

# **Developmental outcomes of HIV-exposed infants in a low-income South African context**

**By**

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## ABSTRACT

<b>UNIVERSITY OF PRETORIA</b> <b>FACULTY OF HUMANITIES</b> <b>DEPARTMENT OF SPEECH-LANGUAGE PATHOLOGY AND AUDIOLOGY</b>	
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<b>Title</b>	Developmental outcomes of HIV-exposed infants in a low-income South African context
<p><b>Abstract</b></p> <p><b>Background:</b> Effective Human Immunodeficiency Virus (HIV) transmission prevention strategies have led to a growing population of vulnerable HIV-exposed (HE) infants in sub-Saharan Africa, however uncertainty exists in literature regarding their developmental outcomes.</p> <p><b>Objective:</b> The aim was to determine the developmental outcomes of six- to 12-month-old HE infants in a low-income South African context, when compared to HIV-unexposed (HU) counterparts.</p> <p><b>Method:</b> In this prospective cross-sectional, group comparison study, the development of 41 HE and 40 HU infants (mean age = 8.4 months, SD = 2.1 months) from a low-income context was assessed. Caregivers were interviewed using a background interview and the Vineland Adaptive Behavior Scales, Third Edition (Vineland-3) to evaluate infants' communication, daily living, socialisation and motor skills.</p> <p><b>Results:</b> Based on the overall test scores, the majority of HE participants had age-appropriate development (90.2%; n=37). Some HE participants, however, presented with delays in the domains of communication (9.8%; n=4), daily living skills (2.4%; n=1), socialisation (19.5%; n=8) and motor development (7.3%; n=3). HU participants also demonstrated some domain-specific delays, thus delays were present in both groups. No statistically significant differences were found between the development of HE and HU participants.</p> <p><b>Conclusion:</b> Findings were reassuring and suggested that the development of HE participants were similar to that of HU counterparts. Developmental differences may, however, only emerge with age, therefore large-scale longitudinal research is recommended. It is suggested that the entire sample was vulnerable, highlighting the importance of developmental surveillance and early intervention in low-income contexts, irrespective of HIV and antiretroviral exposure.</p> <p><b>Keywords:</b> HIV-exposed infants; antiretroviral exposure; HIV-unexposed infants; low-income context; developmental outcomes; Vineland-3; adaptive behaviour; communication development; daily living skills development; socialisation development; motor development.</p>	

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~ Psalm 27 ~

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## LIST OF ABBREVIATIONS

<b>3TC</b>	lamivudine
<b>ABC</b>	Adaptive Behaviour Composite
<b>ART</b>	antiretroviral treatment
<b>ARV</b>	antiretroviral
<b>AZT</b>	zidovudine
<b>CG</b>	control group
<b>EFV</b>	efavirenz
<b>FTC</b>	emtricitabine
<b>HE</b>	HIV-exposed
<b>HI</b>	HIV-infected
<b>HIV</b>	Human Immunodeficiency Virus
<b>HPCSA</b>	Health Professions Council of South Africa
<b>HU</b>	HIV-unexposed
<b>LMIC</b>	lower-middle-income country
<b>MTCT</b>	mother-to-child transmission
<b>NVP</b>	nevirapine
<b>PCR</b>	polymerase chain reaction
<b>PHC</b>	primary healthcare clinic
<b>PMTCT</b>	prevention of mother-to-child transmission
<b>RG</b>	research group

<b>RTHB</b>	Road to Health Booklet
<b>SADoSD</b>	South African Department of Social Development
<b>SANAC</b>	South African National AIDS Council
<b>SANDoH</b>	South African National Department of Health
<b>SD</b>	standard deviation
<b>SLT</b>	speech-language therapist
<b>SPSS</b>	Statistical Package for the Social Sciences
<b>SSA</b>	sub-Saharan Africa
<b>TDF</b>	tenofovir disoproxil fumarate
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNICEF</b>	United Nations Children's Fund
<b>Vineland-3</b>	Vineland Adaptive Behavior Scales, Third Edition
<b>WHO</b>	World Health Organization

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# 1. INTRODUCTION

## 1.1. Chapter aim and outline

This chapter provides background regarding the Human Immunodeficiency Virus (HIV) epidemic and advances in prevention of mother-to-child transmission (PMTCT) of HIV, which have led to an emerging and vulnerable population of HIV- and antiretroviral (ARV)-exposed infants in South Africa. An overview of the inconsistent and limited literature regarding HIV-exposed (HE) infants' development during late infancy is given. The problem statement, rationale, and research question are then provided. The chapter concludes with a clarification of terminology used in the dissertation, as well as an outline of the chapters.

## 1.2. The HIV epidemic and the growing population of HE infants

Approximately 37.9 million people are living with HIV worldwide (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2019a). More specifically, 20.3% of the global number of people living with HIV (7.7 million) reside in South Africa, a lower-middle-income country (LMIC) in sub-Saharan Africa [SSA] (UNAIDS, 2019b). In 2018, 260 000 South African children were living with HIV (UNAIDS, 2019b) and 40% of children who died in hospital between 2012 and 2013, were either infected with, or exposed to HIV (Hall, Nannan, & Sambu, 2016).

The HIV prevalence among infants is significantly influenced by maternal HIV status (Hall et al., 2016), as mother-to-child transmission (MTCT) is the main mode of HIV transmission in infants (le Doare, Bland, & Newell, 2012). MTCT can occur prenatally, perinatally, and postnatally; which then occurs predominantly through breastfeeding (Abubakar, van Baar, van de Vijver, Holding, & Newton, 2008). HIV can damage the central and peripheral nervous system, as well as infants' developing brains, leading to neurodevelopmental impairments in neurological, motor, cognitive, and language functioning (Abubakar, 2014; van Rie, Harrington, Dow, & Robertson, 2007). These impairments usually persist into adolescence and adulthood and may affect educational achievement, productivity, socio-economic status, as well as quality of life (Abubakar et al., 2008; Coelho, Tricarico, Celsi, & Crovella, 2017).

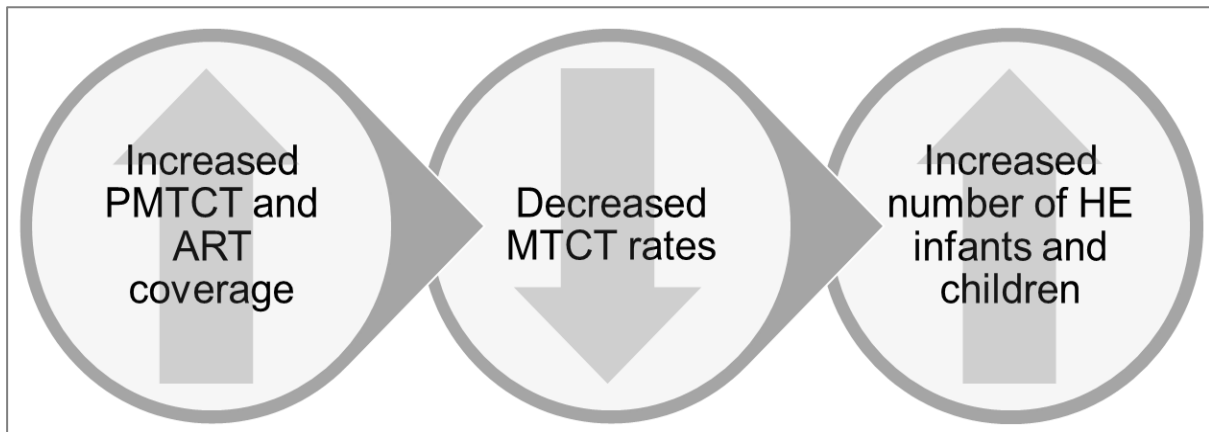
MTCT of HIV can be prevented by providing antiretroviral treatment (ART) to HIV-infected (HI) mothers and their infants (World Health Organization [WHO], 2016). For PMTCT of HIV, the World Health Organization (WHO) recommends lifelong combination ART for all pregnant and breastfeeding women, regardless of their WHO clinical stage and CD4 cell count (WHO, 2016). The WHO clinical stage refers to four stages of severity and progression of HIV infection (Weinberg & Kovarik, 2010), whereas the CD4 cell count refers to the level of CD4+ T-cells, where a lower count signifies weakening of the immune system and progression of the HIV illness (WHO, 2019). The current preferred ART option for pregnant and breastfeeding women in South Africa is a fixed-dose combination of tenofovir disoproxil fumarate (TDF), lamivudine (3TC) or emtricitabine (FTC), and efavirenz [EFV] (South African National Department of Health [SANDoH], 2015).

All infants born to HI mothers should receive prophylactic nevirapine (NVP) from birth to six week of age, irrespective of being breastfed or formula-fed (SANDoH, 2015). Breastfed infants born to HI mothers should receive an additional six weeks of NVP, if their mothers only started using ART less than four weeks before delivery (SANDoH, 2015). If a breastfeeding mother is newly diagnosed with HIV more than 72 hours post-delivery, the infant should be immediately initiated on dual prophylaxis, including NVP and zidovudine [AZT] (SANDoH, 2015). In settings where lifelong ART is supported, it is recommended that HI mothers exclusively breastfeed their infants until they are six months old, where after additional appropriate complementary foods should be combined with breastfeeding (SANDoH, 2015; WHO & United Nations Children's Fund [UNICEF], 2016). Breastfeeding can continue up to 24 months and beyond, and should only be discontinued once a nutritionally adequate and safe solid diet without breastmilk can be provided (WHO & UNICEF, 2016).

The PMTCT program in South Africa has made significant progress since it was implemented 15 years ago (South African National AIDS Council [SANAC], 2019). The percentage of South African pregnant women accessing ART to prevent MTCT of HIV, has increased from 65% in 2010 to 87% in 2018 (UNAIDS, 2019a). Increased coverage of PMTCT programs and ART during and after pregnancy have significantly decreased infant HIV infection rates (Evans, Jones, & Prendergast, 2016; le Roux et al., 2018). In South Africa, MTCT rates at six weeks of age have declined from 3.6% in 2011 to 1.5%



in 2016 (SANAC, 2016). This has in turn, led to a growing population of HIV- and ARV-exposed infants, who are not necessarily infected with HIV (Evans et al., 2016; le Roux et al., 2018). The number of HE, but uninfected children (from birth to age 14) has escalated from 1.7 million in 2008 to 3.5 million in 2018 (UNAIDS, 2019a). These trends are depicted in Figure 1.1.



**Figure 1.1:**Trends in PMTCT of HIV (Evans et al., 2016; le Roux et al., 2018)

Globally, increased attention is being given to the expanding population of HE infants and children (McHenry et al., 2018). The term *HE infants* refers to infants who are born to HI mothers, but whose HIV infection status is still indefinite (SANDoH, 2015; WHO & UNICEF, 2016). It is recommended that all HE infants are tested by means of an HIV polymerase chain reaction (PCR) test at birth, and again at 10 or 18 weeks of age, depending on whether the infant is still receiving prophylaxis (SANDoH, 2015). Two negative PCR test results indicate that the infant is HE, but uninfected (SANDoH, 2015). If either of the PCR test results are positive, a confirmatory PCR test should be conducted and the infant should be initiated on paediatric combination ART while waiting for the test result (SANDoH, 2015). All HE infants should receive a confirmatory HIV antibody detection test at 18 months to determine whether HIV antibodies are present in their bloodstreams, where the presence of antibodies indicates HIV infection (SANDoH, 2015). Since MTCT of HIV can occur through breastfeeding, a definitive HIV infection status can, however, only be determined six weeks after cessation of breastfeeding (SANDoH, 2015).

### 1.3. The developmental outcomes of HE infants

Gestation and the first three years of life are the most critical and rapid period of brain development, which lays the foundation for health, well-being, and productivity throughout life (WHO, UNICEF, & World Bank Group, 2018). During this period, protective factors may lead to the greatest advantage, but adverse risks may cause the greatest damage (Richter et al., 2017; South African Department of Social Development [SADoSD], 2015). The emergent population of HE infants are extensively exposed to HIV and ARVs, however there is limited knowledge about the effect of these exposures on HE infants' development (McHenry et al., 2018). This is concerning, bearing in mind the extremely sensitive period of development from conception to three years of age (Richter et al., 2017). HE infants are thus considered a vulnerable population with uncertain needs (Evans et al., 2016).

PMTCT of HIV is one of the greatest public health achievements of the 21st century (Afran et al., 2014), where ART improves maternal health and maximises the prevention of infant infection (WHO, 2016). Despite these benefits, there are conflicting research findings regarding the effect of ARVs on infant development (Chaudhury et al., 2018). Prolonged ARV exposure during the developmentally-sensitive period of pregnancy and breastfeeding may be associated with risks (Evans et al., 2016). ARV medication that crosses the blood-brain barrier is a concern for early brain development (Ngoma et al., 2014), and it has been reported that ARV exposure could be associated with preterm birth and mitochondrial dysfunction, resulting in neurological and developmental problems (Coelho et al., 2017). It is conversely suggested, however, that ARVs are safe to use during pregnancy and the perinatal period (Sirois et al., 2013), and that ante- and postpartum combination ARV exposure has no adverse effects on infant and child development (Boivin et al., 2019; Chaudhury et al., 2018; Ngoma et al., 2014; Sirois et al., 2013). The impact of prolonged ARV exposure on the development of HE infants is therefore not yet well established (Boivin et al., 2019).

The impact of HIV exposure on HE infants' development is also not yet clear (Evans et al., 2016). It is recognised that HE infants have better motor, cognitive, and language outcomes than HI infants (Hutchings & Potterton, 2014; Rajan, Seth, Mukherjee, & Chandra, 2017; Whitehead, Potterton, & Coovadia, 2014), but there is a dearth of

literature regarding the developmental outcomes of HE infants younger than 12 months of age when compared to their *HIV-unexposed* (HU) counterparts. The majority of available research focuses on the developmental outcomes of HE children older than 12 months of age (Boivin et al., 2019; Chaudhury et al., 2017; le Roux et al., 2018; Ngoma et al., 2014), possibly because developmental outcomes and delays are not easily recognised in infants and young children (Abdoola, Swanepoel, van der Linde, & Glascoe, 2019; Glascoe, 2000). In spite of this difficulty, early identification is vital, as it facilitates timely intervention, which enhances early developmentally-sensitive periods and minimises long-term impairments (Abdoola et al., 2019).

There are also inconsistent findings on the effect of HIV exposure on early development. It has been suggested that HE infants and children may have differences in cognitive, motor, and language development when compared to HU peers (da Silva, de Sá, & Carvalho, 2017; Kerr et al., 2014; le Roux et al., 2018; McHenry et al., 2018; Sherr, Croome, Castaneda, & Bradshaw, 2014; Wedderburn et al., 2019). In contrast, other studies report that HE and HU infants and children have no significant differences regarding motor development, cognition, and language (Boivin et al., 2019; Chaudhury et al., 2017; le Roux, Abrams, Nguyen, & Myer, 2016; Ngoma et al., 2014; Springer et al., 2018). Consequently, there is still uncertainty about the developmental outcomes of HE infants during late infancy (Wedderburn et al., 2019).

Apart from the possible biomedical impact of HIV and ARV exposure on infant development, the social environment in which HE infants grow up, may increase their risk for developmental delay (Filteau, 2009; Whitehead et al., 2014). Many South African infants exposed to HIV are from poor social circumstances, and are predisposed to experience several stressors (Abubakar, 2014; Whitehead et al., 2014). HI caregivers typically experience morbidity, reduced productivity, and increased medical expenses, which place their families at risk for poverty and poor socio-economic status, in turn affecting their HE infants' development (Abubakar, 2014; Filteau, 2009). HI mothers are at increased risk for mental health problems and may have reduced capacity to provide care, nutrition, and stimulation to their infants (Abubakar, 2014; Evans et al., 2016; McDonald et al., 2013), which are important for optimal childhood development (Sherr, Skeen, Hensels, Tomlinson, & Macedo, 2016). Maternal morbidity may also impair the attachment between mother and infant (le

Doare et al., 2012), which is essential for the development of social and cognitive skills in infants (Gibbs, Forste, & Lybbert, 2018). It is also suggested that low income and education levels of HI parents are associated with lower intellectual quotient and literacy among HE children (Kerr, et al., 2014). It is thus, evident that family patterns of interaction and family resources, which include personal characteristics of parents and the families' financial resources, can have an impact on HE infants' development (Guralnick, 2011). Therefore, the context HE infants are exposed to and the reduced capability of parents to provide and care for their infants, may also negatively impact their development.

