their status, they also described barriers which prevented them from adhering to prevention strategies. Women were forced to make difficult choices and found the psychological and social consequences difficult to bear.

"When I was pregnant I tested positive. My child was born negative. He tested again after six months; he was still negative but when he was a year and seven months, he was not walking and he was sick so I took him to the doctor (GP) who wrote me a referral letter to this hospital. It is in this hospital that I found out he (the baby) was positive too. I think he got it from breastfeeding because I breastfed him for too long a time. I had to continue for some months after I should have stopped because I had to feed him something or he would go hungry and get sick. There was no choice, but now I am sorry – because look what I have done."

Regardless of the availability of preventative services, there was also a need for women to take responsibility for testing, and to make use of services which were available to them and their children. Barriers to doing so existed both in the health-care services and also within the women themselves.

"I took a blood test when I was pregnant but I was not told what it was for and I never asked, so in a way I did not test. The next time I had a blood test was at the hospital, but I was not offered Nevirapine. I knew about HIV and AIDS before I was pregnant but I was scared to ask for my results after the blood test. I thought they will tell me voluntarily. I realise now that I should have asked but I did not feel confident and I think they were happy that I didn't want to know – so they did not have the job to tell me."

In cases where alternative caregivers (aunts, grandmothers and a father) had brought children for treatment (having done so in the absence of the mother who was either sick or deceased), the data revealed frustrations with the lack of testing and disclosure on the part of these mothers.

“The baby started getting sick already when his mother was still alive, but his mother did not come out about her own status – and that is how he got infected. We told her all the time to come to the hospital because we hoped she would acknowledge this thing but she would not so we only tested him after his mother passed away. At that time he was very sick.”

“My daughter was not responsible about this; she had too much denial. I brought the child to the hospital one time and they did not want to test because she was not there. I told them the mother was gone and I signed for the test. So I knew the child was positive but I could not tell because it was not legal what I did. Only when she died then I told my husband. Now we bring the child and we have tested ourselves also to show our other children. We are thankful we are negative but my husband still feels a great anger for our daughter who has passed.”

“I have learned to live with it now, but if my girlfriend had told me, we wouldn’t have decided to have another baby, and my child would not be HIV-positive today. We had another child who died – a younger one. Now I see what was happening. I don’t understand how she could not tell me. She was bringing the child here and I did not know. I think how she could not tell – but I think fathers are not coming here because they are more afraid of stigma than the mothers. But I had no choice because my girlfriend has passed away and I had to come.”

This qualitative data demonstrates that regardless of whether or not the diagnosis is expected, it does not in any way ease the burden of experience on these mothers, caregivers or family members who need to negotiate their way through very difficult emotional and social circumstances over the testing, diagnosis and subsequent care of their HIV-positive children.

6.1.4 Getting testing and treatment is not easy

While some caregivers were able to access testing, many also described barriers to determining the child’s status which resulted in delays and restricted access to health care for the child. This, in turn, compounded the challenges of accessing antiretroviral treatment and required significant investment of personal energy and household resources, as well as determination and persistence on the part of the caregiver.

“My baby when he was still very young had breathing difficulties and was admitted to hospital for a week and after that I made attempts to get him tested for HIV because I was worrying about this thing. At first I went to the clinic but I was told to wait for two months for the results to come back to the clinic. So I kept going for the immunisations. Then after two months they said the results were lost. So I was angry and I decided to go to the hospital for the test but they told me that I had to wait for four months to be able to take the test at 12 months. So it was only when my baby had turned one year old that I finally got to test him. Since then I have been able to get him on treatment.”

6.2 ANTIRETROVIRAL TREATMENT, ADHERENCE AND SIDE-EFFECTS

While several barriers and difficulties were reported concerning access to treatment, an overarching theme was the positive experience that families described once they were able to access the treatment and become part of an ongoing antiretroviral treatment programme.

6.2.1 “This medicine is a miracle”

Almost all the caregivers interviewed said that their children had been very ill before starting antiretroviral treatment and that the relief the treatment brought was marked and welcome. As a result, caregivers consistently viewed the antiretroviral treatment in a very positive light, and the positive effects of treatment helped to dispel myths and fears.

“When you have seen your child so sick, and then you see them get so much better then you know that you must give them the medication.”

“She has so much energy now. She is talking and laughing. She is too naughty. This medicine has been too good for her. I never thought it could be that good.”

“My baby was so sick before, she could no longer walk and she stopped talking. She had been in the hospital for six months and I thought I would never be able to take her home. Now she is home, and she is getting stronger. She is still not steady but I have not ever seen her so well and her weight is very much better. She is growing now.”

“It was hard at home. He got sicker and sicker. It just continued on, and people were talking about bewitchment, because they did not understand why this child is not getting better. Now he is on the medicine. He is getting better and is doing much now so they can see it is a sickness and the medicines can work for it.”

6.2.2 “Side-effects are not too difficult to manage”

Most caregivers (58% N=28) reported that children had adjusted well to medication with little or no side-effects; only 14 (29.2%) reported mild side-effects and two (4.2%) reported severe side-effects. Severity and duration were also related in that the more severe the side-effects, the longer the duration of discomfort for the child. In four cases the data on side-effects was missing in the transcripts as caregivers had not reported any and the interviewer had omitted to probe for it specifically.

	NOT APPLICABLE	3 TO 5 DAYS	MORE THAN A WEEK	MORE THAN A WEEK LESS THAN A MONTH	ONGOING	TOTAL
None	27	0	0	0	0	27
Mild	0	10	4	1	0	15
Severe	0	0	0	1	1	2
TOTAL	27	10	4	2	1	44

Table 11: Reported experience of side-effects

* Missing Data N=4

Side-effects included constipation, vomiting, rashes, swollen and painful eyes, thrush and, in some cases, vomiting and rashes which persisted for close to a month. In one severe case, treatment appeared to be failing as the viral load of the child was not reducing and the child was very ill. In this case the doctor was preparing the child and caregiver for an admission. The child had experienced several admissions since commencing treatment and was not considered to be responding well.

Despite side-effects, all caregivers reported that they had very little difficulty encouraging their children to take medication and ensure compliance on the part of the child. In most cases it was the mother (68.8%), grandmother (22.9%), aunts (6.3%) or fathers (2.1%) who delivered the medication.

A large proportion of the children (78%) had a second person assisting with medication in support of, or in place of, the primary caregiver in their absence. A smaller group of children (18.7%) had three people in the household supporting and assisting with medication.

	PRIMARY PERSON HELPING	SECOND PERSON HELPING	THIRD PERSON HELPING
Mother	68.8%	–	–
Father	2.1%	14.6%	–
Grandmother	22.9%	18.8%	2.1%
Grandfather	–	–	2.1%
Aunt	6.3%	12.5%	4.2%
Uncle	–	2.1%	–
Older sibling	–	22.9%	2.1%
Younger sibling	–	–	2.1%
Boyfriend	–	2.1%	–
Other family	–	4.2%	6.3%
Not applicable	–	22.9%	81.3%
TOTAL	100%	100%	100%

Table 12: People who assist the child with medication

6.2.3 “Taking medication is just a way of life for us now”

In general the interview data, observations and group work with caregivers and children demonstrated that both child and caregiver had a good understanding of the beneficial nature of the medication, and that as a result there were very few reports of children resisting or avoiding taking the medication.

In most focus groups, when caregivers were asked about ‘difficulties’ with administering the medication, the question was perceived as a strange one. The medication in most cases was viewed as a fact of life – something that needed to happen every day – and had just become part of normal daily routines.

“He likes taking the medication; he takes it easily. He had a small rash in the beginning, but nothing now, everything is okay. As a reminder, we took the medication at 8 o’clock when Generations started on TV, but now we just remember.”

Likewise, probing and questions about children resisting taking their medication, for example ‘running away’ or refusing to open their mouths, was met with bafflement by caregivers. The contrary appeared to be the case, with children being active participants in the process. In many cases caregivers commented that the child would help with reminders about their medication.

“He is the first one to remember that he has to take his medication. I use water to give him his medication, so he will shout and sing to me in the morning ‘Aphi amanzi wami?’ (Where’s my water?).”

In cases where caregivers did report some difficulties, they did not seem to find them overwhelming. In general, these were not raised as the most salient issues related to antiretroviral treatment. Instead, caregivers were more concerned about other issues such as adequate nutrition and access to financial resources for ensuring adequate care.

“It took her about a month to get used to the medication. I think it was the taste that she did not like because she used to spit it out after I give it to her. But then she got used to it. Now I worry more because it is hard to give her the food she needs because I don’t have money.”

Prior treatment proved to ease the transition onto antiretroviral treatment. In some instances the child had received treatment for TB, prior to commencing antiretroviral treatment.

“Before this medicine he got used to TB medication, so he gives me no problems now with this medication and he knows that medicine helps.”

In dealing with medication administration and compliance, caregivers reported several strategies for managing medication intake and acceptance in young children. Most strategies were common to other chronic illnesses and tended to centre on building a positive association between the medication and wellbeing for the child. This appeared to be helped by the positive recovery experiences of the child.

“I tell my child that he will grow as old as me if he takes his medication. It will make you strong and grow, and then he takes it.”

“You see my child she is just five now; and these five-year-olds they love to hear that they will grow just like you. They come and ask all the time about what will happen to them if they take their medication. If you tell them they will be just like you that makes them happy. They want to do everything you do. If you sweep they want to sweep so we have learnt together and there are no problems.”

“My boy is that age, he wants to be like the older children now. He likes them too much. So when he asks me why he must take it I tell him that he will be big like the boy next door that he plays with; then he gets too excited and is willing to take it.”

Young children also demonstrated a sense of ownership and urgency about taking antiretroviral treatment and were quickly able to master – with appropriate encouragement and prompting – their treatment requirements and regimes.

“Taking medication is not a hassle as she is first to announce that it is time for her medication. She is the one who reminds me that I need to it to give her. Sometimes if I am busy I don’t notice the time but she comes and asks as she knows her day routine.”

6.2.4 “Children are able to do this”

In the group process, children’s responses to treatment questions and cues supported these findings and demonstrated good participation and mastery.

a. Children talk about taking medication

Most children were able to respond verbally or use the silhouette/cut-out figures to demonstrate who assisted them with medication. Those children who were unable to respond also demonstrated other severe developmental difficulties and were most likely limited by these. Most children acknowledged that they took medicine and answered affirmatively when asked if they liked it. When asked what they did not like, the most common reply was “jova” or “injection”.



Above: A two-year-old boy shows the researcher how he can give medicine to the doll.



Above: Despite her illness and frail body, this four-year-old girl is able to talk about her medicine and shows the researcher how to give it.



Right: A four-year-old boy talks and plays with the doll as he is giving it its medicine.

b. Children show us how they take their medication

None of the children who participated in the groups demonstrated negative responses on the presentation of the syringe or teaspoon cues. On simultaneous presentation of the doll and the treatment cue, more than half (65%) of the children spontaneously began administering medication to the doll without any prompting by the researchers or caregivers. The remainder of the children (26.7%) did so with ease upon a request to do so from the researcher. In a few exceptional instances (8.3%) where children had presented with severe developmental difficulties, they were also unresponsive to the treatment cues and instructions. The photographs illustrate examples of young children's responses to the treatment cues in the group settings.

6.3 DISCLOSURE TO CHILDREN, FAMILIES AND COMMUNITIES

The data related to issues of disclosure and support raised several difficulties and challenges at the level of the child, the family and the community.

6.3.1 Telling children

Most caregivers (91.7% N=44) had not as yet disclosed the child's status to them and very few caregivers (8.3 N=4) reported having discussed the nature of the illness with the children. Caregivers who had disclosed to children tended to have children who were older (1=36 months; 2=60 months and 1=66 months). The caregivers (91.7%) who had not disclosed cited the following as reasons for non-disclosure to the child. See Table 13 below.

	NUMBER OF CASES	VALID PERCENTAGE
The child is too young	33	68.8%
I don't know how to tell the child	9	18.8%
It's too hard because of my guilt	2	4.2%
Not applicable/Don't know	4	8.3%
	48	100

Table 13: Reasons stated for non-disclosure to children

In the focus groups, several caregivers expressed concern over how and when to disclose to the child, and how to manage the sensitive and emotional issues which disclosure would elicit. Common concerns around disclosure related to disclosure to siblings, fears of discrimination and difficulties in not knowing how to approach disclosure with a younger child.

"I have not told him why he is taking the medication, you know about the HIV, because he has not asked and I think he is still young, I have also not told his older brother. I wouldn't know what to say."

"He is still too young; I do not know how I will explain it to him."

"To be honest I will be scared to tell him. I think I will have to tell him when he is around five or six years old. I try to explain to him about his status but I am worried because maybe he will tell other children at school, and other children might be horrible to him at school and I am not sure how I will tell him."

"I think he is still too young, but it is a difficult thing and I worry about it a lot and not many people give you advice on this thing. Already there is a problem at home because I can not explain it to my nine-year-old daughter."

She is asking me why her brother is taking medication and she already thinks I love him more than her because he gets too much of my attention and also special food with his medication."

I don't know how to know how old the child must be first before you tell them or what you can say to them so that they don't get scared or hurt and they don't hate me."

Beyond reporting that it was difficult to know the appropriate age at which to disclose to the child, and what language or stories to use in telling the child, many caregivers also cited fears and concerns it raised in dealing with the caregivers' own guilt over infecting the child through vertical transmission.

“I always think about where I will find the courage to tell my child that he has HIV and I gave it to him, because he will ask me where I got it from. I wish there could be a cure for AIDS. I don’t want to have to tell him that I did this to him.”

“I think it makes it a bit easy for me to tell them about HIV because I am not their mother, I did not infect them. I am just their grandmother and caregiver, and I also make reference to the Bible to explain to them about this disease.”

Keeping children safe from harm

Despite the challenges of disclosure, many caregivers reported teaching their children about safe behaviours in order to protect them, without directly speaking about HIV. They reported having received the most guidance about these safety behaviours from the health-care services. The health-care services were reported to have provided more information on safety behaviours, such as what to do in the case of an accident which involves blood, than on other aspects of HIV disclosure to children, such as information about appropriate ages for disclosure, appropriate language for disclosure with young children, or counselling on how to manage feelings of caregiver guilt which may present a further barrier to disclosure.

Caregivers also reported forcing some degree of secrecy on children, or among the children in the family, in an effort to ensure that the status of the child remained protected. In many cases this related to a strongly held fear of stigma and a deep and appropriate desire to protect the child from harm or discrimination within the family or in the community.

“I don’t think the other children found it difficult, it was easy to accept because I told them about their brother and sister who are HIV positive. Disclosure is important in that way so they know if they get hurt and if there is blood they must come straight to me. But they also know that they must not tell other people because they will not understand, just to call me.”

“I have told all my older children about HIV, and that they should not touch one another’s blood. They should tell me first because now there is this infectious diseases. The other children have accepted these two little ones are infected and there is not much stigma in my community so it is okay, but in other places it is not like this.”

“There is no problem here at the clinic. The problem is outside in the community, and we feel like we could be here like this all the time. If only at home was open like here, but there is this perception people have about us, that maybe we are promiscuous and they call us names or that we have killed our children. They do not stigmatise children but that is because we don’t let them. We hide the truth from our children because they will sell us out to everyone. They have no idea what they are doing here, and we are waiting for them to grow up first. I make sure that the young one doesn’t know because she will tell the neighbours.”

6.3.2 Telling families

Most caregivers reported having disclosed to their close families (95.8%) and in general, this referred to the family with whom they were living at the time. In cases where there had been no family disclosure, the reasons cited for limiting disclosure included caregivers being afraid that family members would throw them or the child out on the street or would treat the child differently.

“I have disclosed to my family only. I told the older children why we are taking medication and told them not to tell anyone else. They have no problem because they are old now they understand.”

“At first I was open and I told them at home after I got the treatment. I wanted to avoid people talking behind my back. But I have had experience of that from a neighbour who was talking about my child being sick. She was very nasty about the child. She said the child must not come to her house. Not many people know from the community now because I don’t want people to be horrible to my child and send my child away.”

Difficulties in coping with siblings

The data from the caregiver interviews suggests that within the context of the family, the impact of having an uninfected and/or an untreated sibling needs careful consideration and presents many challenges for caregivers. In addition, where siblings are uninfected there are sometimes difficult parenting issues around the special treatment of the child living with HIV and AIDS.

Caregivers reported that frequently the uninfected sibling felt excluded and did not understand why they were not receiving the treatment too. Some caregivers reported dealing with this by giving the sibling a placebo of some sort, so that both children were going through the same routine. These difficulties were also common where a sibling was also infected, but where caregivers may be waiting for the second sibling to start on antiretroviral treatment.

“The little one (3 years) asks the other one (5 years) why he can’t take the medicine also, but the older one plays with him and says if he wants to take the medicine then he must first come to the clinic and get a injection. This usually satisfies the small one and then he doesn’t want that. But it is hard for my wife and I especially when we have to give special foods to the one and not the other. He is small so it is hard for him to understand.”

6.3.3 Telling communities

Very few caregivers (18.8%) reported disclosing to their broader community. Those who did disclose tended to disclose primarily to neighbours, close friends, church groups and support groups. In general, caregivers were very concerned about stigma and discrimination despite having access to psycho-education and treatment. A similar tendency appears to be present with regard to paediatric HIV and antiretroviral treatment.

“Only my mother knows that my child is on ARVs, but I am going back to school this year and my mother will have to give the pills. I know that by the time I come home in the afternoon the whole neighbourhood will know.”

A notion of ‘self-stigmatisation’ seemed common for many caregivers in the interviews. Many had not actually experienced stigma or discrimination directly but rather perceived and feared. To this extent, they choose not to disclose and in doing so, become more likely to avoid stigma and discrimination and affirm their belief that non-disclosure reduces risk of stigma.

“I trust my family but I do not trust the community because people who have disclosed are treated badly. I don’t want the same kind of discrimination, especially from old people in my community.”

Several caregivers who reported disclosing to members of their community also reported no experience of discrimination in the community, but that rather they experienced support in response to disclosure. Thus some families may not be receiving community support that may otherwise be available to them, due to a fear of the consequences of disclosure.

“My whole community knows about our status and we do not experience any discrimination. My community is also encouraging as they also tell me that in time her daughter will walk.”

Secrets can limit support networks

The lack of community-level disclosure manifested itself in several ways in children’s lives. Of the children who were reported to be attending crèche, less than a quarter of the caregivers reported having told the crèche about the child’s status, illnesses or medication and rather elected to manage the medication from home.

In all these cases, fear of stigma and discrimination against the child was cited as the main reason for not telling the teacher or day-care provider. On probing, no reasons could be elicited for why caregivers should tell other care providers about the child’s illness. In the sample, little insight was expressed by caregivers into the value of disclosure as a means of increasing access to support.

“I told them when he was taking TB medication but I never told them about HIV. I think there is more stigma to HIV than TB because people know that TB can be cured. I do not think the neighbours will allow their children to play with mine if they knew he is positive, and I don’t think they will take him at the crèche.”

“Yes, my baby attends crèche, but I have not told them he is positive. I am afraid they will not treat him well.”

As a result, several caregivers did not access support within the networks where the child is provided with care, and medication could not be integrated into those living and caring spaces. Support networks were limited to the family home and family network.

In one exceptional case, a grandmother had openly disclosed to her community and had started a crèche as she was looking after 16 grandchildren, having lost three daughters to HIV. Below is an extract of her thoughts on disclosure:

“I cannot be involved in stigma. I have lost all my daughters to this thing. I cannot deny it, but I can see how people are afraid for their children. They are in such a bad situation and they don’t want to make it bad for the child. But I have been open in my church and the community. This place is not as bad as others, so I tell people about these three children and about their status. I teach them about how to look after these little ones and people are sending their HIV-positive children to my crèche because they know I also have my own HIV-positive children. They trust me because they know I will accept their children.”

6.4 MEDICAL AND HEALTH-CARE CONTACT PROFILES AND DEVELOPMENTAL STATUS

In exploring the extent to which children had experienced chronic illness prior to the onset of treatment, information provided in caregiver reports suggests that in the majority of the sample (85.4% N=41), prior illnesses were attributable to their HIV status. Only a small number of children had been diagnosed with major medical illness (10.4% N=5) or developmental disorders (4.2% N=2) over and above HIV and AIDS.

Fourteen of the children (30%) were reported not ever to have had an infectious disease or an HIV-specific illness. The remaining 70 percent reported several illnesses common to HIV and AIDS presentations including TB, PCP and persistent diarrhoea. Most children in the sample had been seriously ill prior to commencing treatment and had required at least one admission for a serious illness (32.6%), or several admissions for a serious illness (23.9%). Serious illness was defined as a being hospitalised for more than two weeks.