#### **1.4. Problem statement, rationale and research question**

Biomedical and environmental factors place HE infants at risk for developmental delays (Abubakar, 2014), which may consequently affect social-emotional, academic, and vocational outcomes (Guralnick, 2013; van der Linde et al., 2015). Negative effects of risks and delays can, however, be ameliorated if they are addressed in the early years of life, when brain plasticity is optimal (Slemming & Saloojee, 2013). Infants at risk for developmental delays should therefore be identified early, in order for preventative and early intervention to be initiated (Cioni, Inguaggiato, & Sgandurra, 2016).

Speech-language therapists (SLTs) play a key role in the transdisciplinary team that identifies delays and provides early intervention services to families and infants who have, or are at risk for developmental delays (American Speech-Language-Hearing Association [ASHA], 2008; South African Speech-Language-Hearing Association [SASLHA], 2017). Since developmental domains such as communication, cognitive, motor, social-emotional, and adaptive behaviour are interdependent, SLTs should work in collaboration with team members to provide holistic and comprehensive transdisciplinary services to affected families and their infants (ASHA, 2008; SASLHA, 2017). SLTs, who may be the first point of contact in the primary health care sector for the family, specialise in the assessment and treatment of communication, emergent literacy, cognitive, and social-emotional development, but they can observe other discipline-specific behaviours (e.g. motor skills) and consult with, or refer to, the relevant early intervention team members (ASHA, 2008). Considering their important function in the early intervention team, it is essential that SLTs have knowledge on the

developmental outcomes of HE infants, and be involved in the developmental monitoring and intervention of this population.

There appears to be a shortage of knowledge regarding HE infants' development, due to inconsistent research findings on the impact of pre- and postnatal exposure to HIV and ARVs on development (McHenry et al., 2018; Wedderburn et al., 2019) and limited publications in the age range below 12 months of age. Inadequate knowledge regarding their development may hamper early intervention clinicians, including SLTs, in identifying vulnerable HE infants timeously and implementing preventative early intervention services, before developmental delays are established. Early intervention can provide infants, families, and communities with developmental, educational, and economic benefits (SASLHA, 2017). The following research question was posed: What are the developmental outcomes of infants (six to 12 months of age) with HIV and ARV exposure in a low-income South African context, when compared to developmental outcomes of unexposed counterparts?

## **1.5. Clarification of terminology as used in the dissertation**

### **Antiretroviral treatment (ART)**

The term *antiretroviral (ARV)* refers to the medication used to treat HIV infection (WHO & UNICEF, 2016). *Antiretroviral treatment (ART)* is the lifelong use of a combination of three or more ARV medicines to treat HIV infection, achieve viral suppression, and prevent HIV transmission (SANDoH, 2015; WHO & UNICEF, 2016). This is also called *combination ART* or *highly active ART* (WHO, 2016). The use of ART to prevent the transmission of HIV from an HI mother to her infant during pregnancy and breastfeeding, is termed *prevention of mother-to-child-transmission (PMTCT)* of HIV (WHO, 2016). ART reduces HIV-related deaths, increases life expectancy, and improves quality of life (SANAC, 2019).

### **HIV exposed (HE) infant**

This term refers to an infant born to an HI woman and is at risk of acquiring HIV infection from the mother anytime during pregnancy, birth, or breastfeeding (SANDoH, 2015). The term *infant* refers to a child younger than 12 months of age, whereas the participants of the current study were specifically between six and 12 months of age.

An HIV-exposed infant may either remain uninfected (HIV-exposed but uninfected infant), or become infected with the virus (HIV-exposed and infected infant), which is usually concluded through confirmatory HIV-testing by 18 months of age or six weeks post-cessation of breastfeeding (SANDoH, 2015). In addition, HIV-exposed infants may be pre- and postnatally exposed to maternal and prophylactic ARVs. The term *HIV-exposed (HE)* is therefore used in this dissertation to refer to participants whose mothers were HI, and had pre- and postnatal exposure to HIV and ARVs. Not all HE participants had received a confirmatory test result to determine whether they were HE, but uninfected, because they were younger than 18 months of age and were still breastfeeding.

### **Developmental outcomes**

This term refers to cognitive, language, motor, and social-emotional development during early childhood (WHO et al., 2018). Children are considered to have a developmental delay when they present with one or more delays in the domains of gross motor, fine motor, speech, language, cognitive, intellectual, and social-emotional development (WHO et al., 2018). In the present study, the Vineland Adaptive Behavior Scales, Third Edition (Vineland-3) was used to determine developmental outcomes and delays in terms of communication (receptive and expressive language), daily living skills (personal skills), socialisation (interpersonal relationships and play skills), and motor skills (gross and fine motor skills).

### **1.6. Outline of chapters**

**Chapter 1:** Introduction to the research topic, problem statement, rationale, research question, and explanation of terminology as used in the dissertation.

**Chapter 2:** Research methodology used in the study.

**Chapter 3:** Research article submitted to the journal, *Child: Care, Health and Development*.

**Chapter 4:** Summary of the main research findings, implications, strengths and weaknesses, recommendations for future research, and conclusion.

## **2. METHOD**

### **2.1. Chapter aim and outline**

This chapter aims to describe the research methods employed in the current study to ensure transparency and replicability of the study. The aim, research design, ethical considerations, context, participants, materials, data collection and analysis procedures, as well as reliability and validity have been outlined.

### **2.2. Study aim**

The aim of this study was to determine the developmental outcomes of six- to 12-month-old infants with HIV and ARV exposure in a low-income South African context, when compared to developmental outcomes of unexposed counterparts.

### **2.3. Research design**

A cross-sectional, quantitative, group comparison research design was followed, where a standardised assessment instrument was used to compare the developmental characteristics of two groups in objective and numerical terms (Leedy & Ormrod, 2015; Maxwell & Satake, 2006; Nelson, 2013). A group comparison is non-experimental and involves descriptions of behaviours and characteristics, to compare a group with, and a group without a disorder (Nelson, 2013). Descriptive research aims to identify and describe the characteristics of a phenomenon or population as it is, therefore no variables are modified and no cause-and-effect relationships are determined (Leedy & Ormrod, 2015). A group comparison allowed the researcher to describe the salient features of development of the research group (RG) and determine whether differences and/or similarities between the RG and control group (CG) existed. The RG comprised of infants who were exposed to HIV and ARVs pre- and postnatally, whereas the CG comprised of infants who had no exposure to HIV and ARVs.

### **2.4. Ethical considerations**

#### **2.4.1. Ethical clearance and permission to conduct research**

The researcher obtained ethical clearance from the Faculty of Health Sciences, University of Pretoria (783/2018) [Appendix A], as well as the Department of Health



Tshwane Research Committee (GP\_201812\_019) [Appendix B]. The chief executive officer of the Stanza Bopape Community Development Centre in Mamelodi granted permission for the researcher to conduct research and access participants' Road to Health Booklets (RTHBs) at the clinic (Appendix C).

#### **2.4.2. Voluntary and informed consent**

All participants should have a choice of voluntarily participating in a research study (Leedy & Ormrod, 2015). In the current study, an information leaflet and informed consent letter was provided to potentially participating caregivers in which all the necessary information regarding the study was explained (Appendix D). This information included the nature and purpose of the study, the procedures to be followed, the risks and benefits of participating, the rights of the participants, and the fact that all information will be handled and reported on with confidentiality (Maxwell & Satake, 2006). Caregivers were given the opportunity to ask the researcher questions regarding the study and to decide whether they want to participate or not. The caregivers were also informed that they may withdraw from the study at any time, without any specific reason and without any negative consequence. All caregivers in this study provided voluntary informed consent for themselves and their infants to participate. Caregivers had to be their infant's parent or legal guardian and they had to be 18 years or older to provide informed consent. No participant was asked to disclose their HIV status prior to providing informed consent.

#### **2.4.3. Protection from harm**

Protecting the well-being of participants is one of the main ethical considerations in conducting research (Nelson, 2013). The risk involved in participating in a research study should not be greater than the normal risks of daily living (Leedy & Ormrod, 2015). During this study, participants were protected from the risk of physical or psychological harm, as well as stress and embarrassment. The researcher treated all participants with respect, by being sensitive towards their cultural and socio-economic background, as well as their HIV-specific information, so that they did not feel marginalised. Participating in this study did not cause inconvenience to the participants, as assessments took place during routine follow-up visits to the clinic and no additional travel expenses were required. There were also potential benefits for



participating in the study. After the assessment, all caregivers received verbal feedback on their infant's development, as well as age-specific brochures with general developmental information and guidelines to stimulate optimal child development (Appendix E). If concerns regarding infants' development were noted, necessary referrals were made, for the infant and their family to receive appropriate developmental therapeutic services (Appendix F).

#### **2.4.4. Privacy and confidentiality**

Every participant has a right to privacy (Leedy & Ormrod, 2015). During the process of data collection, analysis, and reporting, measures were taken to protect the privacy and maintain the confidentiality of the participants. Only the researcher had access to each participant's personal information, and it was handled with the strictest confidentiality. A numerical code was assigned to each participant and the journal article and dissertation did not include any identifying information of the participants. This was done to ensure confidentiality of participants' identities. The participants' codes and data were uploaded onto an Excel spreadsheet on a password-protected computer. The data are stored securely electronically and in hardcopy in room 2-12 in the Department of Speech-Language Pathology and Audiology for a minimum 15 years according to the University of Pretoria's data storage guidelines. To further ensure privacy of the caregivers and infants during the data collection period, the researcher conducted the assessment procedures in a private space within the clinic. HE participants were not isolated and identifiable to other patients in the clinic, as the participants' HIV-related information was obtained from their RTHBs and by interviewing caregivers within a private space.

#### **2.5. Research context**

Data were collected in Mamelodi, an urban settlement situated northeast of the city of Tshwane in Gauteng province, South Africa. It has a population of 334 577 people and a population density of 7403 persons per square kilometre (Statistics South Africa, 2011). Northern Sotho is spoken by 42.3% of the inhabitants, which makes it the language most commonly spoken in this area (Statistics South Africa, 2011). Mamelodi is considered a low-income community, as a monthly household income of less than ZAR1600 is received by 40.1% of the population (Statistics South Africa, 2011) and

most residents have a low socio-economic status (Eskell-Blokland, 2005; Timm & Eskell-Blokland, 2011). Thirty-nine per cent of homes are informal dwellings and only 35.9% of homes have piped water inside the dwelling (Statistics South Africa, 2011).

Most residents in Mamelodi make use of primary healthcare clinics (PHCs) to receive first-line basic healthcare services (Schoeman, Swanepoel, & van der Linde, 2017). The Stanza Bopape Community Development Centre, a PHC in Mamelodi, was therefore a suitable facility for participant recruitment. Data collection took place at the baby wellness and immunisation clinic at the Stanza Bopape PHC, which offers community-based services to promote health, prevent sickness, and cure illnesses (City of Tshwane, 2015).

## **2.6. Participants**

### **2.6.1. Sampling method**

Participants were recruited by the researcher through nonprobability purposive sampling, which refers to the selection of participants for a unique purpose, as they were considered the best source of information for the research study (Leedy & Ormrod, 2015; Nelson, 2013). This allowed the researcher to recruit caregivers of HE and HU infants aged between six and 12 months. It further enabled the researcher to obtain groups of comparable numbers and participants with similar demographic characteristics, within a limited timeframe of data collection. The participants were recruited from the same setting and were purposively selected, in order to be matched for age and gender as far as possible, to limit confounding variables. The selection of participants was done in accordance with the inclusion and exclusion criteria, depicted in Table 2.1.

## 2.6.2. Inclusion and exclusion criteria

Participants were selected based on the following inclusion and exclusion criteria as set out in Table 2.1.

**Table 2.1:** Inclusion and exclusion criteria

Groups	Research Group: HE participants	Control Group: HU participants
<b>Inclusion criteria</b>	<ol style="list-style-type: none"> <li>1. Infants aged between six and 12 months</li> <li>2. Infants with pre- and postnatal HIV and ARV exposure</li> <li>3. Caregivers who were 18 years or older to provide informed consent</li> <li>4. Caregivers who were able to answer interview questions in English</li> </ol>	<ol style="list-style-type: none"> <li>1. Infants aged between six and 12 months</li> <li>2. Infants with no pre- and postnatal HIV and ARV exposure</li> <li>3. Caregivers who were 18 years or older to provide informed consent</li> <li>4. Caregivers who were able to answer interview questions in English</li> </ol>
<b>Exclusion criteria</b>	<ol style="list-style-type: none"> <li>1. Infants with a confirmed positive HIV-status</li> <li>2. Infants with congenital disorders</li> </ol>	

HIV and ARV exposure was determined by maternal HIV status and ART use during pregnancy. Infants were thus included in the RG if their mothers were HIV-positive and used ART during pregnancy. Infants born preterm, with low birth weight, or other illnesses were also included in the study, as these conditions are often associated with HIV (Evans et al., 2016). Infants with congenital disorders, as well as confirmed HIV-positive infants were excluded from the study.

## 2.6.3. Participant description

A sample of 81 participants, consisting of 41 HE infants and 40 HU infants between the ages of six and 12 months, was included in the study. A smaller sample size is considered adequate, when characteristics of the participants are more similar (Leedy & Ormrod, 2015; Maxwell & Satake, 2006), which was the case with participants' demographic characteristics. In addition, the software program G\*Power version 3.1.9.4 was used to compute the minimum sample size requirement and the achieved power. The minimum sample size required to obtain a power of at least 0.95 is equal to 69. In this study, a sample size of 81 produced an achieved power of 0.977.

The mean age of the sample was 8.4 months with a standard deviation (SD) of 2.1 months. Home language distribution was Northern Sotho (43.2%), Tsonga (11.1%), Setswana (9.9%), IsiZulu (8.6%), Shona (6.2%), Ndebele (4.9%), Venda (3.7%),

Xhosa (3.7%), Southern Sotho (3.7%), SiSwati (2.5%), and Chichewa (2.5%). All caregivers reported English as an additional language and were therefore able to answer interview questions in English. Table 2.2 represents the infant and maternal characteristics of the RG and CG.

**Table 2.2:** Demographic characteristics of participants (n=81)

Characteristics		Research Group: HE participants (n=41)	Control Group: HU participants (n=40)	p-value <sup>a</sup>
<b>Infant age (months), mean (SD)</b>		8.3 (2.1)	8.5 (2.0)	0.622
<b>Infant gender</b>	Male	13 (31.7%)	19 (47.5%)	0.176
	Female	28 (68.3%)	21 (52.5%)	
<b>Birth weight (grams), mean (SD)</b>		2962.6 (432.5)	3060.1 (468.6)	0.242
<b>Gestational age*</b>	Full term (≥38 weeks)	39 (95.1%)	34 (87.2%)	0.258
	Preterm (≤37 weeks)	2 (4.9%)	5 (12.8%)	
<b>Infant feeding during first six months of life</b>	Exclusive breastfeeding	26 (63.4%)	25 (62.5%)	0.107
	Exclusive formula feeding	6 (14.6%)	1 (2.5%)	
	Breast- and formula feeding	9 (22.0%)	14 (35.0%)	
<b>Maternal age (years), mean (SD)</b>		31.2 (5.0)	28.9 (6.0)	0.026**
<b>Maternal education level</b>	Less than Grade 8	1 (2.4%)	1 (2.5%)	0.872
	Grade 9-10	6 (14.6%)	5 (12.5%)	
	Grade 11-12	28 (68.3%)	25 (62.5%)	
	Tertiary education	6 (14.6%)	9 (22.5%)	
<b>Maternal substance abuse during pregnancy</b>	Smoking	4 (9.8%)	1 (2.5%)	0.359
	Alcohol or drugs	2 (4.9%)	3 (7.5%)	0.675

<sup>a</sup> p-values of the Mann-Whitney test for the continuous variables and the p-values of the Fisher's Exact test for the frequencies (i.e. the counts)

\* Missing value in control group, due to non-disclosure of information (n=1)

\*\* Indicates a statistically significant difference between groups ( $p < 0.05$ )

There were no significant differences between the RG and CG in terms of age ( $p=0.622$ ), gender ( $p=0.176$ ), birth weight ( $p=0.242$ ), gestational age ( $p=0.258$ ), and feeding type ( $p=0.107$ ). There were also no significant differences between the groups for maternal education level ( $p=0.872$ ) or substance abuse during pregnancy ( $p=0.359$ ;  $p=0.675$ ). The mean age of the RG mothers was significantly higher than that of the CG mothers ( $p=0.026$ ).