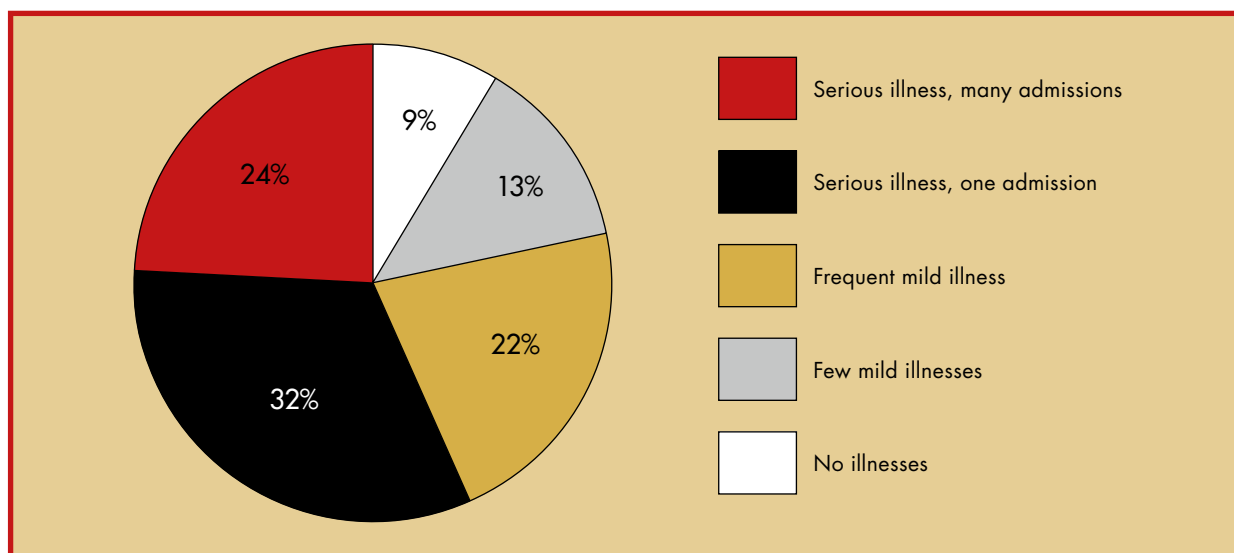


Figure 15: Degree of illness prior to onset of treatment

The findings demonstrated a statistically significant correlation ($P=.456$ $p < 0.01$) between the number and severity of admissions and the child's current developmental status. The age of the child, as well as the length and nature of their previous illnesses and HIV disease progression, and the severity of the current developmental difficulties or delays are all likely to impact on the child's future developmental trajectory. Developmental outcomes were recorded as follows:

- 1 = Normal
- 2 = Mild delay
- 3 = Moderate delay
- 4 = Severe delay
- 5 = Developmental disorder

Caregivers reported a marked improvement in developmental progress and catch-up as a direct result of starting antiretroviral treatment. Most commonly reported improvements were in the domains of language and motor skill acquisitions and recovery. However, examination of the developmental observation data indicates that these are also the most marked delays for most children in the sample (suggesting that the delays would continue to impact on the child).

The longer the child takes to access treatment, the greater the severity of the developmental consequences, in what appears to be a double effect: not only are the illnesses themselves debilitating in the child's physiological development, but the illness also prevents them from participating in the normal developmental tasks for their age. The young child is not able to explore and engage with the environment in the same manner as a well child of the same age and, as a result, developmental delay is compounded.

6.5 PSYCHOSOCIAL ASSISTANCE AND SUPPORT REQUIRED FOR ART PROGRAMMING

In examination of the data related to psychological and social support, a finding of concern was that nearly a fifth of the sample of caregivers reported that there was 'nothing' that could help them cope

with the child's diagnosis and treatment. This may indicate a particular vulnerability and sense of hopelessness, and it certainly suggests a need for support and care to assist them to cope in order to improve the outcomes for their children.

For the balance of the sample, one of the most useful activities which was seen to help caregivers cope was a reliance on spiritual belief systems, religious practices and traditional beliefs – all of which helped them to reach some degree of acceptance. This was recognised by the caregivers themselves as beneficial.

“I trust in God but as long as my grandson is taking the medication he will be fine.”

Other practices mentioned included counselling, disclosure and peer support as outlined in Table 14 below.

HELPFUL PRACTICES	NUMBER OF CASES	VALID PERCENTAGE
Religion/Spiritual/Traditional practices	21	43.8%
Reaching acceptance	11	22.9%
None	10	20.8%
Counselling	3	6.3%
Peer support	2	4.2%
Disclosure	1	2.1%
TOTAL	48	100%

Table 14: Helpful support practices

6.5.1 The pain in daily activities

Despite the positive experience of antiretroviral treatment, some caregivers explained that the daily processes and rituals involved in taking medication were emotionally difficult for them. As caregivers, the processes served as a constant reminder of their HIV status and the fact that they had infected their child. Every day they are reminded of their health status and the health status of their child and it was difficult to resolve the conflicts between giving a life-saving medicine and, at the same time, facing up to potentially early death.

6.5.2 Coping practices

In coping with these difficult situations, caregivers indicated several sources of support and help including family, community and health services support. Most caregivers listed only two sources of support and help and this was most commonly family first and health services second as indicated in Table 15.

	THE MOST IMPORTANT SOURCE OF HELP (1ST ORDER)	OTHERS IMPORTANT SOURCES OF HELP (2ND ORDER)	OTHER SOURCES OF HELP IF ANY (3RD ORDER)
Family support	75%	10.4%	2.1%
Health service support	16.7%	54.2%	6.3%
None	4.2%	29.2%	91.7%
Community support	4.2%	6.3%	–
TOTAL	100%	100%	100%

Table 15: Sources of help

Of concern in the data on family and other sources of support, was that often a caregiver was reliant on a single person close to them, rather than a network of support. This increased their vulnerability to isolation and lower levels of social support.

“I got tested before my husband. When I told him I was positive, we handled it together and I forgave him. Accepting it has helped me through.”

“I solve my problems on my own, and I try to live on. I have no friends or family I can talk to. Coming to the clinic and talking to people here is much better.”

“My only hope was my husband; since he passed away I have been on my own. I pray to God to help me through my problem.”

6.5.3 Support systems

For many of the caregivers, the hospital services and clinic were experienced as a positive and supportive environment. This extended beyond the delivery of medical or treatment services to encompass the attitudes of the staff towards caregivers and their children.

Caregivers reported that they felt they were treated with respect at the clinic and were not discriminated against because of their status. Coming to the clinics provided an opportunity to meet other people in similar circumstances and to share experiences and talk.

“The clinic is very supportive. It is comfortable.”

“The nurses pay attention to us. It is much better than other places. They are welcoming and easy to talk to.”

“The clinic is very supportive and they gave us sufficient information before we started. Even the doctors want to know whether we know how to give medication and they ask us to demonstrate for them.”

“It is helpful for us to come here because this is where we are free to talk about it since we are all here for the same reason. But most importantly it is accepting that makes us strong.”

A potential drawback identified in these discussions was that because of this positive experience, many caregivers and their families did not want to leave the hospital clinic to return to the primary level clinic in their area for step-down services.

There are complex factors that seem to impact on the reluctance to attend local clinics. Firstly, caregivers reported that they did not want to be seen attending local clinics as their neighbours would then learn of their status. Secondly, the level of care received at the hospital was perceived to be of a higher standard than that which would be received at the local clinic. And thirdly, an informal support network appeared to have been built at the hospital clinic where caregivers, who would otherwise not be connected to one another, got to see each other regularly when they come for medication.

Lastly, when caregivers were asked about what other support they required, they pointed to the need for financial support, transport, nutrition, counselling and peer support. The caregivers were asked to identify the order of importance of the needs identified along a continuum. The results are summarised in Table 16.

	LISTED AS THE MOST SALIENT NEED	LISTED AS THE SECOND MOST SALIENT NEED	LISTED AS THE THIRD MOST SALIENT NEED
Not specified	16.6	35.4	45.8
Grant or financial support	70.8	4.2	–
Transport	–	31.2	12.5
Nutrition	–	25	22.9
Information	4.2	2.1	14.6
Counselling and care	4.2	2.1	4.2
Social support	4.2	–	–
TOTAL	100%	100%	100%

Table 16: Support needs as ranked by caregivers

6.6 CONCLUSION

As has been evidenced in other research in Africa and in the international literature, the findings suggest that the social and psychological stresses surrounding diagnosis and disclosure are the most dominant concerns raised by caregivers (see for example, Murphy, Marelich, Stritto, Swendeman & Witkin, 2002). The challenges talked about by many caregivers in this small research study are not uncommon to those reported on in the literature; for example, Armistead & Forehand (1995) have explored difficult parenting decisions faced by HIV-positive mothers. Varga, Sherman, Maphosa & Jones (2005) in a study in Johannesburg, showed that most mothers preferred receiving an early HIV diagnosis (at four months rather than 12) for their child. This meant they did not have to deal with the uncertainty and fear of an unknown diagnosis. Especially for sero-discordant couples, the early diagnosis created enormous stress on the mother who faced issues of disclosure and stigma as well. Careful counselling and support are advocated in the event of early diagnosis of HIV in infants.

The literature offers useful models for understanding some of the ways in which mothers and families with young children can cope with HIV and AIDS (see for example, Hough et al, 2003). One issue highlighted by this research, but which is seldom explored in the literature, is that even in circumstances where all preventative methods have been applied, it is possible that some transmission will occur, and that this is very distressing to caregivers and health-care providers.

As has been demonstrated by other literature (Abadio-Barrero & Castro, 2006), caregivers were concerned about disclosure and protecting children from discrimination as they grew older. This concern has also been highlighted in other literature from South Africa (Domek, 2006). Most caregivers showed little awareness about how to begin talking to young children about HIV and few resources were made available to them. Naeem-Sheik & Gray (2005) provide some useful guidance for clinicians on the importance of early disclosure and awareness amongst caregivers. Many caregivers chose not to disclose in community settings as they did not see any possible positive gains to doing so. Some experts have argued that increased disclosure may offer a gateway to building a more positive effective response to HIV and AIDS at a community level (Norman, Chopra, & Kadiyala, 2005).

It is heartening that treatment adherence did not emerge as a major barrier and that antiretroviral treatment is easily integrated into everyday life. Children responded well to being on medication, demonstrating ownership and acceptance, and caregivers reported feeling motivated by the child's health improvements. No negative responses to treatment cues were observed and children easily demonstrated how the doll should take medication. Given the critical developmental achievements in the first five years of a child's life, early access to treatment appeared to prevent major developmental delays. Children starting treatment later had poorer developmental outcomes, including delays in language and cognitive development and gross motor skills.