All participants (n=81) were accompanied by their primary caregivers, of which 77 (95.1%) were participants' mothers, one (1.2%) was a father, and three (3.7%) were participants' family members, such as grandmothers, who were legal guardians. In the RG, 24 (58.5%) mothers initiated lifelong ART before pregnancy and 17 (41.5%) initiated lifelong ART during pregnancy. Thirty-nine (95.1%) RG mothers were using ARVs at the time of data collection, while two (4.9%) RG mothers stopped using ARVs after pregnancy.

## **2.7. Materials**

### **2.7.1. The Vineland Adaptive Behavior Scales, Third Edition (Vineland-3)**

The Vineland Adaptive Behavior Scales, Third Edition [Vineland-3] (Sparrow, Cicchetti, & Saulnier, 2016), a standardised, norm-referenced tool with indicators of validity and reliability (Pepperdine & McCrimmon, 2018), was used to evaluate the development of the participants. The Vineland-3 assesses the development of adaptive behaviour, which is described as daily functional skills required for personal and social sufficiency, from birth to age 90 (Pepperdine & McCrimmon, 2018; Sparrow et al., 2016). This tool assesses the individual's typical performance in everyday situations, rather than ability during a testing situation (Sparrow et al., 2016). It therefore relates to the activity and participation aspects of the International Classification of Functioning, Disability and Health (ICF) framework (Gleason & Coster, 2012; WHO, 2001). Table 2.3 contains the developmental domains and subdomains that were assessed using the Vineland-3.

**Table 2.3:** Domains and subdomains assessed using the Vineland-3 (Sparrow et al., 2016)

Domains	Subdomains	Description
Communication	Receptive language	Appropriately paying attention, understanding and responding to verbal and nonverbal information from others
	Expressive language	Using gestures, sounds and words to express oneself to others
Daily living skills	Personal	Developing self-sufficiency in terms of eating, dressing and washing
Socialisation	Interpersonal relationships	Demonstrating social and emotional appropriateness in responding and relating to others
	Play and leisure	Participating in play and fun activities with others
Motor skills	Gross motor	Using legs and arms for movements and coordination in daily life
	Fine motor	Using hands and fingers to manipulate objects in daily life

The developmental domains and subdomains were assessed by interviewing participants' caregivers using the Vineland-3 Comprehensive Interview Form (Sparrow et al., 2016) [Appendix G]. Primary caregivers were used as respondents, as they have comprehensive knowledge about their infant's typical everyday behaviour and functioning (Sparrow et al., 2016). When conducting the Vineland-3 Comprehensive Interview Form, the researcher was required to follow the *Vineland semi-structured interview technique*, where open-ended questions were asked to prompt the caregiver to talk about their infant's typical behaviours (Pepperdine & McCrimmon, 2018; Sparrow et al., 2016). Following this approach is beneficial, as it provides a holistic view of the participant and reduces inaccuracies in reporting, due to misunderstanding or misreporting (Sparrow et al., 2016). The researcher made use of open-ended questions as far as possible, but direct questions were asked in some cases. This was done to accommodate caregivers whose first language was not English and did not fully comprehend the general question asked. The researcher additionally observed and elicited infant behaviour where possible, which aided in obtaining developmental information. For example, it was observed whether the participant responded to his/her name being called (Appendix G - receptive language subdomain, item 3), or a toy was presented to the participant, to determine whether he/she could reach for it (Appendix G - fine motor subdomain, item 1).

The Vineland-3 Comprehensive Interview Form comprises of test items grouped according to the subdomains. The test items are scored by means of a rating scale, including the scores 0 (never), 1 (sometimes), and 2 (usually); or in some cases 0 (no) and 2 (yes). These scores reflect the frequency to which participants perform certain behaviours without assistance or prompting (Pepperdine & McCrimmon, 2018). Raw scores are calculated for each subdomain, which are then converted to norm-referenced *v-scale* scores, with a mean of 15 and a SD of 3. The term *v-scale score* conveys the relatively unique use of this scale in the Vineland (Sparrow et al., 2016). The *v-scale* scores are summed to determine domain scores, which are then converted to standard scores, with a mean of 100 and a SD of 15. The communication, daily living skills, and socialisation domain standard scores are then added and converted to an overall test score, the Adaptive Behaviour Composite (ABC), which also has a normative mean of 100 and SD of 15. The Vineland-3 is commonly used to contribute to the diagnosis of a developmental delay (Salomon-Estebanez et al., 2017; Sparrow et al., 2016), where scores of one SD or more below the normative means are interpreted as a developmental delay (Sparrow et al., 2016). Therefore, ABC and domain standard scores of  $\leq 85$  and subdomain scale scores of  $\leq 12$  were interpreted as delayed.

### **2.7.2. Data collection sheet**

A data collection sheet was used to obtain relevant demographic, developmental, medical, and HIV-related information about the participants (Appendix H). Sections from the Risk Assessment checklist (Kritzinger, 2012) were included in the data collection sheet, to delineate prenatal, perinatal, environmental, and established risk factors for developmental delays. The Risk Assessment checklist is a South African tool, which was developed as part of a master's dissertation (Kritzinger, 1994) and revised using literature (Claassen, Pieterse, van der Linde, Krüger, & Vinck, 2016). Information needed to complete the data collection sheet was obtained from a background interview with the caregiver and by perusing the infant's RTHB.

### **2.7.3. Developmental information and stimulation brochure**

Each caregiver received an age-specific brochure from the "Learn the Signs. Act Early." program (Centers for Disease Control and Prevention, 2019) after the



assessment. It included general developmental information and guidelines to stimulate optimal child development. The brochures were provided to increase caregivers' awareness and monitoring of developmental milestones (Gadomski & Riley, 2018) and encourage them to provide optimal stimulation to their infants at home.

## **2.8. Procedures**

### **2.8.1. Data collection**

Data were collected over a two-month period at the Stanza Bopape PHC in Mamelodi. The researcher was the only SLT collecting data and recruiting participants. Potential participants were identified by perusing all RTHBs for age, gender and HIV-related information, and approaching caregivers whose infants met the inclusion criteria. The researcher explained the purpose and procedures of the study to the caregivers of the infants. Caregivers who provided consent for themselves and their infants to participate in the study, were taken to a private space within the clinic, where the assessment took place. The researcher conducted the Vineland-3 Comprehensive Interview Form with the caregiver, to determine the infant's developmental outcomes. The researcher also conducted a background interview with the caregiver and consulted the infant's RTHB, to obtain relevant demographic, developmental, medical, and HIV-related information. This information was used to complete the data collection sheet.

Subsequent to the assessment, the researcher provided all caregivers who participated in the study with verbal feedback on their infant's development, as well as age-specific brochures, including general developmental information and guidelines to stimulate optimal child development. Necessary referrals were made if concerns regarding development were present. The time of the entire assessment procedure was approximately 45 minutes per participant.

### **2.8.2. Data analysis**

Data were analysed using the Statistical Package for the Social Sciences (SPSS) version 25. Descriptive and inferential statistics were used to determine statistically significant differences between the RG and CG. In order to test for normality, the Kolmogorov-Smirnov or the Shapiro-Wilk test statistics may be used. These two tests are the same in that they are both testing for normality, however, the Shapiro-Wilk test



is known to have more power in detecting differences from normality (Field, 2018). Since the majority of the  $p$ -values for the Shapiro-Wilk test, for the different variables under consideration, were less than 0.05, the data are not normally distributed and, accordingly, non-parametric tests were used. Differences in participant characteristics and Vineland-3 results were determined using the Mann-Whitney U and Fisher's Exact tests. Spearman correlations were used to determine associations. All statistical tests were two-sided and  $p$ -values of less than 0.05 were considered significant.

## **2.9. Reliability and validity**

The Vineland-3 is reliable, as it has high internal consistency (Pepperdine & McCrimmon, 2018). The test-retest and the inter-rater reliability range from good (corrected  $r$  value of 0.61) to excellent (corrected  $r$  value of 0.94) (Pepperdine & McCrimmon, 2018; Sparrow, Cicchetti, & Saulnier, 2016). The Vineland-3 is considered an effective, quick, easy, and useful tool to assess the development of adaptive functioning (Pepperdine & McCrimmon, 2018). Furthermore, the researcher is an SLT registered with the Health Professions Council of South Africa (HPCSA) and has clinical experience to observe and elicit desired infant behaviour in addition to the caregiver interview, which aided in describing the developmental characteristics of the participants.

The Vineland-3 is a valid assessment tool in terms of internal structure and content (Pepperdine & McCrimmon, 2018). There is evidence that the Vineland Adaptive Behavior Scales II has high specificity for the diagnosis of developmental delay (Salomon-Estebanez et al., 2017), thus there can be assumed that the Vineland-3 also has high specificity. Although the Vineland-3 was developed and normed in the United States, its previous versions have been used effectively in LMICs (Panigrahi, Das, & Sahoo, 2018; Shin et al., 2009), and with HE children in South Africa (Allen et al., 2014).

### 3. ARTICLE

The following article was submitted to the journal, *Child: Care, Health and Development* (Appendix I). The format and style of the article differs from the rest of the dissertation, as it was written according to the journal's guidelines.

#### **Developmental outcomes of HIV-exposed infants in a low-income South African context**

Carmen Cornelia de Beer, Esedra Krüger, Jeannie van der Linde, Renata Eccles, and Marien Alet Graham

#### **ABSTRACT**

**Background:** Effective Human Immunodeficiency Virus (HIV) transmission prevention strategies have led to a growing population of vulnerable HIV-exposed (HE) infants in sub-Saharan Africa, however there is uncertainty in literature regarding their developmental outcomes. The aim was to determine the developmental outcomes of HE infants in a low-income South African context, when compared to HIV-unexposed (HU) counterparts.

**Methods:** In this prospective cross-sectional, group comparison study, the development of 41 HE and 40 HU infants (mean age = 8.4 months, SD = 2.1 months) from a low-income context was assessed. Caregivers were interviewed using a background interview and the Vineland Adaptive Behavior Scales, Third Edition (Vineland-3) to evaluate infants' communication, daily living, socialisation, and motor skills. Descriptive and inferential statistics were used.

**Results:** Based on the overall test scores, the majority of HE participants had age-appropriate development (90.2%; n=37). Some HE participants, however, presented with delays in the domains of communication (9.8%; n=4), daily living skills (2.4%; n=1), socialisation (19.5%; n=8), and motor development (7.3%; n=3). HU participants also demonstrated some domain-specific delays, thus delays were present in both groups. No statistically significant differences were found between the development of HE and HU participants.

**Conclusions:** Findings were reassuring and suggested that the development of HE participants were not statistically significantly different from HU counterparts. Developmental differences may, however, only emerge with age, therefore large-scale longitudinal research is recommended. It is suggested that the entire sample was vulnerable, highlighting the importance of developmental surveillance and early intervention in low-income contexts, irrespective of HIV and antiretroviral exposure status.

**Keywords:** HIV-exposed infants; developmental outcomes; low-income context; Vineland-3.

## KEY MESSAGES

- Effective HIV transmission prevention strategies have led to an expanding population of vulnerable HIV-exposed infants, although uncertainty remains regarding their developmental outcomes.
- The current study found no statistically significant differences between the developmental outcomes of HIV-exposed and HIV-unexposed infants during late infancy.
- Future large-scale longitudinal studies are required, as developmental differences may only emerge during later childhood.
- Developmental delays were identified in both groups of infants, suggesting that the entire sample may have been vulnerable.

## INTRODUCTION

Approximately 37.9 million people are living with Human Immunodeficiency Virus (HIV) worldwide, of which 20.3% reside in South Africa, a lower-middle-income country (LMIC) in sub-Saharan Africa [SSA] (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2019). More than 87% of South African pregnant women living with HIV access antiretroviral treatment (ART) to prevent mother-to-child transmission (MTCT) of HIV (UNAIDS, 2019). In SSA, prevention of mother-to-child transmission (PMTCT) programs and ART during and after pregnancy have led to a decrease in infant HIV infection rates and a growing population of vulnerable HIV-exposed (HE) infants, who are not necessarily infected with the virus (le Roux et al., 2018).

Prevention strategies, such as ART, improve maternal health and prevent infant HIV infection (UNAIDS, 2019), but there are conflicting findings regarding the effect of antiretroviral (ARV) exposure on infant development (Sirois et al., 2013). ARVs that cross the blood-brain barrier are a concern for early brain development (Ngoma et al., 2014), and it has been reported that ARV exposure could be associated with preterm birth and mitochondrial dysfunction, resulting in neurological and developmental problems (Coelho, Tricarico, Celsi, & Crovella, 2017). It is conversely suggested, however, that ARVs are safe to use during pregnancy and the perinatal period (Sirois et al., 2013), and that ante- and postpartum combination ARV exposure has no adverse effects on infant and child development (Boivin et al., 2019; Ngoma et al., 2014). Therefore, the impact of prolonged ARV exposure on the development of HE infants is not yet well established (Boivin et al., 2019).

The impact of HIV exposure on HE infants' development is also not yet clear. It is recognised that HE infants have better motor, cognitive, and language outcomes than HIV-infected (HI) infants (Whitehead, Potterton, & Coovadia, 2014), but there is a dearth of literature regarding the developmental outcomes of HE infants below 12 months when compared to their HIV-unexposed (HU) counterparts. The majority of available research focuses on the developmental outcomes of HE children older than 12 months of age (Boivin et al., 2019; Chaudhury et al., 2017; le Roux et al., 2018; Ngoma et al., 2014), possibly because developmental outcomes and delays are not easily recognised in infants and young children, although early identification leads to timeous intervention (Abdoola, Swanepoel, van der Linde, & Glascoe, 2019).

There are also inconsistent findings on the effect of HIV exposure on early development (Boivin et al., 2019; Chaudhury et al., 2017; le Roux et al., 2018; Ngoma et al., 2014; Sherr, Croome, Castaneda, & Bradshaw, 2014; Wedderburn et al., 2019). It has been suggested that HE children may have differences in cognitive, motor, and language development when compared to HU peers (le Roux et al., 2018; Sherr et al., 2014; Wedderburn et al., 2019). In contrast, other studies report that HE and HU children have no significant differences regarding motor development, cognition, and language (Boivin et al., 2019; Chaudhury et al., 2017; Ngoma et al., 2014). Consequently, there is still uncertainty about the developmental outcomes of HE infants during late infancy.

Apart from the possible biomedical impact of HIV and ARV exposure on infant development, the social environment in which HE infants grow up, may increase risks for developmental delay (Whitehead et al., 2014). HI parents typically experience morbidity, reduced productivity, and increased medical expenses, which place families at risk for poverty and lower socio-economic status, in turn affecting development (Abubakar, 2014). Maternal morbidity may also impair mother-child attachment and limit the provision of care and stimulation to infants, which are essential for optimal child development (le Doare, Bland, & Newell, 2012; Sherr, Skeen, Hensels, Tomlinson, & Macedo, 2016).

Biomedical and environmental factors place HE infants at risk for developmental delays (Abubakar, 2014). Inadequate knowledge regarding their development may hamper health professionals in identifying vulnerable HE infants timeously and implementing preventative early intervention services, before developmental delays are established. Early intervention can provide infants, families, and communities with developmental, educational, and economic benefits (South African Speech-Language-Hearing Association [SASLHA], 2017). The aim of this study was to determine the developmental outcomes of infants with HIV and ARV exposure in a low-income South African context, when compared to developmental outcomes of unexposed counterparts.

## **METHODS**

### **Setting**

Data were collected at a primary healthcare clinic in an urban settlement in South Africa. It is considered a low-income context, as a monthly household income of less than ZAR1600 (GBP83.73) is received by 40.1% of the population, and most residents have a low socio-economic status (Statistics South Africa, 2011). Thirty-nine per cent of homes are informal dwellings and only 35.9% of homes have piped water inside the dwelling (Statistics South Africa, 2011).

### **Participants**

Purposive sampling was used to recruit 81 infants, aged six to 12 months. Infants were included if caregivers were older than 18 years and were able to answer interview

questions in English. Infants with pre- and postnatal HIV and ARV exposure were included in the research group (RG), therefore their mothers were HIV-positive and used ARVs during pregnancy. Infants were included in the control group (CG) if they had exposure to neither HIV nor ARVs. Infants with congenital disorders and confirmed HIV-positive statuses were excluded.

## **Procedures**

This study received approval from the institutional review board and Gauteng Department of Health (783/2018; GP\_201812\_019). Data were collected prospectively for two months in this cross-sectional, group comparison study. Caregivers provided consent for themselves and their infants to participate. Developmental assessments were conducted by one speech-language pathologist in a private space during routine clinic visits. Subsequent to assessments, all caregivers received feedback and age-specific brochures from the “Learn the Signs. Act Early.” Program, to increase awareness and monitoring of developmental milestones (Centers for Disease Control and Prevention, 2019). Necessary referrals were made if concerns regarding development were identified.

## **Measures**

### Demographic characteristics

Caregivers were briefly interviewed to obtain demographic and background information. In addition, the infants’ medical records were consulted for relevant developmental, medical, and HIV-related information.

### Infant developmental outcomes

The Vineland Adaptive Behavior Scales, Third Edition (Vineland-3) Comprehensive Interview Form (Sparrow, Cicchetti, & Saulnier, 2016) was administered with caregivers. The Vineland-3 assesses the development of adaptive behaviour, which is described as daily functional skills required for personal and social sufficiency (Pepperdine & McCrimmon, 2018; Sparrow et al., 2016). It relates to the activity and participation aspects of the International Classification of Functioning, Disability and Health (ICF) framework (Gleason & Coster, 2012; World Health Organization [WHO],

2001). This measure evaluates developmental domains (and subdomains), namely communication (receptive and expressive language), daily living skills (personal skills), socialisation (interpersonal relationships and play skills), and motor skills [gross and fine motor skills] (Sparrow et al., 2016). The Vineland-3 is a standardised, norm-referenced tool that has high internal consistency, good to excellent test-retest and inter-rater reliability, as well as validity in terms of internal structure and content (Pepperdine & McCrimmon, 2018; Sparrow et al., 2016). The Vineland-3 was developed and normed in the United States (Sparrow et al., 2016), although its previous version has been used effectively with HE children in South Africa (Allen et al., 2014). This tool is commonly used in the diagnosis of a developmental delay (Sparrow et al., 2016).

### **Data Analysis**

The Vineland-3 test items are scored by means of a rating scale, including the scores 0 (never), 1 (sometimes), and 2 (usually); or in some cases 0 (no) and 2 (yes). These scores reflect the frequency to which participants perform certain behaviours without assistance or prompting (Pepperdine & McCrimmon, 2018). Raw scores are calculated and converted to standard scores for domains and scale scores for subdomains. Three of the four domain standard scores, namely communication, daily living skills, and socialisation domain standard scores are used to compute an overall test score, the Adaptive Behaviour Composite (ABC). The ABC and domain standard scores have a mean of 100 and a standard deviation (SD) of 15, whereas the subdomain scale scores have a mean of 15 and a SD of three (Sparrow et al., 2016). Scores of one SD or more below the normative means are interpreted as a developmental delay (Sparrow et al., 2016). Therefore, ABC and domain standard scores of  $\leq 85$  and subdomain scale scores of  $\leq 12$  were interpreted as delayed.

Data were analysed using the Statistical Package for the Social Sciences (SPSS) version 25. Descriptive and inferential statistics were used to determine statistically significant differences between the RG and CG. In order to test for normality, the Kolmogorov-Smirnov or the Shapiro-Wilk test statistics may be used. These two tests are the same in that they are both testing for normality, however, the Shapiro-Wilk test is known to have more power in detecting differences from normality (Field, 2018). Since the majority of the  $p$ -values for the Shapiro-Wilk test, for the different variables



under consideration, were less than 0.05, the data are not normally distributed and, accordingly, non-parametric tests were used. Differences in participant characteristics and Vineland-3 results were determined using the Mann-Whitney U and Fisher's Exact tests. Spearman correlations were used to determine associations. All statistical tests were two-sided and  $p$ -values of less than 0.05 were considered significant.

## RESULTS

A sample of 81 participants (mean age = 8.4 months, SD = 2.1 months) was recruited and divided into a RG of 41 HE participants and a CG of 40 HU participants. The software program G\*Power version 3.1.9.4 was used to compute the minimum sample size requirement and the achieved power. The minimum sample size required to obtain a power of at least 0.95 is equal to 69. In this study, a sample size of 81 produced an achieved power of 0.977. Home language distribution was Northern Sotho (43.2%), Tsonga (11.1%), Setswana (9.9%), IsiZulu (8.6%), Shona (6.2%), Ndebele (4.9%), Venda (3.7%), Xhosa (3.7%), Southern Sotho (3.7%), SiSwati (2.5%), and Chichewa (2.5%). All caregivers reported English as an additional language and were therefore able to answer interview questions in English.

There were no statistically significant differences between the RG and CG in terms of age ( $p=0.622$ ), gender ( $p=0.176$ ), birth weight ( $p=0.242$ ), gestational age ( $p=0.258$ ), and feeding type ( $p=0.107$ ) [Table 3.1]. There were also no significant differences between the groups for maternal education level ( $p=0.872$ ) or substance abuse during pregnancy ( $p=0.359$ ;  $p=0.675$ ). The mean age of the RG mothers was significantly higher than that of the CG mothers ( $p=0.026$ ).

All participants ( $n=81$ ) were accompanied by their primary caregivers, of which 77 (95.1%) were participants' mothers, one (1.2%) was a father, and three (3.7%) were participants' family members such as grandmothers, who were legal guardians. In the RG, 24 (58.5%) mothers initiated lifelong ART before pregnancy and 17 (41.5%) initiated lifelong ART during pregnancy. Thirty-nine (95.1%) RG mothers were using ARVs at the time of data collection, while two (4.9%) RG mothers stopped using ARVs after pregnancy.



**Table 3.1: Demographic characteristics of participants (n=81)**

Characteristics		Research Group: HE participants (n=41)	Control Group: HU participants (n=40)	p-value <sup>a</sup>
<b>Infant age (months), mean (SD)</b>		8.3 (2.1)	8.5 (2.0)	0.622
<b>Infant gender</b>	Male	13 (31.7%)	19 (47.5%)	0.176
	Female	28 (68.3%)	21 (52.5%)	
<b>Birth weight (grams), mean (SD)</b>		2962.6 (432.5)	3060.1 (468.6)	0.242
<b>Gestational age*</b>	Full term (≥38 weeks)	39 (95.1%)	34 (87.2%)	0.258
	Preterm (≤37 weeks)	2 (4.9%)	5 (12.8%)	
<b>Infant feeding during first six months of life</b>	Exclusive breastfeeding	26 (63.4%)	25 (62.5%)	0.107
	Exclusive formula feeding	6 (14.6%)	1 (2.5%)	
	Breast- and formula feeding	9 (22.0%)	14 (35.0%)	
<b>Maternal age (years), mean (SD)</b>		31.2 (5.0)	28.9 (6.0)	0.026**
<b>Maternal education level</b>	Less than Grade 8	1 (2.4%)	1 (2.5%)	0.872
	Grade 9-10	6 (14.6%)	5 (12.5%)	
	Grade 11-12	28 (68.3%)	25 (62.5%)	
	Tertiary education	6 (14.6%)	9 (22.5%)	
<b>Maternal substance abuse during pregnancy</b>	Smoking	4 (9.8%)	1 (2.5%)	0.359
	Alcohol or drugs	2 (4.9%)	3 (7.5%)	0.675

<sup>a</sup> p-values of the Mann-Whitney U test for the continuous variables and the p-values of the Fisher's Exact test for the frequencies (i.e. the counts)

\* Missing value in control group, due to non-disclosure of information (n=1)

\*\* Indicates a statistically significant difference between groups ( $p < 0.05$ )

HE: Human Immunodeficiency Virus (HIV)-exposed; HU: HIV-unexposed; SD: standard deviation

The majority of participants from the RG (90.2%, n=37) presented with age-appropriate development, based on the ABC overall test scores. The ABC scores of four (9.8%) RG participants and seven (17.5%) CG participants were delayed. It is important to note that the ABC score is computed using the communication, daily living skills, and socialisation domain standard scores, but not the motor domain standard score. Motor delays were identified in three (7.3%) RG and two (5%) CG participants. No significant differences regarding the amount of delays were found between the groups (Table 3.2). In the total sample (n=81), the most delays occurred within the socialisation domain (18.5%; n=15) and its relating interpersonal relationships subdomain (25.9%; n=21). Conversely, the least delays occurred within the motor domain (6.2%, n=5) and its relating gross motor subdomain (7.4%, n=6).

Since the maternal age of the RG and CG differed significantly ( $p=0.026$ ), correlations were run separately for the two groups, to determine whether associations between maternal age and infant development were present. For the RG, there were no significant correlations between maternal age and the communication ( $p=0.474$ ), daily living skills ( $p=0.536$ ), socialisation ( $p=0.088$ ), and motor ( $p=0.881$ ) domain scores; the

ABC score ( $p=0.126$ ); or any subdomain scores. Interestingly, the maternal age of the CG correlated significantly with the communication ( $p=0.007$ ) and socialisation ( $p=0.020$ ) domain scores; the ABC score ( $p=0.017$ ); as well as the gross motor subdomain score ( $p=0.022$ ). All correlations were positive, therefore as maternal age increased, the developmental scores improved. These associations were, however, not enough to result in between-group differences for developmental outcome comparisons.

**Table 3.2: Comparison of domain- and subdomain-specific delays (n=81)**

Domains and subdomains	Amount of delays			$p$ -value <sup>a</sup>
	Total sample (n=81)	Research Group: HE participants (n=41)	Control Group: HU participants (n=40)	
<b>Communication</b>	11 (13.6%)	4 (9.8%)	7 (17.5%)	0.387
<b>Receptive language</b>	14 (17.3%)	4 (9.8%)	10 (25.0%)	0.080
<b>Expressive language</b>	11 (13.6%)	7 (17.1%)	4 (10.0%)	0.519
<b>Daily living skills</b>	6 (7.4%)	1 (2.4%)	5 (12.5%)	0.210
<b>Personal</b>	9 (11.1%)	4 (9.8%)	5 (12.5%)	0.775
<b>Socialisation</b>	15 (18.5%)	8 (19.5%)	7 (17.5%)	1.000
<b>Interpersonal relationships</b>	21 (25.9%)	12 (29.3%)	9 (22.5%)	0.614
<b>Play</b>	8 (9.9%)	4 (9.8%)	4 (10.0%)	0.318
<b>ABC overall test score</b>	11 (13.6%)	4 (9.8%)	7 (17.5%)	0.670
<b>Motor</b>	5 (6.2%)	3 (7.3%)	2 (5.0%)	1.000
<b>Gross motor</b>	6 (7.4%)	5 (12.2%)	1 (2.5%)	0.138
<b>Fine motor</b>	15 (18.5%)	10 (24.4%)	5 (12.5%)	0.205

<sup>a</sup> Fisher's Exact test applied

HE: Human Immunodeficiency Virus (HIV)-exposed; HU: HIV-unexposed; ABC: Adaptive Behaviour Composite

## DISCUSSION

No statistically significant between-group differences imply that the RG had similar developmental outcomes to that of the CG. The current study concurs with recent research that reported no developmental differences between HE and HU infants and children (Boivin et al., 2019; Chaudhury et al., 2017; Ngoma et al., 2014), contrasting to other studies that have found differences regarding their development. (le Roux et al., 2018; Sherr et al., 2014; Wedderburn et al., 2019). This finding is reassuring, considering the growing population of HE infants in SSA (le Roux et al., 2018), increased ART provision to pregnant women, and prolonged ARV exposure for HE infants (Ngoma et al., 2014). Resilience and the ability to overcome the adverse effects associated with HIV may be attributed to maternal coping strategies, positive parenting, and a good mother-child relationship (Allen et al., 2014). The findings are,

however, based on a small, young sample and may not be generalised to other communities. Large-scale longitudinal studies are warranted, as it is proposed that developmental differences may be subtle in early life and may only emerge in later childhood (Chaudhury et al., 2017; Ngoma et al., 2014).

The overall prevalence of delays in the total sample (13.6%, n=11) is lower than reported cognitive and socioemotional delays in LMICs [35.8%] (McCoy et al., 2016), but higher than estimates for developmental delays in the United States [4.55%] (Zablotsky, Black, & Blumberg, 2017). Delays that occurred in both the RG and CG may suggest that the entire sample was a vulnerable, at-risk group of infants. A possible explanation for this finding is that infants and children from LMICs, like the included population, face multiple risks that can potentially hinder development (Britto et al., 2017). These risks may include poverty, poor health, malnutrition, violence, alcohol and other substance abuse, as well as insufficient learning and stimulation opportunities (Samuels, Slemming, & Balton, 2012). The study did not aim to specifically investigate environmental and socioeconomic factors that may be associated with developmental outcomes, therefore further research is necessary.

The finding that most delays were identified in the socialisation domain, should be interpreted with caution, as the Vineland-3 was not normed and standardised for the South African population (Sparrow et al., 2016). The tool might not be sensitive to possible cultural differences, as socialisation and interactions vary across cultures (Luke & Kale, 1997). Cultural adaptations of standardised assessment instruments, such as the Vineland-3, should thus be considered in future research.

The least delays were identified in the motor domain and its relating gross motor subdomain. Children from low-income South African contexts have been shown to have high gross motor proficiency, perhaps due to high levels of physical activity and outdoor unstructured play (Draper, Achmat, Forbes, & Lambert, 2012).

Not all participants presented with delays, however, it cannot be overlooked that some domain- (communication: 13.6%; daily living skills: 7.4%; socialisation: 18.5%; and motor: 6.2%) and subdomain-specific delays (receptive language: 17.3%; gross motor: 7.4%) were identified in this sample. Early delays may increase with age (Chaudhury et al., 2017) and possibly impact later academic and vocational success (Abdoola et

al., 2019). Delays should be addressed early in life to optimise neural plasticity, so that the negative effects of risks and delays can be ameliorated (Slemming & Saloojee, 2013). Early developmental screening can be employed to facilitate early detection and intervention for developmental delays in vulnerable children (Abdoola et al., 2019). Preventative and timeous intervention enhances early developmentally-sensitive periods and minimises long-term impairments, providing infants, families, and communities with developmental, educational, and economic benefits (Abdoola et al., 2019; SASLHA, 2017). It is therefore recommended that health professionals prioritise developmental monitoring and early identification of delays in vulnerable infants from low-income contexts, irrespective of HIV and ARV exposure.

The findings, although based on a small sample, are valuable for early intervention clinicians. The two groups were comparable in terms of demographic characteristics, strengthening the findings. Another strength was the use of a valid and reliable assessment tool which is commonly used for diagnosing developmental delays (Sparrow et al., 2016). Large-scale longitudinal studies will be valuable.

## **CONCLUSIONS**

The current study contributes to the pool of research suggesting that the developmental outcomes of HE infants during late infancy do not differ significantly from their HU peers. Developmental differences may only emerge with increasing age (Chaudhury et al., 2017), and therefore continued longitudinal research efforts on the developmental needs of the HE population is recommended. In addition, delays were present in both groups, suggesting that the entire sample was a vulnerable group requiring developmental monitoring. The study highlights the importance of developmental surveillance and early intervention for all infants in low-income contexts, irrespective of their HIV and ARV exposure status.

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## **4. IMPLICATIONS AND CONCLUSION**

### **4.1. Chapter aim and outline**

This chapter provides an overview of the main findings, as well as the theoretical and clinical implications of the study findings. A critical evaluation of the study, including the strengths and weaknesses, is provided. The chapter ends with recommendations for future research and a conclusion.