While the literature describes the challenges involved in the scale-up of antiretroviral treatment (Van Damme, Kober & Laga, 2006), efforts should be made to test and treat children as early as possible to lessen the effect of HIV on children's development. Children's subjective experiences of being on treatment did not correspond to popular perceptions that treatment for very young children is difficult to manage because of complex and bad-tasting formulations. Contrary to popular belief, children expressed little concern about medication ingestion and reported few side-effects. Resources should be provided to assist caregivers to talk about their children's status and treatment, and sources of support including assistance with nutrition and transport should be delivered at or near to treatment sites to enable long-term adherence.

CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS

7.1 YOUNG CHILDREN AND HIV AND AIDS

The evidence is clear that both poverty and HIV and AIDS put children at greater developmental risk in the early years through the direct physiological impact of infection, the consequences of deprivation and the indirect consequences of severe stress on the caregiver-child relationship.

Poverty affects not only material resources, but also the quality of care-giving that a young child is likely to receive, because the stressors occasioned by poverty conditions make it difficult to provide sensitive, responsive and stimulating care for young children. Thus poverty increases the chances that numerous risk factors will be present simultaneously and that fewer protective factors are likely to be present.

Very young children have been shown to be extremely vulnerable to the effects of HIV and AIDS, not only physically and medically, but also socially, emotionally and psychologically. They experience multiple losses through infection, loss of health, loss of parents and caregivers, economic support and access to health care (Richter & Foster, 2005).

The evidence from research on children's development and HIV and AIDS highlights the vital role of caregivers in the holistic development of the young child. The caregiver's role is not limited to physical and material care, but incorporates a complex, interactive and reflexive relationship that is vital for healthy development in all domains. Even when children are born HIV negative despite exposure to HIV and AIDS, evidence suggests that they are at greater risk than are children in the general population. The children living with HIV and AIDS, however, face the bleakest prospects until such time as antiretroviral treatment is readily available to them when they require it. Comprehensive systematic international reviews have demonstrated the impact of HIV on early childhood development outcomes, and these are supported by several studies in Africa and South Africa. Furthermore, antiretroviral treatment has been proven to be highly effective for children living with HIV and AIDS, including those in resource-poor settings. Evidence suggests that rapid initiation of antiretroviral treatment restores and preserves immune functions, promotes normal growth and development, and prolongs life.

Considering the abundance of evidence on HIV and AIDS and its direct impact on early childhood development, along with the large body of evidence which demonstrates the benefits of intervening with young children, there can be no doubt about the value of early intervention. When resources are limited, guidelines are needed to prioritise health investments, and the evidence on HIV and AIDS and early childhood development suggests that simple, low-cost, scaled-up interventions to protect health and wellbeing are as urgently needed as new technologies or processes for the treatment of HIV and AIDS. Appendices 7 and 8 offer some examples of how psychosocial intervention opportunities can be taken up, at time points linked to routine health services, and using current health-care human resources.

However, several barriers exist to the adequate roll-out of paediatric treatment programmes in developing countries, including South Africa. Formulations have remained expensive in comparison to adult treatment and they are difficult to handle, bad tasting and complex to administer and manage. Diagnostic tools for children under 18 months are largely unavailable and medical staff report being poorly trained to treat children. Despite these barriers, the comprehensive paediatric HIV and AIDS management programme as run at the three sample hospitals, which collectively service approximately 1 600 children, offers good examples of best-practice service delivery in an entirely public-funded programme.

The evidence speaks clearly. More children need to get onto antiretroviral treatment, and they need to get on to it as soon as possible to avoid chronic and debilitating illnesses which will have life-time consequences for their human development. Beyond-treatment children and their caregivers need psychosocial and material support.

7.2 CHILD AND CAREGIVER EXPERIENCES

To date, the psychosocial and developmental needs and experiences of very young children on antiretroviral treatment have been relatively unexplored in research in South Africa. It is argued that developing appropriate and sensitive interventions and programming requires a deeper understanding of young children's needs and experiences.

In this research, social and psychological stresses surrounding diagnosis and disclosure constitute the most dominant concerns raised by caregivers. Caregivers expressed concerns about disclosure and the protection of children from discrimination as they grew older. Most caregivers demonstrated a low awareness of how to begin talking about HIV to young children and few resources were available to them. Many caregivers chose not to disclose in community settings which reduces their access to social support networks. Caregivers need to be encouraged to disclose to all those involved in the child's care, and resources should be provided to assist them to talk about their child's status and treatment.

The research also revealed a 'double-developmental bind' where the developmental challenges faced by chronically ill children, due to biological and physiological factors, are further compounded by a lack of opportunity and capacity to explore their environment. This natural process of exploration is hampered by physical constraints and results in fewer opportunities to grow and develop.

Treatment adherence did not emerge as a major barrier. Caregivers reported feeling motivated by the child's health improvements and children responded well to being on medication, demonstrating ownership and acceptance. No negative responses to treatment cues were observed. Children's subjective experiences of being on treatment did not correspond to popular perceptions that treatment for very young children is difficult to manage because of complex and bad-tasting formulations. Contrary to popular belief, children expressed minimal anxiety about medication ingestion and their caregivers reported few side-effects.

7.3 LIMITATIONS OF THE RESEARCH

This research makes a valuable contribution in integrating and summarising the literature, canvassing the expertise of South African paediatric resources, and elucidating the experiences of caregivers and children receiving antiretroviral treatment and care.

While qualitative research offers valuable insight into the everyday and lived experiences of children, families and communities (who are the recipients of our health-care services), it is by its nature and purpose always limited in its ability to generalise to broader populations.

In particular, the findings of this research are limited by resource and time constraints. The research took place in one province only, and participants were likely to represent a special group of patients who have accessed treatment fairly early in the antiretroviral treatment scale-up process.

Further, the majority of the sample was enrolled from outpatient services and were thus more likely to represent treatment successes than treatment failures which would more likely be treated in inpatient care facilities. Inpatient services were approached in the course of the research but reported few children in wards on antiretroviral treatment. The staff reported that occasionally children are admitted to wards in the final stages of their illness.

7.4 RECOMMENDATIONS FOR RESEARCH, POLICY AND PRACTICE

7.4.1 Research

Further research is required to evaluate psychological, social and developmental interventions to improve developmental outcomes in children. Specifically research is required in the following areas:

1. Appropriate developmental screening tools which can be used in clinic settings and which can provide initial screening to facilitate referrals and include guidelines for immediate action.
2. In essence, while children appear to make significant progress on antiretroviral treatment and display remarkable 'catch up' with their same age peers, the long term consequences of this early deprivation remain to be seen. For many, the extent of the damage may only become apparent when schooling commences.
3. Interventions and applications such as those developed in smaller scale studies (for example, Potterton, 2007) should be tested at scale for usability and cost effectiveness.
4. Conduct a rapid analysis of materials developed to assist children across age groups with disclosure and adherence in order to identify gaps, best-practice examples and make recommendations to the National Department of Health on distribution.

7.4.2 Policy

Advocacy for early intervention for children living in poverty and in the context of HIV and AIDS is timely and critical. Policy advocacy should continue to focus on increasing children's access to care and interventions and specifically to:

1. Advocate for the earliest possible initiation of treatment and the value of mainstreaming children's psychological and developmental care into health programming.
2. Advocate for the development and improvement of diagnostic tools and formulations.
3. Advocate for the rights of children to timely, sensitive, developmentally appropriate treatment, support and care.
4. Develop an early childhood development reference group which can assist in ensuring timely dissemination of current paediatric evidence to the National Department of Health, and hold biannual think-tanks to ensure protocols and policy remain aligned to the best evidence emerging from research and practice.

7.4.3 Practice

Several opportunities for improving practice exist along a continuum – from very small to much larger range of interventions. Interventions to improve care require the empowerment of caregivers and health professions on the benefits of compassionate and appropriate care for children. Specific practice could benefit by:

1. Ensuring wider distribution of support and training materials already available for use and greater sharing of best practice experiences.
2. The development of simple guidelines for counsellors, nurses and doctors which offer practical mini-interventions based on psychological, social, cultural and developmental aspects of care and which make use of the monthly contact sessions to build the developmental potential of the child. Appendix 9 illustrates examples of how developmental screening and referrals can be integrated into health-care services in antiretroviral treatment centres.
3. The implementation on a wide scale of the training of health-care professionals on *The psycho-social care of babies and young children living with HIV and AIDS* (Cotlands & UNICEF, 2007). This training has been developed and specifically addresses several of the issues raised in this research.

APPENDICES

Appendix 1: List of databases searched for literature review

DATABASE	DESCRIPTION
NISC: AIDSSearch	Combination of three databases on AIDS-related topics (MEDLINE AIDS/HIV AID TRIALS and AIDS DRUGS)
NISC: Family and society studies worldwide	Databases focused on family and gender-related topics including social work, social science and family practice
Blackwell Synergy	850 Blackwell Publishing Journals
Cochrane Library	Systematic reviews and clinical trials evidence
SABINET Current and Completed Research	Research projects listed for South Africa
Association of African Universities: Database of African Thesis and Dissertations (DATAD)	Theses and dissertations completed at African universities in all subject areas
EBSCO host Web and Electronic Journal Service (EJS)	Gateway to special selection of full-text e-journals
Oxford University Press: Oxford Journals	Collection of OUP full-text journals
Cambridge Scientific Abstracts (CSA): PAIS International	References to more than 553 300 articles, books, research reports and other publications
PsycARTICLES	Searchable full-text peer reviewed scholarly and scientific articles in psychology
PsycINFO	Linked to the American Psychological Association (APA) with more than 2 million citations
SA ePublications	Most comprehensive collection of full-text electronic journals in South Africa
Elsevier Science Direct	Over 2 000 journals from Elsevier
World Bank E-Library	Online fully cross-searchable portal for over 3 000 World Bank documents
NCBI PubMed	Online service of the US National Library of Medicine that includes over 17 million citations from MEDLINE and other life science journals for biomedical articles and includes links to full-text articles and other related resources
POPLINE	Population information online is the world's largest database on reproductive health, provides more than 350 000 citations with abstracts to scientific articles, reports, books, and unpublished reports in the field of population, family planning, and related health issues

Appendix 2: Developmental tasks and care strategies age 0 to 12 months

AGE:	DEVELOPMENTAL TASK:	CARE STRATEGIES:
0–2 months	The baby learns to use sounds, gestures and facial expressions to communicate and to regulate their eating, sleeping and emotions. Connects sounds with sources.	Observe and soothe the baby, respond to and communicate with the baby through mirroring them.
2–6 months	At this age, the baby starts to develop communication and language skills (smiling, cooing, babbling, pausing, waiting for response, imitating). They also start to explore their environment by looking, holding objects and putting them in their mouth. The baby starts to roll, reach out and grasp objects, and sits with assistance.	Engage, interact with gestures and words. Introduce toys/objects of interest and let the baby hold and explore these. Place the baby in different positions.
6–9 months	At 6 months, the baby can sit unassisted and their exploration of the world within their grasp continues. They learn to communicate their needs and wants through sounds, gestures and facial expressions. This is when they imitate simple words like “dada” and “mama” and the gestures of primary caregiver. They start to use toys in more complex ways as their motor skills improve. They can now roll over, begin to crawl and stand with some help. They also become better co-ordinated.	This is the time to talk a lot with the baby, respond to their communication and imitate their sounds. Allow the baby time to imitate your actions. Create an environment that is safe for exploration and provide safe toys to play with.
9–12 months	Their development of social, emotional, language, intellectual and motor skills is vast. They begin to pull themselves up to stand and may even take their first step. At this stage, their cognitive development becomes apparent as their memory skills improve and they learn object constancy. This may lead to separation issues when caregivers have to leave. Babies engage in a lot of repetitive behaviour; this is how they learn, strengthening neural pathways and building self-confidence through mastery. Exploration of their environment increases as they become more mobile.	Acknowledge feelings and offer comfort when your baby communicates, keep conversing and engaging with baby. Play ‘disappearing and reappearing’ to help cope with separation, but it is also important to offer reassurance when leaving. Be a learning partner to the baby, follow their lead in activities, but let them direct play.