### **4.2. Summary of the main findings**

The aim of the present study was to determine the developmental outcomes of infants with HIV and ARV exposure (RG) in a low-income South African context, when compared to their unexposed counterparts (CG). The majority of the RG participants demonstrated age-appropriate development according to the Vineland-3. Some overall and domain-specific delays were present in the RG, as well as in the CG, however no statistically significant between-group differences were found. This finding contributes to the body of research evidence suggesting that there are no significant differences between the developmental outcomes of HE and HU infants and children (Boivin et al., 2019; Chaudhury et al., 2017; le Roux et al., 2016; Ngoma et al., 2014; Springer et al., 2018).

### **4.3. Theoretical and clinical implications**

The findings of the current study are reassuring, since they revealed that the RG had similar developmental outcomes compared to the CG during late infancy. The findings are consistent with literature reporting no developmental differences between HE and HU infants and children (Boivin et al., 2019; Chaudhury et al., 2017; le Roux et al., 2016; Ngoma et al., 2014; Springer et al., 2018). Recent South African and Kenyan longitudinal studies have also found no significant developmental differences between HE and HU infants, however, at follow-up assessment, HE toddlers demonstrated poorer language development than their HU peers (Alcock, Abubakar, Newton, & Holding, 2016; Wedderburn et al., 2019). Developmental differences may, therefore, be subtle in early life and only emerge with increasing age (Chaudhury et al., 2017). This could be due to the cumulative effect of development becoming more complex and longer exposure to risk factors (Alcock et al., 2016; McHenry et al., 2018). It is also

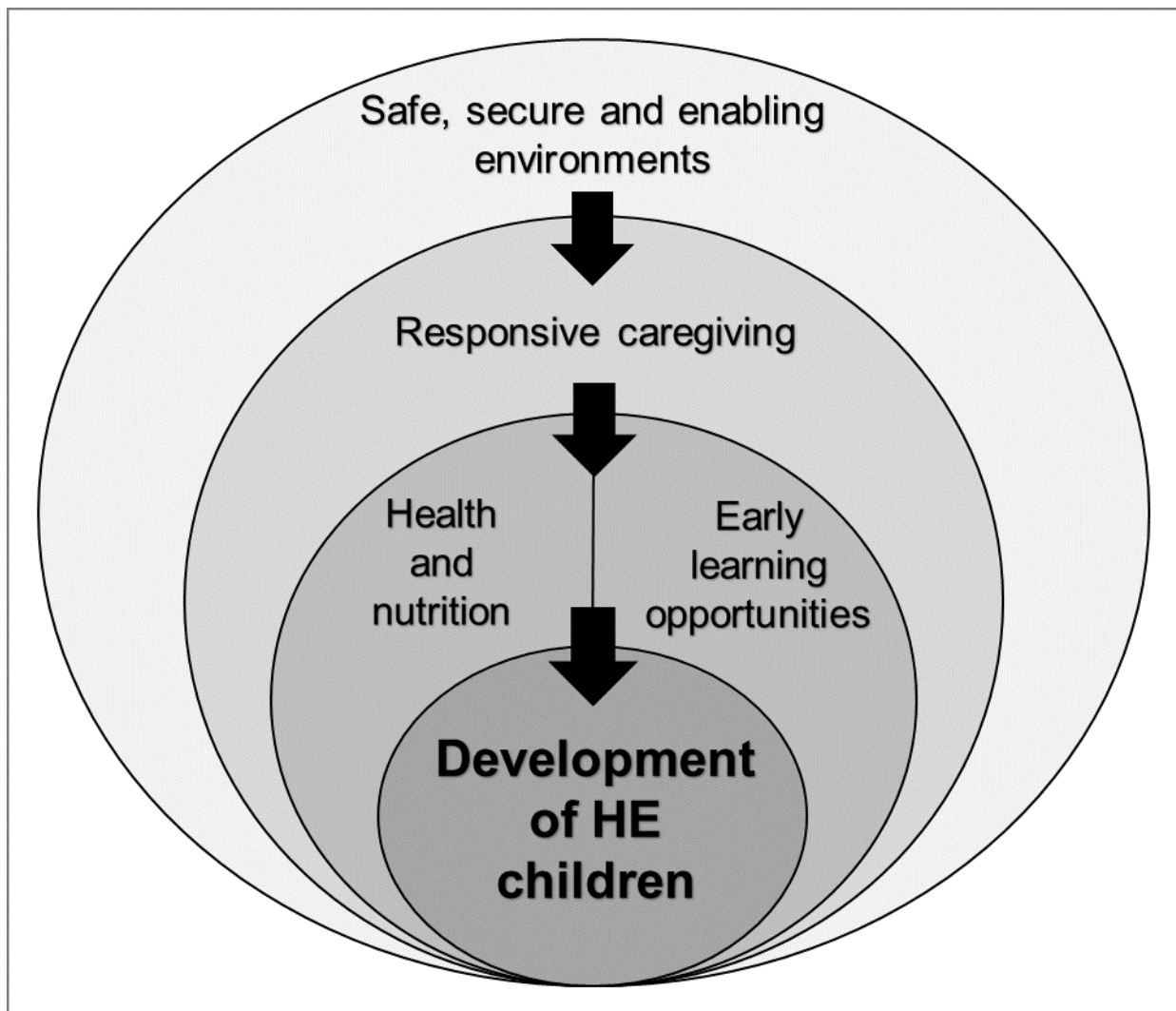
possible that developmental delays may not be evident during infancy, as it is difficult to test and determine developmental outcomes and delays in infants and young children (Abdoola et al., 2019; Glascoe, 2000). The development of the RG was not significantly different from the CG during late infancy, however, it does not exclude the possibility of delays emerging over time, or that delays were under-detected at such a young age. Undergraduate curricula of future healthcare and early intervention professionals should ideally include this perspective in order to highlight the need for continued developmental monitoring of the HE infant population. The current study also reiterates that large-scale longitudinal research efforts are necessary to track long-term developmental progression of HIV- and ARV-exposed children.

Even though no between-group differences were found, some overall and domain-specific delays were identified in both the RG and CG of the study. This implies that the entire sample may have been a vulnerable group, at risk for developmental delays. A possible explanation is that infants and toddlers from LMICs, especially low-income communities, face multiple risks that can potentially hinder development (Britto et al., 2017; Rademeyer & Jacklin, 2013). In LMICs, an estimated 43% of children under five years of age are at risk for not reaching their developmental potential, due to poverty and stunting (Black et al., 2017). More specifically, SSA has the highest prevalence (66%) of children at risk for suboptimal development (Black et al., 2017). It is, however, argued that the burden of poor development in LMICs, such as South Africa, may be underestimated (Richter et al., 2017). Routine developmental monitoring during the first years of life is therefore vital, not only in high priority groups, such as infants exposed to HIV and ARVs, but also in the general infant and toddler population from low-income contexts.

The findings of the present study are in agreement with literature suggesting that children from low-income settings, including older HE children, are predisposed to developmental delays (Alcock et al., 2016; Black et al., 2017; Chaudhury et al., 2017; Wedderburn et al., 2019). HIV- and ARV-exposed children may be at an even greater risk for poor development, due to the added burden of living in an HIV-affected household within a low-income community (Abubakar, 2014; Whitehead et al., 2014). Since early child development lays the foundation for educational success and future economic productivity (Wedderburn et al., 2019), healthcare and early intervention

professionals should prioritise developmental surveillance and preventative early intervention for vulnerable HE children. SLTs should be particularly involved in this population, as they provide family-centred early intervention services to young children who have, or are at risk for developmental delays (ASHA, 2008; SASLHA, 2017). In addition, most developmental delays in the current study occurred in the domains of socialisation and communication. Social communication skills positively affect cognitive and social-emotional development, while language proficiency is a key predictor for literacy development and educational achievement (Zauche, Thul, Mahoney, & Stapel-Wax, 2016). Considering the importance of communication development, SLTs should take the lead with protecting, monitoring and promoting the development of HE children from low-income South African contexts.

For children to develop to their potential, they require nurturing care (WHO et al., 2018) [Figure 4.1]. Nurturing care is defined as conditions that enable caregivers to provide their children with protection from adversities, responsive and emotionally-supportive care, adequate healthcare and nutrition, as well as early learning opportunities (WHO et al., 2018). HI caregivers may, however, have decreased capacity to provide nurturing care to their HE children, as their family environment is often characterised by morbidity, poverty, violence, depression, as well as suboptimal caretaking, stimulation, and parent-child interactions (Abubakar, 2014; Evans et al., 2016; Filteau, 2009; le Doare et al., 2012; Sherr et al., 2016). Interventions, services, and policies should thus focus on creating safe and supportive environments that enable HI caregivers to provide responsive care to their children (Jamieson & Richter, 2017). Responsive caregiving will consequently allow HI caregivers to be sensitive towards their children's health and nutritional needs, as well as their needs for social engagement, emotional regulation and cognitive stimulation, which forms the basis for early learning and development (WHO et al., 2018).



**Figure 4.1:** Components of nurturing care contributing to HE children’s development (WHO et al., 2018)

Positive parenting, caregiver coping strategies, and good parent-child relationships lead to resilience in HE children, equipping them to overcome adverse effects associated with HIV (Allen et al., 2014). SLTs should therefore raise awareness about the importance of nurturing care, and coach HI caregivers to foster responsive caregiver-child interactions and attachment (ASHA, 2008; SASLHA, 2017). Affectionate, sensitive, and responsive caregiving will facilitate early learning and stimulation opportunities for HE children, including communication and play activities, use of home-made toys, shared book-reading, story-telling, day-care, and pre-primary education (WHO et al., 2018). These experiences can ultimately improve the HE child’s ability to learn and develop optimally (WHO et al., 2018). In addition to awareness and caregiver coaching initiatives, SLTs should collaborate with early intervention team

members, such as nurses and occupational therapists, to prioritise early developmental screening in the PHC context, as it will facilitate early detection and intervention for possible developmental delays in the HE population (Abdoola et al., 2019). Preventative and timeous intervention will enhance early developmentally-sensitive periods and minimise long-term impairments, providing HE children, their families, and communities with developmental, educational, and economic benefits (Abdoola et al., 2019; SASLHA, 2017).

#### **4.4. Critical evaluation of study**

##### **4.4.1. Strengths of the study**

- The developmental outcomes of the RG were compared to that of a CG from the same community. Previous studies investigating the development of HE infants have been limited by a lack of comparison to HU counterparts (Chaudhury et al., 2017), therefore including HU infants as controls in the current study, strengthened the findings.
- The RG and CG were comparable in terms of age, gender, birth weight, gestational age, and feeding type. The similarity of the groups' demographic characteristics has limited confounding variables that could influence development, improving the reliability of the findings.
- The Vineland-3 is a valid and reliable assessment tool, with high specificity for diagnosing developmental delays (Pepperdine & McCrimmon, 2018; Salomon-Estebanez et al., 2017). This ensured accurate measurement of participants' developmental outcomes and identification of possible delays. Furthermore, all the developmental assessments were conducted by one person, therefore consistency in data collection was achieved.

##### **4.4.2. Weaknesses of the study**

- Due to a limited timeframe of data collection, the current study had a small sample size, which reduced the generalisability of the findings to other communities. A smaller sample is, however, considered adequate when characteristics of the participants are more similar (Leedy & Ormrod, 2015; Maxwell & Satake, 2006), which was the case in the current study, where the

two groups of participants had similar demographic characteristics. In addition, the statistical requirements for minimum sample size and power were met.

- The current study added to the knowledge base of the developmental outcomes of HE infants, but it is possible that delays were under-detected in this young cohort, due to difficulty determining delays in infants (Abdoola et al., 2019; Glascoe, 2000) and the suggestion that developmental differences may only emerge with increasing age (Alcock et al., 2016; Chaudhury et al., 2017). Therefore, due to the study's cross-sectional nature and lack of follow-up assessments of infants at older ages, the results may not be applicable to older HE children.
- All caregivers were able to answer interview questions in English, however no caregiver reported English as their home language, which may have influenced the ability of caregivers to accurately provide developmental information.
- The use of a caregiver-reported assessment tool may have resulted in reporting bias, as caregivers might have been unaware of subtle developmental difficulties their young infants could have experienced. The researcher observed and elicited infant behaviour where possible, however, it was not possible to elicit all test items included in the Vineland-3.

#### **4.5. Recommendations for future research**

- Developmental differences may be subtle or difficult to recognise during infancy, thus it may only become apparent during later childhood (Abdoola et al., 2019; Chaudhury et al., 2017). Large-scale, longitudinal research studies are, therefore, recommended to confirm and improve generalisability of the findings. This will additionally enable researchers to determine whether delays truly emerge with age in the HE population, which will motivate the importance of developmental surveillance.
- The Vineland-3 has not been standardised for the South African population, even though it has been used effectively with HE children in South Africa (Allen et al., 2014). Cultural adaptations of standardised assessment instruments, such as the Vineland-3, as well as assessment in participants' home languages should be considered in future research.



- It is recommended that future research considers using a clinician-administered assessment instrument in conjunction with a caregiver-reported tool. This will limit reporting bias and provide the researcher with a holistic view of the participants' development, and in turn improve the reliability of the findings.
- Not only biomedical factors such as HIV and ARV exposure, but also the social environment in which infants grow up, may impact HE infants' development (Abubakar, 2014). Future research should therefore ideally include the assessment of environmental and socioeconomic factors of participants, to determine to what extent environmental factors have an influence on HE children's development.

#### **4.6. Conclusion**

The current study attempted to address the limited and conflicting literature findings regarding six-to 12-month-old HE infants' development, and revealed that HE infants had similar developmental outcomes to HU counterparts during late infancy. This finding is encouraging, however large-scale longitudinal studies are required to confirm the findings, as developmental differences may only become recognisable in later childhood. In addition, the entire sample was deemed vulnerable, as delays were identified in both groups. The findings are valuable for early interventionists, including SLTs, as it not only improves their knowledge about the developmental outcomes of HE infants, but also highlights the importance of developmental surveillance and timeous intervention for all infants and young children from low-income contexts, irrespective of HIV and ARV exposure status. Providing nurturing care to the HE population may promote their resilience and developmental outcomes.

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## **APPENDIX A: Faculty of Health Sciences ethical clearance certificate**



Faculty of Health Sciences

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 03/14/2020.

28 February 2019

**Approval Certificate  
New Application**

**Ethics Reference No.: 783/2018**

**Title: Developmental outcomes of HIV-exposed infants in a resource limited South African context**

Dear Miss CC van Eck

The **New Application** as supported by documents received between 2019-02-20 and 2019-02-27 for your research, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 2019-02-27.

Please note the following about your ethics approval:

- Ethics Approval is valid for 1 year and needs to be renewed annually by 2020-02-29.
- Please remember to use your protocol number (783/2018 ) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, monitor the conduct of your research, or suspend or withdraw ethics approval.

**Ethics approval is subject to the following:**

- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

**Yours sincerely**



**Dr R Sommers**

MBChB MMed (Int) MPharmMed PhD

**Deputy Chairperson** of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

*The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health)*

Research Ethics Committee  
Room 4-60, Level 4, Tswelopele Building  
University of Pretoria, Private Bag X323  
Arcadia 0007, South Africa  
Tel +27 (0)12 356 3084  
Email [deepeka.behari@up.ac.za](mailto:deepeka.behari@up.ac.za)  
[www.up.ac.za](http://www.up.ac.za)

**Fakulteit Gesondheidswetenskappe  
Lefapha la Disaense tša Maphelo**



## **APPENDIX B: Tshwane Research Committee clearance certificate**



**GAUTENG PROVINCE**  
HEALTH  
REPUBLIC OF SOUTH AFRICA

Enquiries: Mpho Moshime-Shabagu  
Tel: +27 12 451 9036  
E-mail: Mpho.Moshime@gauteng.gov.za

**TSHWANE RESEARCH COMMITTEE: CLEARANCE CERTIFICATE**

DATE ISSUED: 28/02/2019  
PROJECT NUMBER: 11/2019  
NHRD REFERENCE NUMBER: GP\_201812\_019

TOPIC: Developmental Outcomes of HIV-exposed infants in a resource limited South African context

Name of the Researcher: Carmen van Eck  
Name of the Supervisors: Mrs. E Krüger  
Dr. J van der Linde  
Mrs. R Eccles  
Facility: Stanza BopapeCHC  
Name of the Department: University of Pretoria

**NB: THIS OFFICE REQUEST A FULL REPORT ON THE OUTCOME OF THE RESEARCH DONE AND**


**NOTE THAT RESUBMISSION OF THE PROTOCOL BY RESEARCHER(S) IS REQUIRED IF THERE IS DEPARTURE FROM THE PROTOCOL PROCEDURES AS APPROVED BY THE COMMITTEE.**

DECISION OF THE COMMITTEE: APPROVED

  
.....

Mr. Peter Silwimba  
Deputy Chairperson: Tshwane Research Committee

Date: 28/02/19

  
.....

Mr. Mothomone Pitsi  
Chief Director: Tshwane District Health

Date: 2019.03.01

## **APPENDIX C: PHC permission letter**

30 January 2019  
Attention: Mr. Otsheleng  
Executive Director

[sammy.otsheleng@gauteng.gov.za](mailto:sammy.otsheleng@gauteng.gov.za)

Dear Mr. Otsheleng

**Request to collaborate with Stanza Bopape Primary Health Clinic in a research study**

I am Carmen van Eck, a Master's student from the Department of Speech-Language Pathology and Audiology at the University of Pretoria. I will be conducting a research study, with the title being "*Developmental outcomes of HIV-exposed infants in a resource limited South African context*". The main objective of my study is to determine the developmental outcomes of infants exposed to HIV and ART, when compared with infants who have not been exposed to HIV or ART.

I would like to request permission to conduct an assessment with infants aged six to 12 months at the Baby Wellness Clinic of the Stanza Bopape Primary Health Clinic in Mamelodi. I would also like to request a private and quiet room to conduct the assessment, to maintain confidentiality of the participants' information.

**Design and procedure:** All infants aged six to 12 months will be included in the study. The developmental outcomes of six to 12-month old HIV-exposed infants will be compared to that of HIV-unexposed infants. Parents/legal guardians of the participants will be approached by the researchers at the Baby Wellness Clinic at the Stanza Bopape clinic. The researcher will approach all parents/legal guardians with infants in the six to 12-month age range, thus no one will be asked to reveal their HIV status to the researcher before giving informed consent. Parents/legal guardians will be provided with information regarding the study. Should they provide consent for their baby and themselves to participate in the study, the assessment process will ensue. The researcher will conduct an informal interview with the parents/legal guardians and the infant's medical file and Road to Health Booklet will be consulted for further information. Developmental assessment tools will be used to assess the infants' development through further interviews with the parents/legal guardians. The entire procedure will take approximately 45 minutes to 1 hour per infant.

**Ethical considerations:** Ethical clearance has been obtained from the Research Ethics Committees of the Department of Speech-Language Pathology and Audiology and Faculty of Health Sciences at the University of Pretoria, as well as the Department of Health Tshwane Research Ethics Committee. The researcher will treat all participants with respect, by being sensitive towards their culture, socioeconomic position and health status. Participants' and the clinic's information will be kept strictly confidential. Data that may be reported in research reports and journal articles in accredited journals will not include any identifying information, as each participant will be represented by a number. The data will be securely stored, electronically and on hardcopy, for a minimum of 15 years at the University of Pretoria.

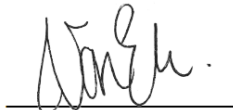
**Confidentiality:** Information that may identify participants will remain confidential. I intend to protect the personal identity of the participants by assigning each individual a numeric code.

**Risk and benefits:** The assessment will not cause any physical discomfort or pain to the participants of the study. The clinic staff might experience inconvenience, as the researcher will require a private room for the assessment and will consult the medical files of the participants. However, I will liaise with the staff to minimise any disruptions. The benefits involve parents receiving feedback on their infants' development and early identification of developmental delays. If a delay is present, the family will be referred to Stanza Bopape clinic to receive appropriate specialist, medical and developmental therapeutic services.


**Ethical approval:** This study has received approval from the Research Ethics Committee of the Department of Speech-Language Pathology and Audiology, University of Pretoria, telephone number 012 420 2916. The researcher has also obtained permission from the Research Ethics Committee of the Faculty of Health Sciences, University of Pretoria, telephone numbers 012 356 3084 / 012 356 3085. This study has been guided by the ethical principles described in the Declaration of Helsinki.

Please feel free to contact me or my research supervisors should you have any queries or require further information. Thank you in advance.


Yours sincerely,



C. van Eck  
Researcher  
Tel: 072 443 2122  
Email: [carmen.vaneck@gmail.com](mailto:carmen.vaneck@gmail.com)



Mrs. E. Krüger  
Research Supervisor  
Tel: 012 420 4910  
Email: [esedra.kruger@up.ac.za](mailto:esedra.kruger@up.ac.za)



Mrs. R. Eccles  
Research Supervisor  
Tel: 012 420 2814  
Email: [renata.mosca@up.ac.za](mailto:renata.mosca@up.ac.za)



Dr J. van der Linde  
Acting Head: Department of Speech-language Pathology and Audiology  
Tel: 012 420 2948  
Email: [jeannie.vanderlinde@up.ac.za](mailto:jeannie.vanderlinde@up.ac.za)

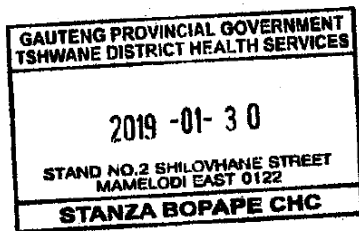
**Declaration of permission from the Facility manager at Stanza Bopape Clinic**

Herewith, I, M.S. Otsheleng, Facility manager at Stanza Bopape Clinic in Mamelodi, grant permission to Carmen van Eck to approach parents/caregivers of infants aged 6-12 months visiting the Baby Wellness Centre for her study titled: **Developmental outcomes of HIV-exposed infants in a resource limited South African context**. She is granted permission to use the facilities to conduct a private interview with the participants and to consult their medical files. I have been informed regarding the type, procedure, risks and benefits of the research studies.

I am fully aware that the data obtained will be used solely for the purpose of present and future research and may be presented in the format of a report, scientific article, lecture, conference or case study. It was explained to me that the participants' identities will at all times be kept confidential.

M.S. Otsheleng  
Mr. Otsheleng  
FACILITY MANAGER: STANZA BOPAPE CLINIC

30. 01. 2019  
Date





**Annexure 1**

**Declaration of intent from the clinic manager or hospital CEO**

I give preliminary permission to Carmen Cornelia van Eck to do her research on

The Developmental Outcomes of HIV-exposed infants in a resource limited South African context

in \_\_\_\_\_ (name of clinic) or

*Stanza Bepape*

\_\_\_\_\_ (name of CHC ) or

\_\_\_\_\_ (name of hospital).

I know that the final approval will be from the Tshwane Regional Research Ethics Committee and that this is only to indicate that the clinic/hospital is willing to assist.

Other comments or conditions prescribed by the clinic or CHC manager or hospital CEO:

\_\_\_\_\_  
Signature  
Clinic Manager/CHC Manager/CEO

*20.01.2019*  
\_\_\_\_\_  
Date

## **APPENDIX D: Parent/legal guardian information leaflet and informed consent**



March/April 2019

Dear Parent/legal guardian

## PARENT/LEGAL GUARDIAN INFORMATION LEAFLET AND INFORMED CONSENT

### Title of research study:

**Developmental outcomes of HIV-exposed infants in a resource limited South African context**  
(Carmen van Eck; 072 443 2122)

### INTRODUCTION

I invite you to participate in a research project. This information leaflet will help you to decide if you want to participate. Before you agree to take part, you should fully understand what is involved. If you have any questions that this leaflet does not fully explain, please ask the researcher (Carmen van Eck).

### THE NATURE AND PURPOSE OF THIS STUDY

All babies of six to 12 months at this clinic are being asked to participate in this project and that is why I have approached you. Today, many babies that are born have had contact with HIV and antiretroviral treatment (ARTs). The aim of this project is to evaluate the development of babies who have had contact with HIV and ARTs, compared to babies who have not had contact with it. No matter what your or your baby's HIV status is, you as a parent/legal guardian are a very important source of information on how your baby is growing and developing.

### EXPLANATION OF PROCEDURES TO BE FOLLOWED

If you agree to participate in the research project and give informed consent, you will be interviewed by the researcher (Carmen). I will use a private room to speak with you and you can bring your baby with you. You will firstly be asked for personal information, such as your age and contact information. I will also ask you questions about your pregnancy and your baby's birth and health. I will then read your baby's medical file and *Road to Health* booklet for more information. Lastly, I will ask you questions about your baby's learning, talking and movement, by using a cell phone application and interview form. Your information will be kept private and the only person who will know this information is the researcher (Carmen). The interview procedures will not cause any discomfort or pain to you or your baby.

### RISK AND DISCOMFORT INVOLVED

There are no risks for you or your baby in participating in the study. I will see you when you come for your clinic visit, so you will not have extra travel costs. The interview procedures will take about 45 minutes to one hour of your time.

### POSSIBLE BENEFITS OF THIS STUDY

You will benefit directly because at the end of the study you will receive feedback on your baby's development. If I am concerned, I will discuss recommendations with you. The results of the project will also help me to better understand and help babies who have had contact with HIV and ARTs in the future.

### WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

You and your baby's participation in this project is entirely voluntary. You can refuse to participate or stop at any time during the project without giving any reason. Your leaving will not affect you or your baby's access to services at the clinic in any way.

### HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study has received approval from the Research Ethics Committee of the Department of Speech-Language Pathology and Audiology, University of Pretoria, telephone number 012 420 2916. The

researcher has also received permission from the Research Ethics Committee of the Faculty of Health Sciences, University of Pretoria, telephone numbers 012 356 3084 / 012 356 3085. This study has been guided by the ethical principles described in the Declaration of Helsinki, which tells health care professionals how to treat participants in research studies.

#### COMPENSATION

Your participation is voluntary. The study will occur during one of your clinic visits, so you will not have extra travel costs. You will not be paid to take part in the study.

#### CONFIDENTIALITY

All information that you give will be kept strictly confidential and private. Once I have looked at the information, no one will be able to identify you or your baby. Parents/legal guardians will be given a code so that no identifying information is linked to the data. Research reports and articles in scientific journals will not include any information that may identify you or your baby. Data will be securely stored on paper and compact disc (CD) for at least 15 years at the Department of Speech-Language Therapy and Audiology, University of Pretoria.

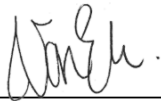
#### INFORMATION AND CONTACT PERSON

The contact person for the project is Carmen van Eck. If you have any questions about the project, please contact me at the following telephone number: 072 443 2122. You can also contact me through email at [carmen.vaneck@gmail.com](mailto:carmen.vaneck@gmail.com).

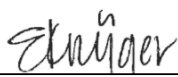
Alternatively, you may contact my supervisors, Mrs. Esedra Krüger, at [esedra.kruger@up.ac.za](mailto:esedra.kruger@up.ac.za); or my co-supervisors, Dr Jeannie van der Linde at [jeannie.vanderlinde@gmail.com](mailto:jeannie.vanderlinde@gmail.com), or Mrs. Renata Eccles, at [renata.mosca@up.ac.za](mailto:renata.mosca@up.ac.za).

If you are willing to participate in the research studies, please sign the attached consent form.

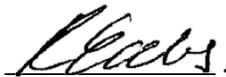
Kind regards



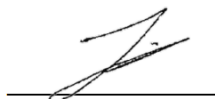
C. van Eck  
Researcher



Mrs. E. Krüger  
Supervisor



Mrs. R. Eccles  
Supervisor



Dr J. van der Linde  
Acting Head: Department of Speech-Language Pathology and Audiology

**CONSENT TO PARTICIPATE IN THIS STUDY**

I confirm that the person asking my consent to take part in this project has told me about nature, process, risks, discomforts and benefits of the study. I have also received, read and understood the above written information (Information Leaflet and Informed Consent) regarding the study. I give permission to the researcher to interview me and to read my baby's medical file and *Road to Health* booklet. I am aware that the results of the study, including personal details, will be confidentially processed into research reports. I am participating willingly. I have had time to ask questions and have no objection to participate in the study. I understand that there is no penalty should I wish to discontinue with the study and my withdrawal will not affect any treatment / access to services in any way.

I give permission that data may be used in future studies:  Yes  No

Parent/legal guardian name.....(Please print)

Parent/legal guardian signature ..... Date.....

Participant's name .....(Please print)

Researcher's name .....(Please print)

Researcher's signature ..... Date.....

Witness's Name .....(Please print)

Witness's signature ..... Date.....

**VERBAL INFORMED CONSENT**

I, the undersigned, have read and have fully explained the participant information leaflet, which explains the nature, process, risks, discomforts and benefits of the study to the participant whom I have asked to participate in the study.

The participant indicates that s/he understands that the results of the study, including personal details regarding the interview will be confidentially processed into a research report. S/he gives permission to the researcher to interview him/her and to read his/her baby's medical file and *Road to Health* booklet. The participant indicates that s/he has had time to ask questions and has no objection to participate in the interview. S/he understands that there is no penalty should s/he wish to discontinue with the study and his/her withdrawal will not affect any treatment / access to services in any way. I hereby certify that the client has agreed to participate in this study.

I give permission that data may be used in future studies:  Yes  No

Parent/legal guardian name .....(Please print)

Parent/legal guardian signature ..... Date.....

Participant's name .....(Please print)

Researcher's name.....(Please print)

Researcher's signature ..... Date.....

Witness's Name .....(Please print)

Witness's signature ..... Date.....

## **APPENDIX E: Developmental information and stimulation brochure**

# Your Baby at 6 Months



Child's Name \_\_\_\_\_

Child's Age \_\_\_\_\_

Today's Date \_\_\_\_\_

Milestones matter! How your child plays, learns, speaks, acts, and moves offers important clues about his or her development. Check the milestones your child has reached by 6 months. Take this with you and talk with your child's doctor at every well-child visit about the milestones your child has reached and what to expect next.

## What Most Babies Do by this Age:

### Social/Emotional

- Knows familiar faces and begins to know if someone is a stranger
- Likes to play with others, especially parents
- Responds to other people's emotions and often seems happy
- Likes to look at self in a mirror

### Language/Communication

- Responds to sounds by making sounds
- Strings vowels together when babbling ("ah," "eh," "oh") and likes taking turns with parent while making sounds
- Responds to own name
- Makes sounds to show joy and displeasure
- Begins to say consonant sounds (jabbering with "m," "b")

### Cognitive (learning, thinking, problem-solving)

- Looks around at things nearby
- Brings things to mouth
- Shows curiosity about things and tries to get things that are out of reach
- Begins to pass things from one hand to the other

### Movement/Physical Development

- Rolls over in both directions (front to back, back to front)
- Begins to sit without support
- When standing, supports weight on legs and might bounce
- Rocks back and forth, sometimes crawling backward before moving forward

## You Know Your Child Best.

Act early if you have concerns about the way your child plays, learns, speaks, acts, or moves, or if your child:

- Is missing milestones
- Doesn't try to get things that are in reach
- Shows no affection for caregivers
- Doesn't respond to sounds around him
- Has difficulty getting things to mouth
- Doesn't make vowel sounds ("ah", "eh", "oh")
- Doesn't roll over in either direction
- Doesn't laugh or make squealing sounds
- Seems very stiff, with tight muscles
- Seems very floppy, like a rag doll

**Tell your child's doctor or nurse if you notice any of these signs of possible developmental delay and ask for a developmental screening.**

If you or the doctor is still concerned

1. Ask for a referral to a specialist and,
2. Call your state or territory's early intervention program to find out if your child can get services to help. Learn more and find the number at [cdc.gov/FindEI](http://cdc.gov/FindEI).

For more information, go to [cdc.gov/Concerned](http://cdc.gov/Concerned).

**DON'T WAIT.**  
Acting early can make a real difference!



[www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly)  
1-800-CDC-INFO (1-800-232-4636)



Download CDC's  
Milestone Tracker App



Learn the Signs. Act Early.