Appendix 3: Developmental tasks and care strategies age 12 to 24 months

AGE:	DEVELOPMENTAL TASK:	CARE STRATEGIES:
12–18 months	Communication skills develop exponentially as vocabulary and understanding of simple instructions and concepts increase.	Encourage the child to use words to communicate, rather than gestures. Play games that include instructions. Read with the toddler to develop vocabulary and concepts. Create safe spaces for child to explore. Offer toys that represent objects in the child’s world, as well as novel objects.
18–24 months	Infants become eager for independence and control; however, they lack impulse control and do not fully understand the consequences of their actions. Play and exploration becomes more complex as their imagination develops. With improved motor skills and co-ordination, their activity levels increase, as does their knowledge about their environment. As vocabulary increases vastly, so does sentence development.	Use verbal language to increase the child’s communication skills to help them expand their vocabulary, learn to communicate their feelings, regulate their emotions and describe consequences that are linked to their behaviour. Provide objects and toys that foster imaginative play and creativity. Turn activities and play into learning opportunities.

Appendix 4: Developmental milestones ages 3 to 5 years

AGE	DEVELOPMENTAL MILESTONES
3 years	<p>Language skills develop as vocabulary increases and the child learns more about their environment and themselves. They are able to follow more complex instructions and communicate with strangers.</p> <p>Cognitive skills develop as they learn to match and sort objects by shape and colour. They can complete simple puzzles as they increasingly understand concepts and their creativity and imagination develops.</p> <p>Motor movement, gross and fine motor skills, co-ordination and balance increases as child explores environment.</p> <p>Social development increases as children learn from and imitate adults and other children. Separation from parents becomes easier.</p>
4 years	<p>Language increases to include concepts, more complex sentences and grammar improves. They begin to develop story-telling skills.</p> <p>Cognitive development broadens with numeric knowledge, knowledge of colours, simple problem-solving, a sense of time. Concepts of same versus different start to emerge.</p> <p>Range of motor movement increases, as do agility, hand-eye co-ordination and motor skills.</p> <p>Play involves fantasy and inventiveness, but the child can often not distinguish between this and reality.</p> <p>The child starts to view themselves as a whole person involving mind, body and feelings; their social interest develops as they co-operate with peers and explore new experiences. They also start to engage in self-care.</p>
5 years	<p>At this age, the child begins to master their motor skills. They are better able to balance and are more co-ordinated. They can use tools and utensils and begin to print symbols or even letters. Their vocabulary and language is broader and they begin to recall and relate stories with longer sentences and the use of different tenses. Play involves acting, singing and dancing and they are able to distinguish fantasy from reality most of the time.</p> <p>They begin to develop emotional maturity, understanding rules and wanting to please family and peers. Self-care improves as they learn independence in toileting, dressing and washing.</p>

Appendix 5: Studies on the impact of HIV on child development, Sherr (2005)

STUDY	PLACE	SAMPLE	MEASURES	FINDINGS
Aylward et al (1992)	USA	12 HIV+ 45 HIV-	Bayley Scales of Infant Development	HIV+ children scored lower than negative children.
Bachanas et al (2001)	Canada and Brazil	36 HIV+ 32 HIV-	Psychological adjustment; locus of control, coping	25% HIV+ clinically significant emotional or behavioural problems. More adjustment problems.
Belman et al (1996)		32 HIV+ 99 HIV- 116 controls	Neurological functioning	HIV+ significantly more neurological problems. Severe, pervasive neurological problems with early AIDS diagnosis.
Blanchette et al (2001), (2002)		Various	Various	HIV+ significantly lower on mental scale and performance scale. CT abnormalities, developmental delays. Subtle motor impairments in HIV+.
Bruck et al (2001)		43 HIV+ 67 Controls	Various	Significant neuro-developmental delay in HIV+ group.
Buchacz (1997)		N= 983 HIV+	Various	Immunosuppression associated with delayed pubertal onset.
Chase et al (1995)		24 HIV+	Bayley Scales of Infant Development	HIV+ delayed motor & mental development.
Cohen et al (1991)		15 HIV+ 33 Controls	School achievement	Significant negative effects on school achievement.
Coplan et al (1998)		91 HIV+ 69 HIV-	Various	Language deterioration among HIV+
Fishkin et al (2000)		40 HIV+ 40 HIV-	Wechsler Scale	HIV+ significantly lower scores on block design.
Fowler et al (2000)		114 HIV+ 481 HIV-	Various	HIV+ abnormal mental and motor growth. Early and marked cognitive delays and declines.
Gay et al (1995)		28 HIV+ 98 HIV-	Mental and motor scores	Mean mental and motor scores significantly lower in HIV+.
Hilgartner et al (1993)		62% HIV+ 38% HIV-	Various	HIV+ height decline, delays in sexual maturation, 50% more likely to score below expected level.
Knight et al (2000)		25 HIV+ 25 HIV-	Bayley Scales of Infant Development	HIV+ significantly lower score on mental and motor development.
Levenson et al (1992)		41 HIV+ 8 sero-converters	McCarthy Scales of Children's Abilities	44% with low scores. HIV+ significantly worse than seroconverters.
Llorente et al (2003)		N=157 HIV+	Bayley Scales, Neurological markers and mortality	Greater predicted mortality for those with lower quartile scores.
Macmillan et al (2001)		N=1094 147 HIV+	Bayley Scales of Infant Development	HIV+ children had significant delays which persisted at 24 months.
McKinney & Robertson (1993)		N=170 62 HIV+ 10 HIV-	Physical examination	HIV+ smaller weight and length for age.
Mellins & Ehradt (1994)		25 families	Bayley Scales of Infant Development	Loss and separation particular problems. Negative effects on siblings and caregivers.
Mellins et al (2003)		96 HIV+ 211 reverts	Behavioural Rating Scale	High level of behavioural problems in HIV+ group.
Mialky et al (2001)		N=85 HIV+	School related issues	53% required special services.
Nozyce et al (1994)		21 HIV+ 95 HIV-	Various	HIV+ scored significantly lower.
Pilowsky et al (2001)		N=73 HIV+	Depression	High risk of depression and anxiety symptoms.
Pollack et al (1996)		N=65	Cognitive motor development	HIV+ infants impaired compared to HIV-.
Scafidi et al (1997)		N=48	Brazelton Behavioural Scale	Infants of HIV+ mothers had more orienting problems and abnormal reflexes. May be precursors to later visual spatial delays.
Smith et al (2001)		N=114 HIV+	Neurological functioning	Early HIV infection increased risk of poor neuro-developmental functioning.
Whitt et al (1993)		25 HIV+ 38 HIV-	6 domains of functioning	High incidence of subtle deficits when compared to age norms.

Appendix 6: Studies of impact of HIV on child development conducted in Africa

STUDY	PLACE	SAMPLE	MEASURES	FINDINGS FOR HIV+
Bell et al (1997)	Cote d'Ivoire	76 HIV+ 77 HIV–	Various	Comparatively early death in HIV-infected children in Africa compared to West.
Boivin et al (1995)	Zaire	14 HIV+ 16 Control	Denver Developmental Screening Test	Motor and visual-spatial deficits. Maternal infection undermines cognitive development in children.
McGrath et al (2006)	Tanzania	327 children	The Bayley Scales of Infant Development	Psychomotor developmental delays.
Kauchali & Davidson (2006)	Sub-Saharan Africa	HIV+ infants	Various	Neuro-developmental delay is prevalent in HIV-positive children.
Bam, Kritzing & Louw (2003)	South Africa	10 HIV+	Rosetti Infant-Toddler Language Scale	General developmental delay, particularly with regard to communication.
Bobat et al (2001)	South Africa	48 HIV+ 93 HIV–	Physical measures	HIV+ children lowered length for age.
Kotras (2002)	South Africa	74 HIV+	Revised Griffiths Scales of Mental Development	Below average performance, developmental delays on variable subscales.
Popich, Louw & Eloff (2007)	South Africa	HIV+ infants	Linguistics assessment	Communication disorders and language delays.
Du Toit & Van der Merwe (2006)	South Africa	18 HIV+ 10 HIV –	Various	Delayed milestones, perceptual-motor delays; poor self-esteem.
Miller et al (2001)	South Africa	92 HIV+ 439 HIV–	Clinical Assessment	HIV+: failure to thrive and growth abnormalities.
Potterton (2007)	South Africa	122 HIV+ infants < 2½	Bayley Scales of Infant Development	Wasting, stunting, severe delays in cognitive and motor development.
Sandison (2005)	South Africa	HIV+ children	Developmental profiles	Delayed milestones.
Wilmschurst et al (2006)	South Africa	7 HIV+	Case studies, Neuro-imaging	Severe, progressive neuropathology.