## Help Your Baby Learn and Grow



You can help your baby learn and grow. Talk, read, sing, and play together every day. Below are some activities to enjoy with your 6-month-old baby today.

### What You Can Do for Your 6-Month-Old:

- Play on the floor with your baby every day.
- Learn to read your baby's moods. If he's happy, keep doing what you are doing. If he's upset, take a break and comfort your baby.
- Show your baby how to comfort herself when she's upset. She may suck on her fingers to self soothe.
- Use "reciprocal" play—when he smiles, you smile; when he makes sounds, you copy them.
- Repeat your child's sounds and say simple words with those sounds. For example, if your child says "bah," say "bottle" or "book."
- Read books to your child every day. Praise her when she babbles and "reads" too.
- When your baby looks at something, point to it and talk about it.
- When he drops a toy on the floor, pick it up and give it back. This game helps him learn cause and effect.
- Read colorful picture books to your baby.
- Point out new things to your baby and name them.
- Show your baby bright pictures in a magazine and name them.
- Hold your baby up while she sits or support her with pillows. Let her look around and give her toys to look at while she balances.
- Put your baby on his tummy or back and put toys just out of reach. Encourage him to roll over to reach the toys.

Milestones adapted from CARING FOR YOUR BABY AND YOUNG CHILD: BIRTH TO AGE 5, Fifth Edition, edited by Steven Shelov and Tanya Remer Altmann © 1991, 1993, 1998, 2004, 2009 by the American Academy of Pediatrics and BRIGHT FUTURES: GUIDELINES FOR HEALTH SUPERVISION OF INFANTS, CHILDREN, AND ADOLESCENTS, Third Edition, edited by Joseph Hagan, Jr., Judith S. Shaw, and Paula M. Duncan, 2008, Elk Grove Village, IL: American Academy of Pediatrics.

This milestone checklist is not a substitute for a standardized, validated developmental screening tool.

[www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly) | 1-800-CDC-INFO (1-800-232-4636)



Learn the Signs. Act Early.



# Your Baby at 9 Months <sup>★</sup>



Child's Name \_\_\_\_\_

Child's Age \_\_\_\_\_

Today's Date \_\_\_\_\_

Milestones matter! How your child plays, learns, speaks, acts, and moves offers important clues about his or her development. Check the milestones your child has reached by 9 months. Take this with you and talk with your child's doctor at every well-child visit about the milestones your child has reached and what to expect next.

## What Most Babies Do by this Age:

### Social/Emotional

- May be afraid of strangers
- May be clingy with familiar adults
- Has favorite toys

### Language/Communication

- Understands "no"
- Makes a lot of different sounds like "mamamama" and "bababababa"
- Copies sounds and gestures of others
- Uses fingers to point at things

### Cognitive (learning, thinking, problem-solving)

- Watches the path of something as it falls
- Looks for things he sees you hide
- Plays peek-a-boo
- Puts things in her mouth
- Moves things smoothly from one hand to the other
- Picks up things like cereal o's between thumb and index finger

### Movement/Physical Development

- Stands, holding on
- Can get into sitting position
- Sits without support
- Pulls to stand
- Crawls

## You Know Your Child Best.

Act early if you have concerns about the way your child plays, learns, speaks, acts, or moves, or if your child:

- Is missing milestones
- Doesn't bear weight on legs with support
- Doesn't sit with help
- Doesn't babble ("mama", "baba", "dada")
- Doesn't play any games involving back-and-forth play
- Doesn't respond to own name
- Doesn't seem to recognize familiar people
- Doesn't look where you point
- Doesn't transfer toys from one hand to the other

**Tell your child's doctor or nurse if you notice any of these signs of possible developmental delay and ask for a developmental screening.**

If you or the doctor is still concerned

1. Ask for a referral to a specialist and,
2. Call your state or territory's early intervention program to find out if your child can get services to help. Learn more and find the number at [cdc.gov/FindEI](http://cdc.gov/FindEI).

For more information, go to [cdc.gov/Concerned](http://cdc.gov/Concerned).

**DON'T WAIT.**  
**Acting early can make a real difference!**

### ★ It's time for developmental screening!

At 9 months, your child is due for general developmental screening, as recommended for all children by the American Academy of Pediatrics. Ask the doctor about your child's developmental screening.



[www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly)  
1-800-CDC-INFO (1-800-232-4636)



Download CDC's  
Milestone Tracker App



Learn the Signs. Act Early.



## Help Your Baby Learn and Grow



You can help your baby learn and grow. Talk, read, sing, and play together every day. Below are some activities to enjoy with your 9-month-old baby today.

### What You Can Do for Your 9-Month-Old:

- Pay attention to the way he reacts to new situations and people; try to continue to do things that make your baby happy and comfortable.
- As she moves around more, stay close so she knows that you are near.
- Continue with routines; they are especially important now.
- Play games with “my turn, your turn.”
- Say what you think your baby is feeling. For example, say, “You are so sad, let’s see if we can make you feel better.”
- Describe what your baby is looking at; for example, “red, round ball.”
- Talk about what your baby wants when he points at something.
- Copy your baby’s sounds and words.
- Ask for behaviors that you want. For example, instead of saying “don’t stand,” say “time to sit.”
- Teach cause-and-effect by rolling balls back and forth, pushing toy cars and trucks, and putting blocks in and out of a container.
- Play peek-a-boo and hide-and-seek.
- Read and talk to your baby.
- Provide lots of room for your baby to move and explore in a safe area.
- Put your baby close to things that she can pull up on safely.

Milestones adapted from CARING FOR YOUR BABY AND YOUNG CHILD: BIRTH TO AGE 5, Fifth Edition, edited by Steven Shelov and Tanya Remer Altmann © 1991, 1993, 1998, 2004, 2009 by the American Academy of Pediatrics and BRIGHT FUTURES: GUIDELINES FOR HEALTH SUPERVISION OF INFANTS, CHILDREN, AND ADOLESCENTS, Third Edition, edited by Joseph Hagan, Jr., Judith S. Shaw, and Paula M. Duncan, 2008, Elk Grove Village, IL: American Academy of Pediatrics.

This milestone checklist is not a substitute for a standardized, validated developmental screening tool.

[www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly) | 1-800-CDC-INFO (1-800-232-4636)



Learn the Signs. Act Early.

# Your Child at 1 Year



Child's Name \_\_\_\_\_

Child's Age \_\_\_\_\_

Today's Date \_\_\_\_\_

Milestones matter! How your child plays, learns, speaks, acts, and moves offers important clues about his or her development. Check the milestones your child has reached by age 1. Take this with you and talk with your child's doctor at every well-child visit about the milestones your child has reached and what to expect next.

## What Most Children Do by this Age:

### Social/Emotional

- Is shy or nervous with strangers
- Cries when mom or dad leaves
- Has favorite things and people
- Shows fear in some situations
- Hands you a book when he wants to hear a story
- Repeats sounds or actions to get attention
- Puts out arm or leg to help with dressing
- Plays games such as "peek-a-boo" and "pat-a-cake"

### Language/Communication

- Responds to simple spoken requests
- Uses simple gestures, like shaking head "no" or waving "bye-bye"
- Makes sounds with changes in tone (sounds more like speech)
- Says "mama" and "dada" and exclamations like "uh-oh!"
- Tries to say words you say

### Cognitive (learning, thinking, problem-solving)

- Explores things in different ways, like shaking, banging, throwing
- Finds hidden things easily
- Looks at the right picture or thing when it's named
- Copies gestures
- Starts to use things correctly; for example, drinks from a cup, brushes hair
- Bangs two things together
- Puts things in a container, takes things out of a container
- Lets things go without help
- Pokes with index (pointer) finger
- Follows simple directions like "pick up the toy"

### Movement/Physical Development

- Gets to a sitting position without help
- Pulls up to stand, walks holding on to furniture ("cruising")
- May take a few steps without holding on
- May stand alone

## You Know Your Child Best.

Act early if you have concerns about the way your child plays, learns, speaks, acts, or moves, or if your child:

- Is missing milestones
- Doesn't crawl
- Can't stand when supported
- Doesn't search for things that she sees you hide.
- Doesn't say single words like "mama" or "dada"
- Doesn't learn gestures like waving or shaking head
- Doesn't point to things
- Loses skills he once had

**Tell your child's doctor or nurse if you notice any of these signs of possible developmental delay and ask for a developmental screening.**

If you or the doctor is still concerned

1. Ask for a referral to a specialist and,
2. Call your state or territory's early intervention program to find out if your child can get services to help. Learn more and find the number at [cdc.gov/FindEI](http://cdc.gov/FindEI).

For more information, go to [cdc.gov/Concerned](http://cdc.gov/Concerned).

**DON'T WAIT.**  
**Acting early can make a real difference!**



[www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly)  
1-800-CDC-INFO (1-800-232-4636)



Download CDC's  
Milestone Tracker App



**Learn the Signs. Act Early.**

# Help Your Child Learn and Grow



You can help your child learn and grow. Talk, read, sing, and play together every day. Below are some activities to enjoy with your 1-year-old child today.

## What You Can Do for Your 1-Year-Old:

- Give your child time to get to know a new caregiver. Bring a favorite toy, stuffed animal, or blanket to help comfort your child.
- In response to unwanted behaviors, say “no” firmly. Do not yell, spank, or give long explanations. A time out for 30 seconds to 1 minute might help redirect your child.
- Give your child lots of hugs, kisses, and praise for good behavior.
- Spend a lot more time encouraging wanted behaviors than punishing unwanted behaviors (4 times as much encouragement for wanted behaviors as redirection for unwanted behaviors).
- Talk to your child about what you’re doing. For example, “Mommy is washing your hands with a washcloth.”
- Read with your child every day. Have your child turn the pages. Take turns labeling pictures with your child.
- Build on what your child says or tries to say, or what he points to. If he points to a truck and says “t” or “truck,” say, “Yes, that’s a big, blue truck.”
- Give your child crayons and paper, and let your child draw freely. Show your child how to draw lines up and down and across the page. Praise your child when she tries to copy them.
- Play with blocks, shape sorters, and other toys that encourage your child to use his hands.
- Hide small toys and other things and have your child find them.
- Ask your child to label body parts or things you see while driving in the car.
- Sing songs with actions, like “The Itsy Bitsy Spider” and “Wheels on the Bus.” Help your child do the actions with you.
- Give your child pots and pans or a small musical instrument like a drum or cymbals. Encourage your child to make noise.
- Provide lots of safe places for your toddler to explore. (Toddler-proof your home. Lock away products for cleaning, laundry, lawn care, and car care. Use a safety gate and lock doors to the outside and the basement.)
- Give your child push toys like a wagon or “kiddie push car.”

Milestones adapted from CARING FOR YOUR BABY AND YOUNG CHILD: BIRTH TO AGE 5, Fifth Edition, edited by Steven Shelov and Tanya Remer Altmann © 1991, 1993, 1998, 2004, 2009 by the American Academy of Pediatrics and BRIGHT FUTURES: GUIDELINES FOR HEALTH SUPERVISION OF INFANTS, CHILDREN, AND ADOLESCENTS, Third Edition, edited by Joseph Hagan, Jr., Judith S. Shaw, and Paula M. Duncan, 2008, Elk Grove Village, IL: American Academy of Pediatrics.

This milestone checklist is not a substitute for a standardized, validated developmental screening tool.

[www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly) | 1-800-CDC-INFO (1-800-232-4636)



Learn the Signs. Act Early.

## APPENDIX F: Referral letter



Date: \_\_\_\_\_

Dear Parent/legal guardian

Thank you for your participation in the research study titled “The developmental outcomes of HIV-exposed infants in a resource limited South African context”. Ethically, one of the benefits of participation in this study is therapeutic referral, if deemed necessary, to an allied healthcare professional.

During the developmental screening, it was noted that your child may need further assessment and/or therapy. We would like to refer your child, \_\_\_\_\_, to:

Audiologist	
Occupational Therapist	
Speech-language Therapist	
Other	

We urge you to attend to this as soon as possible at either of the following:

- Stanza Bopape Community Health Centre - 082 452 3843
- Eersterust Clinic - 012 806 1300
- Mamelodi Hospital - 012 841 8300
- University of Pretoria Clinic for High Risk Babies (CHRIB) - 012 420 4910 / 012 420 2814

Kind Regards

\_\_\_\_\_  
**Carmen van Eck**  
Researcher

\_\_\_\_\_  
**Mrs. E. Krüger**  
Supervisor

\_\_\_\_\_  
**Mrs. R. Eccles**  
Supervisor

\_\_\_\_\_  
**Dr. J. van der Linde**  
Head: Department of Speech-Language Pathology & Audiology

## **APPENDIX G: Vineland-3 Comprehensive Interview Form**



Year  Month  Day   
 Test Date   
 Birth Date   
 Test Age

### Score Summary

Subdomains	Raw Score	v- Scale Score	Age Equivalent (AE)	Growth Scale Value (GSV)	% Est
Receptive (rec)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Expressive (exp)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Written (wrn)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<b>COMMUNICATION (COM)</b> Sum of v- Scale Scores:	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Personal (per)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Domestic (dom)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Community (cmm)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<b>DAILY LIVING SKILLS (DLS)</b> Sum of v- Scale Scores:	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Interpersonal Relationships (lpr)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Play and Leisure (pla)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Coping Skills (cop)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<b>SOCIALIZATION (SOC)</b> Sum of v- Scale Scores:	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Gross Motor (gmo)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Fine Motor (fmo)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<b>MOTOR SKILLS (MOT)</b> Sum of v- Scale Scores:	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<b>Domain and Adaptive Behavior Composite</b>					
Sum of v- Scale Scores	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
85% Confidence Interval	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
90% Confidence Interval	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
95% Confidence Interval	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Percentile Rank	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

See Table B.3 to convert to ABC

Adaptive Behavior Composite (ABC)

Motor Skills (MOT)

Sum of v-  
Scale Scores

85% Confidence Interval

90% Confidence Interval

95% Confidence Interval

Percentile Rank

Sum of v-  
Scale Scores

Age Equivalent (AE)

Growth Scale Value (GSV)

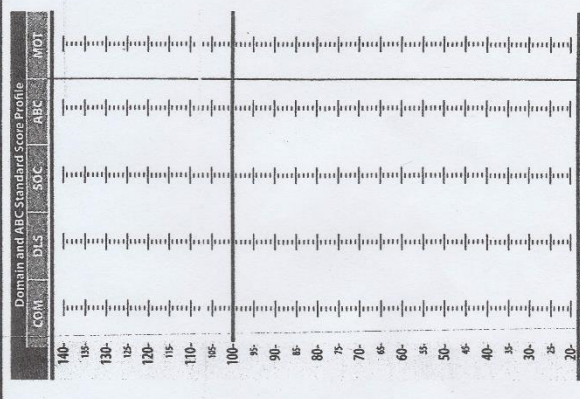
% Est

Raw Score

Subdomains

Subdomain v-  
Scale Score Profile

Subdomain	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	
rec																									
exp																									
wrn																									
per																									
dom																									
cmm																									
lpr																									
pla																									
cop																									
gmo																									
fmo																									



Test Date   
 Birth Date   
 Test Age

Raw Score  v-  
Scale  
Score

Internalizing

1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Externalizing

11.	12.	13.	14.	15.	16.	17.	18.	19.	20.
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Raw Score  v-  
Scale  
Score

Internalizing

1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Externalizing

11.	12.	13.	14.	15.	16.	17.	18.	19.	20.
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

STRENGTH/WEAKNESS ANALYSIS

Standard Score	Strength of Ability	10 or 15 Critical Value	Base Rate
COM	S or W	<input type="text"/>	<input type="text"/>
DLS	S or W	<input type="text"/>	<input type="text"/>
SOC	S or W	<input type="text"/>	<input type="text"/>
MOT	S or W	<input type="text"/>	<input type="text"/>

Calculation of Mean Domain Standard Score

Sum of SS:  No. of domains:  Mean SS:

PARWISE DIFFERENCE COMPARISONS

Standard Score	Standard Score	Standard Score Difference	10 or 15 Critical Value	Statistically Significant	Base Rate
COM	DLS	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
COM	SOC	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
DLS	SOC	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
COM	MOT	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
DLS	MOT	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
SOC	MOT	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Subdomain Comparisons