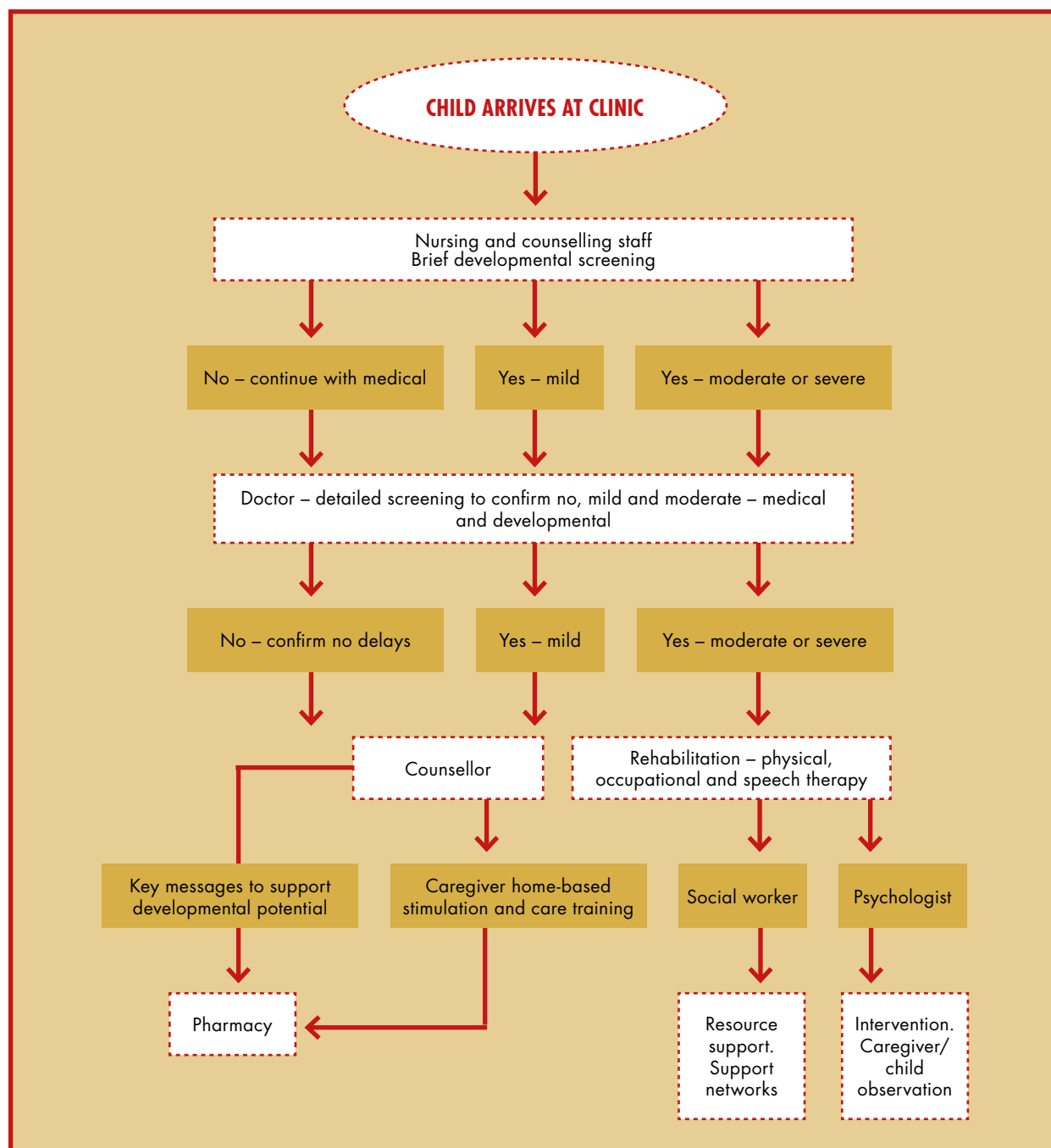
Appendix 7: Intervention opportunities in antenatal and postnatal care

STAGE	INTERVENTION OPPORTUNITY	CONSEQUENCE	RESOURCES REQUIRED
Pregnancy	PMTCT	Prevention of HIV transmission	Health-care staff
	Nutrition	Improved caregiver physical and psychological wellbeing and social support networks	Dietician
	Socio-economic support		Social worker Counselling staff
	Psychological support		
	Psycho-education re foetal development		
Birth	PMTCT	Prevention of HIV transmission	Health-care staff
	Psychological support	Improved caregiver psychological wellbeing	Social work & Counselling staff Health-care staff
	Psycho-education re neo-natal needs; development; responsive caregiving	Improved care of new born	
Early immunisations	HIV test	Early diagnosis and access to treatment	Health-care staff Laboratory service
	Nutrition	Improved child health	Dietician
	Socio-economic support		Child registration Grant support
	Psychological support	Improved caregiver psychological wellbeing	Social work & Counselling staff
	Psycho-education re normal development; support services available	Early recognition of developmental delay and referral for intervention	Health-care staff

Appendix 8: Intervention opportunities in paediatric care

STAGE	INTERVENTION OPPORTUNITY	CONSEQUENCE	RESOURCES REQUIRED
Paediatric clinic visits	Developmental screening	Early recognition of developmental delay and referral for intervention	Health-care staff
	Nutrition	Improved child health	Dietician Counselling staff
	Socio-economic support		Social protection
	Psychological support	Improved caregiver psychological wellbeing	Social work & Counselling staff Health-care staff
	Psycho-education re normal development; support services available	Early recognition of developmental delay and referral for intervention	Social work & Counselling staff Health-care staff

Appendix 9: Integration of developmental screening and early referral into health-care service



REFERENCES

- Abadio-Barrero, C. E., & Castro, A. (2006). Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS. *Social Science and Medicine*, 62, 1219–1228.
- Abell, S. C., Wood, W. & Liebman, S. J. (2001). Children's Human Figure Drawings as Measures of Intelligence: The Comparative Validity of Three Scoring Systems. *Journal of Psychoeducational Assessment*, 19(3) 204–215.
- Algren C (1985). Role perceptions of mothers who have hospitalised children. *Child Health Care*, 14, 6–9.
- ANECOA. (2005). Early diagnosis of Pediatric HIV infection in Sub-Saharan Africa. Advocacy Statement. www.anecca.org.
- Antle B., Wells L., Goldie R., DeMatteo D., King S. (2001). Challenges of Parenting for Families Living with HIV/AIDS. *Social Work*, 46(2), 159–169.
- Armistead, L., & Forehand, R. (1995). For whom the bell tolls: Parenting decisions and challenges faced by mothers who are HIV-infected. *Clinical Psychology: Science and Practice*, 2, 239–250.
- Aylward, E. H., Butz, A. M., Hutton, N., Joyner, M. L., & Vohlgut, J. W. (1992). Cognitive and motor development in infants at risk for human immunodeficiency virus. *Development in HIV-Infected Infants*, 146, 218–222.
- Bagenda, D., Nassali, A., Kalyesubula, I., Sherman, B. D., Boivin, M. J., & Olness, K. (2006). Health, neurologic and cognitive status of HIV-infected, long-surviving antiretroviral-naïve Ugandan children. *Paediatrics*, 117, 729–740.
- Biersteker, L. & Rudolph, N. (2003). *Protecting the rights of orphans and vulnerable children aged 0–9*. Report Phase 1: South African Action Research Programme.
- Biggar, H. & Forehand, R. (1998). The relationship between maternal HIV status and child depressive symptoms: Do maternal depressive symptoms play a role? *Behavior Therapy*, 29, 409–422.
- Black, M. (2003). *Opening minds, opening opportunities: Children's participation in action for working children*. London: Save the Children.
- Black, R. E., Morris, S.S. & Bryce, J. (2003). Where and Why Are 10 Million Children Dying Every Year? *Lancet*, 361, (9376) 2226–2234.
- Black, M., Nair, P., & Harrington, D. (1994). Maternal HIV infection: Parenting and early child development. *Journal of Paediatric Psychology*, 19, 595–616.
- Blanchette, N. (2000). Cognitive and motor development in children with vertically transmitted HIV infection. Unpublished Master dissertation. Master's in Social Science. Canada: University of Toronto.
- Bradshaw, D., Groenewald, P., Laubscher, R., Nannan, N., Nojilana, B. (2003). *Initial burden of disease for South Africa, 2000*. Cape Town, South Africa: Medical Research Council.
- Bradshaw, D. & Nannan, N. (2006). Mortality and morbidity among women and children. In P. Ijumba & A. Padarath (Eds.), *The South African Health Review* (pp. 127–150). Durban: Health Systems Trust.
- Brandt, R. (2005). *Maternal Wellbeing, child care and child adjustment in the context of HIV/AIDS: What does the psychological literature say?* (Rep. No. 135). Cape Town: The Centre for Social Science Research.
- Brookes, H., Shisana, O., & Richter, L. (2004). *National Household HIV Prevalence and Risk Survey of South African Children*. Human Sciences Research Council.
- Bronfenbrenner, U. (1979). *The Ecology of Human Development*. Cambridge: Harvard University Press.
- Brown, L. K. & Lourie, K. J. (2000). Children and adolescents living with HIV and AIDS: A review. *Journal of Child Psychology and Psychiatry*, 41, 81–96.
- Chiriboga, C. A., Fleishman, Champion, S., Gaye-Robinson, L., & Abrams, E. J. (2005). Incidence and prevalence of HIV encephalopathy in children with HIV infection receiving highly active antiretroviral therapy (HAART). *J Pediatr*, 146, 402–407.
- Clacherty, G. & Kushlik, A. (2004). Meeting the challenge of research with very young children: a practical outline of methodologies used in the formative research and pre-testing of the Takalani Sesame HIV and AIDS television and radio programmes. In *Fourth International Education Entertainment Conference* (pp. 1–16). Cape Town: Clacherty & Associates and Ochre Communication.
- Clarke, A., Hutchinson, S., & Weiss, E. (2005). *Horizons programs dealing with psychosocial support and children*. The Population Council.

- Coplan, J., Contello, K., Cunningham, C., Wiener, L., Dye, T., Roberge, L. et al (1998). Early language development in children exposed to or infected with Human Immunodeficiency Virus. *Paediatrics*, 102, 1–8.
- Cotlands (2007). *Psychosocial Care of Babies and Young Children Living with HIV and AIDS*. Training Manual: UNICEF & Department of Health.
- Coutsoudis, A., Pillay, K., Kuhn, L., Spooner, E., Tsai, W., & Coovadia, H. (2001). Method of feeding and transmission of HIV-1 from mothers to children by 15 months of age: prospective cohort study from Durban, South Africa. *AIDS*, 379–387.
- Crowley, S. (2007) Health for children affected by HIV. *World Health Organisation presentation at the UNICEF Interagency Task Team (IATT) on children and HIV and AIDS*. April: Washington DC.
- Day, C. & Gray, A. (2006). Health and related indicators. In P. Ijumba & A. Padarath (Eds.), *The South African Health Review* (pp. 369–506). Durban: The Health Systems Trust.
- Department of Health. (2007). *Government National AIDS Plan 2007–2011*. Pretoria: National Department of Health.
- Doherty, T. & Chopra, M. (2006). HIV and infant feeding. In P. Ijumba & A. Padarath (Eds.), *The South African Health Review* (pp. 221–234). Durban: The Health Systems Trust.
- Domek, G. (2006). Social Consequences of antiretroviral therapy: preparing for the unexpected futures of HIV-positive children. *Lancet*, 367, 1367–1369.
- Dorsey, S., Chance, M. W., Forehand, R., Morse, E., & Morse, P. (1999a). Children whose mothers are HIV-infected: Who resides in the home and is there a relationship to child psychosocial adjustment? *Journal of Family Psychology*, 13, 103–117.
- Dorsey, S., Forehand, R., Armistead, L., Morse, E., Morse, P., & Stock, M. (1999b). Mother knows best? Mother and child report of behavioural difficulties of children of HIV-infected mothers. *Journal of Psychopathology and Behavioural Assessment*, 21, 191–206.
- Dunn, A. (2005). *HIV/AIDS: What about very young children?* Working paper, 35. The Hague: Bernard van Leer Foundation.
- Eley, B., Nuttall, J., Davies, M., Smith, L., Cowburn, C., Buys, H. et al (2004). Initial experience of a public sector antiretroviral treatment programme for HIV-infected children and their infected parents. *South African Medical Journal*, 94.
- Flanagan, C. M. (1990). *People and change*. Hillside, New Jersey: Lawrence Erlbaum Associates.
- Forehand, R., Steele, R. G., Armistead, L., Morse, E., Simon, P., & Clark, L. (1998). The Family Health Project: Psychosocial adjustment of children whose mothers are HIV infected. *J Consult Clin Psychol*, 66, 513–520.
- Foster, G. (2005). *Bottlenecks and dripfeeds: channelling resources to communities responding to orphans and vulnerable children in Southern Africa*. London: Save The Children.
- Garbarino, J. & Ganzel, B. (2000) The human ecology of early risk. (pp. 76–93) In Shonkoff, J. & Meisels, S. (Eds.), (2000). *Handbook of early childhood intervention* (2nd Ed.). Cambridge, USA: The Cambridge University Press.
- Grantham-McGregor, S., Bun Cheung, Y., Cueto, S., Glewwe, P., Richter, L., & Strupp, B. (2007). Developmental potential in the first 5 years for children in developing countries. *Lancet*, 369, 60–70.
- Goldman-Fraser J, Fernandez MT, & Marfo K (2005). Separation and Continuity in the Lives of Infants and Toddlers: Introduction to the Issue. *ZERO TO THREE*, 25, 4–7.
- Govender, L., Rochat, T., Richter, L., & Rollins, N. C. (2006). Paediatric nursing in the context of the HIV/AIDS epidemic in resource-poor settings – balancing the ‘art and the science’. *Journal of Holistic Nursing Practice*, 247–254.
- Hackl, K., Somlai, A., Kelly, J., Kalichman, S. (1997) Women Living with HIV/AIDS: The dual challenge of being a patient and a caregiver. *Health and Social Work*, 22(1), 53–62.
- Hart, R. A. (1997). *Children’s participation: The theory and practice of involving young citizens in community development and environmental care*. London: Earthscan.
- Heckman, J. (2006). Investing in disadvantaged young children is an economically efficient policy. In: *Building the economic case for investments in preschool* (pp. 1–30). New York: Committee for Economic Development & The Pew Charitable Trusts & PNC Financial Services Group.
- Hendricks, M., Eley, B., & Bourne, L. (2006). Child Nutrition. In P. Ijumba & A. Padarath (Eds.), *The South African Health Review* (pp. 203–220). Durban: The Health Systems Trust.

- Hough, E. S., Brumitt, G., Templin, T., Saltz, E., & Mood, D. (2003). A model of mother-child coping and adjustment to HIV. *Social Science & Medicine*, 56(3), 643–655.
- Ickovics, J. R., Hamburger, M. E., Vlahov, D., Schoenbaum, E. E., Schuman, P., Boland, R. J. et al (2001). Mortality, CD4 cell count decline, and depressive symptoms among HIV-seropositive women. Longitudinal analysis from the HIV epidemiology research study. *JAMA*, 285, 1466–1474.
- Johnson, V. & Ivan-Smith, E. (1998). The Way Forward. In E.Ivan-Smith & V. Johnson (Eds.), *Stepping Forward: Children and young people's participation in the development process*. London: Intermediate Technology Publications.
- Juma, M., Okeyo, T., & Kidenda, G. (2004). *Our hearts are willing, but... Challenges of elderly caregivers in rural Kenya*. Nairobi: The Population Council.
- Katapa, R. S. (2004). Caretakers of AIDS patients in rural Tanzania. *International Journal of STD and AIDS* 15: 673–678.
- Kegels, G. & Marchal, B. (2005). *AIDS in the health workforce in Africa: making sense*. Antwerp: Department of Public Health, Institute of Tropical Medicine.
- Killian, B. (2005). Risk and resilience. In R. Pharoah (Ed.), *A generation at risk? HIV/AIDS, vulnerable children and security in Southern Africa*. (Chapter 3, 33–63). Pretoria: Institute of Security Studies.
- Koekkoek, S., Eggermont, L., De Sonnevile, L., & Jupimai, T. (2006). Effects of highly active antiretroviral therapy (HAART) on psychomotor performance in children with HIV disease. *Journal of Neurology*, 253, 1615.
- Krebs, Rochat & Stein (2003). Maternal health and child development: Applying what we know to the context of HIV. In *UNAIDS (2005) Aids in Africa: Three Scenarios to 2025*. Geneva: Joint United Nations Programme on HIV/AIDS.
- Kvalsig, J. D., Chagan, M., & Taylor, M. (2006). *Getting Down to Basics: Principles and strategies for inclusion of children on anti-retroviral treatment in the education system, and support for other children affected by HIV and AIDS*. Pretoria: UNICEF.
- Kvalsig, J. D. & Richter, L. (2002). *The Takalani Sesame AIDS baseline study: knowledge, and attitudes of three to five year-old children regarding HIV and AIDS*. Durban: HSRC.
- Laws, S. & Mann, G. (2004). *So you want to involve children in research? A toolkit supporting children's meaningful and ethical participation in research relating to violence against children*. (Rep. No. 2958). Stockholm, Sweden: Save the Children.
- Linsk, N. & Mason, S. (2004). Stress on grandparents and other relatives caring for children affected by HIV/AIDS. *Health and Social Work*, 29, 127–136.
- Lombardi, J. & Bogle, M. (Eds.). (2004). *Beacon of Hope: The promise of Early Head Start for America's youngest children*. Washington DC: ZERO TO THREE Press.
- Luo, C. & Coulter, B. (2002). Diagnosis of Pediatric HIV Infection. In Essex, M., Mboup, S., Kanki, P. J., Marlink, R. G., & Tlou, S. D. (Eds.), *AIDS in Africa* (Second Edition, pp. 458–468). New York: Kluwer Academic/Plenum Publishers.
- Marchal, B., De Brouwere, V., & Kegels, G. (2005). HIV/AIDS and the health workforce crisis: what are the next steps? *Tropical Medicine and International Health*, 10, 300–304.
- Médecins Sans Frontières (MSF). (2005). *Fact Sheet: MSF Campaign for Access to Essential Medicines*. Geneva, Switzerland: Medecins sans Frontiers.
- Médecins Sans Frontières (MSF). (2007). *Help Wanted. Confronting the health care worker crisis to expand access to HIV/AIDS treatment: MSF experience in southern Africa*. Johannesburg: Médecins Sans Frontières (MSF).
- Meyers, T., Moultrie, H., Sherman, G., Cotton, M., & Eley, B. (2006). Management of HIV-infected children. In P. Ijumba & A. Padarath (Eds.), *The South African Health Review* (pp. 235–254). Durban: The Health Systems Trust.
- Michaels, D., Eley, B., Ndhlovu, L., & Rutenberg, N. (2006). *Exploring Current Practices in Paediatric Antiretroviral Roll-out and Integration with Early Childhood Programmes in South Africa: A Rapid Situational Analysis*. Washington DC: The Population Council.
- Miller, R., Goldman, E., & Bor, R. (1994). Application of a family system approach to working with people affected by HIV disease – two case studies. *Journal of Family Therapy*, 16, 295–312.
- Mitchell, C. D. (2006). HIV-1 encephalopathy among perinatally infected children: Neuropathogenesis and response to highly active antiretroviral therapy. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 216–222.

- Murphy, D. A., Marelich, W. D., Stritto, M. E. D., Swendeman, D., & Witkin, A. (2002). Mothers living with HIV/AIDS, mental, physical and family functioning. *AIDS Care*, 14, 633–644.
- Naar-King, S., Arfken, C., Frey, M., Harris, M., Secord, E., & Ellis, D. (2006). Psychosocial factors and treatment adherence in paediatric HIV/AIDS. *AIDS Care*, 18, 621–628.
- Naeem-Sheik, A. & Gray, G. (2005). HIV Disclosure in Children. *The Southern African Journal of HIV Medicine*, 46–48.
- Nakiyangi, J. S., Bracher, M. B., Whitworth, J. A., Ruberantwari, A., Busingye, J., Mbulaiteye, S. M., Zaba, B. (2003). Child survival in relation to mother's HIV infection and survival: evidence from a Ugandan cohort study. *AIDS*, 17, 1827–1834.
- Norman, A., Chopra, M., & Kadiyala, S. (2005). *HIV disclosure in South Africa: enabling the gateway to effective response*. Cape Town: International Food Policy Institute.
- Orner, P. (2006). Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care*, 18(3), 236–240.
- Papousek, H., Papousek, M. (1997). Fragile aspects of early social integration. In: Murray, L., Cooper, P., (Eds). (1997). *Postpartum depression and child development*. United Kingdom: Guilford.
- Perinatal HIV Research Unit (2006). *Priorities in AIDS care and treatment: A collection of South African resources on AIDS care and treatment*. Johannesburg: University of Witwatersrand, Perinatal HIV Research Unit & USAID.
- Potterton, J., Eales, C. (2001). Prevalence of developmental delay in infants who are HIV-positive. *South African Journal of Physiotherapy*, 57(3), 11–15.
- Potterton, J. & van Aswegen, H. (2006) Paediatric HIV in South Africa: An Overview for Physiotherapists. *South African Journal of Physiotherapy*, 62(1), 19–22.
- Potterton, J. L. (2007). *A longitudinal study of neurodevelopmental delay in HIV infected children*. Unpublished doctoral dissertation, Faculty of Health Sciences, University of the Witwatersrand.
- Puoane, T., Sanders, D., Ashworth, A., Chopra, M., Strasser, S. & McCoy, D. (2004). Improving the hospital management of malnourished children by participatory research. *International Journal of Quality of Care*, 16, 31–40.
- Rabie, H., Marais, B. J., & Cotton, M. (2006). Maintaining infants and children on highly active antiretroviral therapy. *South African Family Practise*, 48.
- Rahman, A., Bunn, J., Lovel, H., & Creed, F. (2007). Maternal depression increases infant risk of diarrhoeal illness: a cohort study. *Archives of Diseases in Childhood*, 92, 24–28.
- Ramkisson, A., Coutsooudis, A., Coovadia, H., Mthembu, P., Hlazo, J., & Smit, J. (2006). Options for HIV-positive women. In P. Ijumba & A. Padarath (Eds.), *The South African Health Review* (pp. 315–332). Durban: The Health Systems Trust.
- Reidy, M., Taggart, M-E., Asselin, L. (1991). Psychosocial needs expressed by the natural caregivers of HIV infected children. *AIDS Care*, 3(3), 331–343.
- Richter, L. (2004a). Poverty, underdevelopment, and infant mental health. *Infant Mental Health Journal*, 25, 440–452.
- Richter, L. (2004b). *The importance of caregiver-child interactions for the survival and healthy development of young children: A review*. Geneva, Switzerland: The World Health Organisation.
- Richter, L. (2005). *The role of the health sector in strengthening systems to support children's healthy development in communities affected by HIV/AIDS* Geneva: World Health Organisation.
- Richter, L. & Foster, G. (2005). *Strengthening systems to support children's healthy development in communities affected by HIV/AIDS*. Geneva: The World Health Organisation.
- Richter, L., Foster, G., & Sherr, L. (2006a). *Where the heart is: Meeting the psychosocial needs of very young children in the context of HIV/AIDS*. The Hague, The Netherlands: Bernard van Leer Foundation.
- Richter, L. & Rama, S. (2006b). *Building resilience: A Rights Based Approach to Children and HIV/AIDS in Africa*. Stockholm, Sweden: Save the Children.
- Robinson, C. (1987). Roadblocks to family-centred care when a chronically ill child is hospitalised. *Maternal-Child Nursing Journal*, 16, 181–193.
- Rochat, T., Richter, L., Doll, H., Buthelezi, N., Tomkins, A., Stein, A. (2006). Depression among pregnant rural South African women undergoing HIV testing. *JAMA*, 295, 1376–1378.

- Rollins, N. C. (2007). Infant Feeding and HIV: Avoiding transmission is not enough. *British Medical Journal*, 487–488.
- Saavedra-Lozano, J., Fox, J., & Sungkanuparph, S. (2006). Salvage therapy with abacavir and other reverse transcriptase inhibitors for human immunodeficiency-associated encephalopathy. *The Paediatric Infectious Disease Journal*, 25, 1142–1152.
- Saloojee, H. & Bamford, L. (2006). Key childhood health promotion and disease prevention programmes. In P. Ijumba & A. Padarath (Eds.), *The South African Health Review* (pp. 181–202). Durban: Health Systems Trust.
- Sandison, A. (2005). *Exploring the developmental profile of Black HIV-positive/AIDS infants and children, a longitudinal study*. Unpublished master's thesis: Nelson Mandela Metropolitan University.
- Sameroff, A. J. & Fiese, B. H., (2000). Transactional Regulation: The development ecology of early intervention. (pp. 135–159) In: Shonkoff, J. & Meisels, S. (Eds.), (2000). *Handbook of early childhood intervention* (2nd Ed.). Cambridge, USA: The Cambridge University Press.
- Savage, E. & Callery, P. (2000). Parental participation in the care of hospitalised children: a review of the research evidence. In E. A. Glasper & L. Ireland (Eds.), *Evidence-based Child Health Care. Challenges in Practice*. (pp. 57–89). Basingstoke: Macmillan.
- Save the Children (2002). *The role of stigma and discrimination in increasing the vulnerability of children and youth infected and affected by HIV/AIDS*. Report on participatory workshops. Pretoria: Save the Children UK.
- Save the Children (2006). *Missing Mothers. Meeting the needs of children affected by AIDS*. London: Save the Children.
- Schor, E., Billingsley, M., Golden, A., McMillan, J., Meloy, L., & Pendarvis, B. (2003). Family Pediatrics: Report of the task force on the family. *Pediatrics*, 111, 1541–1571.
- Shelov, S. P. & Hannemann, R. E. (Eds.), (2006). *Caring for your baby and young child: Birth to age 5* (4th Ed.). Illinois, USA: American Academy of Pediatrics Publications.
- Sherr, L. (2005). *Young children and HIV/AIDS: mapping the field* (Working paper no. 33). The Hague: Bernard van Leer Foundation.
- Shonkoff, J. & Meisels, S. (Eds.), (2000). *Handbook of early childhood intervention* (2nd Ed.). Cambridge, USA: The Cambridge University Press.
- Shun King, M., Mhlanga, R. E., & De Pinho, H. (2006). The context of maternal and child health. In P. Ijumba & A. Padarath (Eds.), *The South African Health Review* (pp. 107–126). Durban: Health Systems Trust.
- Silver, E., Baumann, L., Camacho, S., Hudis, J. (2003). Factors associated with psychological distress in urban mothers with late-stage HIV/AIDS. *AIDS and Behaviour*, 7(4), 421–431.
- Silver, E., Westbrook, L., Stein, R. (1998). Relationship of parental psychological distress to consequences of chronic health conditions in children. *Journal of Pediatric Psychology*, 23(1), 5–15.
- Smith, R., Malee, K., Leighty, R., Brouwers, P., Mellins, C., Hittleman, J. et al (2006). Effects of perinatal HIV infection and associated risk factors on cognitive development among young children. *Pediatrics*, 117, 851–862.
- Stein, A., Krebs, G., Richter, L., Tomkins, A., Rochat, T. & Bennish, M. L. (2005). Babies of a pandemic. *Archives of Diseases in Childhood*, 90, 116–118.
- Sherman, D. W. (2000). Experiences of AIDS-dedicated nurses in alleviating the stress of AIDS caregiving. *Journal of Advanced Nursing*, 31(6), 1501–1508.
- Subedar, H. (2005). Nursing Profession. Production of nurses and proposed scope of practice. In *South African Health Review 2005*. (pp. 88–103). Durban: Health Systems Trust.
- Terre Blanch, M., Durrheim, K., & Painter, D. (Eds.) (2006). *Research in Practice*. (2nd Ed.) Cape Town: University of Cape Town Press.
- The National Institute of Health., (2007). *Speech and Language: Developmental Milestones 0–3 years*. The National Institute for Deafness and Other Communication Disorders. Retrieved September 18, 2007 from <http://www.nidcd.nih.gov/health/voice/speechandlanguage.asp>
- UNAIDS/UNICEF/USAID. (2004). *Children on the brink. A joint report on Orphan estimates and program strategies*. Washington DC, USA.
- UNAIDS/UNICEF/World Health Organisation (WHO). (2007). *Children and AIDS. A stocktaking report*. Switzerland: Unite for Children Against AIDS.
- UNICEF. (2005). *A call to action: Children the missing face of AIDS*. Geneva, Switzerland: Unite for Children Against AIDS.

- UNICEF. (2006). *The State of the World's Children*. Geneva: UNICEF.
- Van Damme, W., Kober, K., & Laga, M. (2006). The real challenge for scaling up ART in sub-Saharan Africa. *AIDS*, 653–656.
- Varga, C. A., Sherman, G. G., Maphosa, J., & Jones, S. A. (2005). Psychosocial consequences of early diagnosis of HIV status in vertically exposed infants in Johannesburg, South Africa. *Health Care for Women International*, 26, 387–397.
- Viviers, A. (2005). *A compendium on key international human rights instruments that impact on the lives of children*. Pretoria: UNICEF.
- Viviers, A. (2006). *Psychosocial care and support of HIV-positive babies and young children on ART*. Pretoria: UNICEF.
- Walker, S. P., Wachs, T. D., Meeks Gardner, J., Lozoff, B., Wasserman, G., Pollit, E. et al (2007). Child development: risk factors for adverse outcomes in developing countries. *Lancet*, 369, 145–157.
- Webb, D., Gulaid, L., Ngalazu-Phiri, S., & Rejbrand, M. (2006). Supporting and sustaining national responses to children orphaned and made vulnerable by HIV and AIDS: Experience from the RAAAP exercise in sub-Saharan Africa. *Vulnerable Children and Youth Studies*, 1, 170–179.
- Weiner, L., Theut, S., Steinberg, S., Riekert, K., Pizzo, P. 1994 The HIV-Infected child: parental responses and psychosocial implications. *American Journal of Orthopsychiatry*, 64(3), 485–492.
- Werner, E. E. & Smith, R. S. (1992). *Overcoming the odds*. Ithaca, New York: Cornell University Press.
- World Health Organisation (WHO) (2005a). *What is the impact of HIV on families?* Copenhagen: Health Evidence Network (HEN). Geneva: World Health Organisation
- World Health Organisation (WHO) (2005b). *Making every mother count*. Geneva: World Health Organisation.
- World Health Organisation (WHO) (2006). *Antiretroviral therapy of HIV infection in infants and children: towards universal access. Recommendations for a public health approach*. Geneva, Switzerland: World Health Organisation.
- Wilfert, C. (2005). *Experience with ARV Regimens for Infants/Children in Resource Constrained Settings*. Elizabeth Glaser Paediatric AIDS Foundation.
- Wilmschurst, J. M., Burgess, J., Hartely, P., & Eley, B. (2006). Specific Neurologic Complications of Immunodeficiency Virus Type 1 (HIV-infection in children). *Journal of Child Neurology*, 21, 788–794.
- Yarrow, L., MacTurk, R., Vietze, P., McCarthy, M., Klein, R., McQuiston, S. (1984). Development course of parental stimulation and its relationship to mastery motivation during infancy. *Developmental Psychology*, 20(3), 492–503.
- Ygge, B.M. & Arnetz, J.E. (2004). A Study of Parental Involvement in Pediatric Hospital Care: Implications for Clinical Practice. *Journal of Pediatric Nursing*, 19, 217–223.
- ZERO TO THREE Foundation. (2007). Milestones for Development. Retrieved 18 September, 2007 from www.zerotothree.org