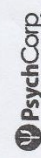
Subdomain	Strength of Ability	10 or 15 Critical Value	Base Rate
rec	S or W	<input type="text"/>	<input type="text"/>
exp	S or W	<input type="text"/>	<input type="text"/>
wrn	S or W	<input type="text"/>	<input type="text"/>
per	S or W	<input type="text"/>	<input type="text"/>
dom	S or W	<input type="text"/>	<input type="text"/>
cmm	S or W	<input type="text"/>	<input type="text"/>
lpr	S or W	<input type="text"/>	<input type="text"/>
pla	S or W	<input type="text"/>	<input type="text"/>
cop	S or W	<input type="text"/>	<input type="text"/>
gmo	S or W	<input type="text"/>	<input type="text"/>
fmo	S or W	<input type="text"/>	<input type="text"/>

Calculation of Mean Subdomain v-  
Scale Score

Sum of v-  
Scale Scores:  No. of subdomains:  Mean v-  
Scale Score:

Abbreviations

COM	Communication	DLS	Daily Living Skills
rec	Receptive	per	Personal
exp	Expressive	dom	Domestic
wrn	Written	cmm	Community
		lpr	Interpersonal Relationships
		pla	Play and Leisure
		cop	Coping Skills
		gmo	Gross Motor
		fmo	Fine Motor



PEARSON



INTERVIEW TOPICS	D Identifying Things	G Understanding Implied Messages	J Attending to Informational Material	one of the
A Repeating	E Following basic Instructions	H Attending to Informational Material		
B Understanding Words	F Understanding Questions	I Following Complex Instructions		
C Understanding Nonverbal Communication				
	Response Options: 2 = Usually, 1 = Sometimes, 0 = Never			
A	1. Looks toward parent or caregiver when hearing parent's or caregiver's voice. Q1. How does he/she react if he/she hears a parent or caregiver's voice when he/she is asleep?			2 1 0
A	2. Looks toward parent or caregiver who is gesturing to get his/her attention. Q1. What does he/she do when you get his/her attention?			2 1 0
A	3. Responds upon hearing his/her name called (for example, turns toward speaker, smiles). Q1. How does he/she react when you call his/her name?			2 1 0
C	4. When parent or caregiver looks or points at something, looks in that direction. Q1. What does he/she do when you look or point towards something?			2 1 0
B	5. Understands at least 10 words. Q1. Score 2 for Yes or No?			2 0
C	6. Responds appropriately to at least three basic gestures (for example, head nod for yes, hand shake for no, hand out for give me, reaching, waving, clapping). Q1. What does he/she do when you give him/her a toy or cup?			2 1 0
B	7. Understands the meaning of no. Q1. What does he/she do when you say "no" to him/her?			2 1 0
C	8. Responds appropriately to at least three facial expressions being made by others (for example, frown, smile, surprised look, angry face). Q1. How does he/she react when you frown or look sad?			2 1 0
B	9. Understands the meaning of yes. Q1. How does he/she react when you say "yes" to him/her?			2 1 0
E	10. Follows instructions requiring only one action (for example, "Sit down"; "Come here"). Q1. How does he/she react when you say "Sit down" or "Come here"?			2 1 0
B	11. Identifies at least three actual objects when asked (for example, points to a dog, cat, cup, key, etc.). Q1. What does he/she do when you ask him/her to identify objects?			2 1 0
B	12. Understands at least 50 words. Q1. Score 2 for Yes or No?			2 0
C	13. Responds to the tone of spoken words (for example, approaches eagerly when "Come here" is spoken lovingly, but hesitantly when "Come here" is spoken sharply). Q1. What does he/she do when you say "Come here" in a loving way and in a sharp way?			2 1 0
D	14. Identifies at least three body parts on self when asked (for example, points to own nose, mouth, hands, feet, etc.). Q1. What does he/she do when you ask him/her to identify body parts?			2 1 0
E	15. Follows instructions with one action and one object (for example, "Bring me the book"; "Close the door"). Q1. What does he/she do when you say "Bring me the book" or "Close the door"?			2 1 0
C	16. Responds appropriately to at least three more advanced gestures (for example, motioning come here, finger over lips meaning be quiet, hands apart to show this big). Q1. What does he/she do when you say "Come here" or "Be quiet" or "Show this big"?			2 1 0
D	17. Identifies at least three objects pictured in a book, magazine, or electronic screen when asked (for example, points to a dog, cat, cup, key, etc.). Q1. What does he/she do when you show him/her pictures in a book, magazine, or electronic screen when asked (for example, points to a nose, a mouth, hands, feet, etc.)?			2 1 0
F	19. Responds to questions that use <i>where</i> (for example, when asked "What is this?", replies "A ball"). Q1. How does he/she react when you ask him/her "What is this?"?			2 1 0
F	20. Responds to questions that use <i>who</i> (for example, when asked "Who is that?" replies "Auntie Keshia"). Q1. How does he/she react when you ask him/her "Who is that?"?			2 1 0
D	21. Identifies at least three basic actions pictured in a book, magazine, or electronic screen when asked (for example, points to someone eating, sitting, jumping, etc.). Q1. What does he/she do when you show him/her pictures in a book, magazine, or electronic screen when asked (for example, points to someone eating, sitting, jumping, etc.)?			2 1 0
F	22. Responds to questions that use <i>where</i> (for example, when asked "Where did Felipe go?", points where Felipe went). Q1. How does he/she react when you ask him/her "Where did Felipe go?"?			2 1 0
E	23. Follows instructions with two related actions (for example, "Pick up those toys and put them away"; "Get your coat and put it on"). Q1. What does he/she do when you say "Pick up those toys and put them away" or "Get your coat and put it on"?			2 1 0
E	24. Follows instructions with one action and two objects (for example, "Bring me the crayons and the ball"; "Put on your shirt and your shoes"). Q1. What does he/she do when you say "Bring me the crayons and the ball" or "Put on your shirt and your shoes"?			2 1 0

INTERVIEW TOPICS	G Using Intermediate Grammatical Forms	J Using Complex Grammatical Forms	M Group Directives	
B Beginning Speech	E Communicating Names & Age	H Using Pronouns	K Expressing Ideas & Experiences	
C Vocabulary	F Using Simple Grammatical Forms	I Asking Questions	L Stating Age, Birthday, & Address	
	Response Options: 2 = Usually, 1 = Sometimes, 0 = Never			
A	1. Makes sounds of pleasure (for example, coos, laugh). Q1. What sounds does he/she make when you sing?			2 1 0
A	2. Cries or fuses when uncomfortable (hissy, hungry, wet, etc.). Q1. What does he/she do when you change his/her diaper or when you are not playing attention to him/her?			2 1 0
A	3. Vocalizes or gestures (for example, cries or waves arms) to get parent's or caregiver's attention. Q1. What does he/she do when you are not playing attention to him/her?			2 1 0
A	4. Makes at least three one-syllable speech sounds (for example, "Ma", "Ba", "Eh", "Oh"). Q1. What does he/she do when you are not playing attention to him/her?			2 1 0
A	5. Babbles in strings of sounds (for example, "Ba-ba-be-be", "Ma-ma-ma-ma", "Da-da-da-da"). Q1. What does he/she do when you are not playing attention to him/her?			2 1 0
A	6. Vocalizes or gestures if he/she wants an activity to keep going or stop (for example, says "Again", shakes head up). Q1. What does he/she do when he/she wants to stop an activity or to keep an activity going?			2 1 0
B	7. Says "Dada," "Mama," or another name for parent or caregiver (including parent's or caregiver's first name or nickname). Q1. What about words to represent them or their names?			2 1 0
D	8. Uses at least three basic gestures (for example, head nod for yes, head shake for no, reaching or pointing toward something desired, waving, clapping). Q1. How does he/she gesture when he/she wants something or wants to stop something?			2 1 0
B	9. Repeats or cries to repeat common words immediately upon hearing them (for example, ball, can, more). Q1. What about repeating words that he/she hears?			2 1 0
B	10. Says "No," must actually mean no, not just repeat the word. Q1. What does he/she say if he/she does not want something?			2 1 0
C	11. Names at least three objects (for example, ball, dog, favorite toy). Q1. What does he/she say about objects such as ball, dog, or favorite toy?			2 1 0
B	12. Says one-word responses (for example, "Want," "More," "Open"). Q1. How does he/she react when you ask him/her questions?			2 1 0
C	13. Names at least 10 objects. Q1. About how many things can he/she identify?			2 0
B	14. Says "Yes," must actually mean yes, not just repeat the word. Q1. What does he/she say if he/she wants the object he/she wants?			2 1 0
C	15. Names at least three actions (for example, drink/drinking, eat/eating, play/playing). Q1. What about talking actions like drinking, eating, or playing?			2 1 0
E	16. Calls brothers, sisters, or friends by their name or nickname. Q1. Whose names or nicknames does he/she use?			2 1 0
C	17. Says at least 50 words. Q1. About how many total words does he/she say?			2 0



E 8. Removes shoes and socks.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
C 9. Drinks from a regular cup or glass (ippy cups don't count); some spilling may occur.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
D 10. Feeds self with a fork; may spill.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
E 11. Removes clothing that opens in the front (for example, a coat or jacket); does not have to unbutton or unzip the clothing.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
F 12. Lets someone know when he/she has a wet or soiled diaper or pants (for example, points, vocalizes, pulls at diaper).	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
H 13. Pulls up clothing with elastic waistbands (for example, underwear, sweatpants).	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
C 14. Drinks from a regular cup or glass without spilling (ippy cups don't count).	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
F 15. Urinates in a toilet or potty chair; parent or caregiver may initiate.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
G 16. Washes hands using soap and water and dries them; does not need to turn the water on and off or adjust the temperature.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
D 17. Feeds self with a spoon without spilling.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
E 18. Removes pullover garments (for example, T-shirt, sweatshirt, dress).	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
H 19. Puts on shoes; may be on the wrong feet and does not need to tie or fasten.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
H 20. Puts on clothing that opens in the front (for example, a coat or jacket); does not need to zip or button.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
F 21. Defecates in a toilet or potty chair; parent or caregiver may initiate.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
F 22. Is toilet-trained during the day; may require help with undressing, flushing, wiping, or washing hands, but must initiate using the toilet.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
H 23. Puts on pullover garments (for example, T-shirt, sweatshirt, dress).	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
I 24. Wipes or blows nose using tissues, napkins, toilet paper, or another appropriate material.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0

**Calculation of Raw Score**

Raw Score =  $(A + B) \times 100 =$    $\times 100 =$

Raw Score =

**Raw Score Calculation**

Raw Score =  $(\text{Number of Correct Responses}) \times 2 =$    $\times 2 =$

Raw Score =

A Beginning Social Behavior	D Identifying Self & Others	G Friendship	J Talking/Others' Perspective
B Responding to Familiar People	E Initiating Others	H Demonstrating Caring	K Interpersonal Flexibility
C Expressing & Re-organizing Emotions	F Interpersonal Appropriateness	I Conversational Skills	

**Response Options: 2 = Usually, 1 = Sometimes, 0 = Never**

A 1. Looks at the face of parent or caregiver.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
A 2. Smiles in response to a smile or a friendly voice.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
B 3. Recognizes family members or other significant people.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
B 4. Smiles or makes sounds when approached by a familiar person.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0

F 18. Uses phrases with a noun and a verb (for example, "Mummy stay," "Give ball").	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
E 19. Says own first name or nickname.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
H 20. Uses pronouns to refer to self; grammar need not be correct (for example, "Give me," "Me want," "Mine toy").	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
F 21. Uses simple adjectives to describe things (for example, <i>dirty, pretty, big, loud</i> ).	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
F 22. Says what he/she is doing using simple sentences; grammar need not be correct (for example, "Ginger and me play," "Dad read me a book").	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
D 23. Uses at least three more advanced gestures (for example, mentioning <i>come here</i> , finger over lips meaning <i>be quiet</i> , hands apart to show <i>this big</i> ).	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
F 24. Uses negatives in sentences; grammar need not be correct (for example, "I won't drink it," "No no go").	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
E 25. Says correct ages when asked; holding up correct number of fingers counts.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
G 26. Uses possessives in phrases or sentences; grammar need not be correct (for example, "This is mine," "Your book," "This is Carol's desk").	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
G 27. Uses <i>and</i> in phrases or sentences (for example, "Moon and Dad," "I want ice cream and cake").	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
I 28. Asks questions beginning with <i>who</i> (for example, "Who's that?"; "Who wear to the store?"), just asking "Who?" (one word) doesn't count.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0

**Calculation of Raw Score**

Raw Score =  $(A + B) \times 100 =$    $\times 100 =$

Raw Score =

A Beginning to Eat	D Using Spoon & Fork	G Cleaning Hands & Face	J Eating/Drinking	M Using Knives When Cutting	P Health Care
B Coping with Dressing & Washing	E Removing Clothing	H Putting on Clothes & Shoes	K Bathing	N Eating & Exercise Choices	
C Beginning to Drink	F Toilet Training	I Hygiene	L Using the Bathroom	O Preparing for Weather	

**Response Options: 2 = Usually, 1 = Sometimes, 0 = Never**

A 1. Opens mouth when food is offered.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
E 2. What does he/she do when you are out some food in front of him/her (e.g., "I like it")?	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
C 2. Drinks from a bottle or spill-proof drinking cup (often called a "ippy cup"); must hold the bottle or cup himself/herself.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
A 3. Sucks or chews on finger foods (for example, crackers, cookies, meats).	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
A 4. Eats solid foods (for example, cooked vegetables, chopped meats).	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
B 5. Cooperates actively in undressing and dressing (raises arms for removing top, holds out feet for putting on pants or shoes, etc.).	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
B 6. Cooperates actively in washing of hands and face (holds out hands, turns face toward parent or caregiver, etc.).	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0
D 7. Feeds self with a spoon, may spill.	<input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 0



INTERVIEW TOPICS

- A. Beginning to Play
- B. Playing With Others
- C. Make-Believe
- D. Sharing
- E. Responding to Social Cues
- F. Following Rules in Games & Sports
- G. Playing Games
- H. Doing Things With Peers
- I. Planning Activities

Responses (points): 2 = Usually, 1 = Sometimes, 0 = Never

A	1. Responds when parent or caregiver is playful (for example, smiles, laughs, claps hands).	2	1	0		
A	2. Shows interest in surroundings (for example, looks or moves around, touches objects or people).	Q1	How does he/she respond when you are playful with him/her?	2	1	0
		Q2	What does he/she do that shows he/she is interested in the things around him/her?	2	1	0
A	3. Plays simple interaction games with others (for example, peek-a-boo, party-cake).	Q1	Has he/she ever played peek-a-boo with you?	2	1	0
		Q2	What about playing party-cake? Has he/she ever played party-cake with you?	2	1	0
A	4. Plays near another child, each doing different things.	Q1	Has he/she ever played with another child when you were not around?	2	1	0
		Q2	How about playing near another child when he/she is playing alone? Do they ever play together?	2	1	0
A	5. Copies the play of a child playing nearby with little or no interaction between the two.	Q1	Has he/she ever copied another child's play when he/she is playing alone?	2	1	0
		Q2	How about copying what a child playing nearby is doing, even though they're not really playing together?	2	1	0
B	6. Plays interactively with one or more children for at least 5 minutes with someone older supervising.	Q1	Has he/she ever played with one or more children for at least 5 minutes with someone older supervising?	2	1	0
		Q2	How long does it take to play interactively with one or more children when someone older is supervising?	2	1	0
B	7. Chooses to join other children who are playing rather than watching them or playing alone.	Q1	When you let him/her watch, how often does he/she choose to join in other children's play, versus just watching or playing by himself/herself?	2	1	0
		Q2	Uses common household objects or other objects for make-believe activities (for example, pretends a block is a car or a box to a house).	2	1	0
B	8. Uses common household objects or other objects for make-believe activities (for example, pretends a block is a car or a box to a house).	Q1	Has he/she ever used a block to pretend it's a car or a house?	2	1	0
		Q2	How often does he/she use common household objects for make-believe activities?	2	1	0
E	9. Shares toys or possessions when told to do so.	Q1	Has he/she ever shared toys or possessions when told to do so?	2	1	0
		Q2	How often does he/she share toys or possessions when told to do so?	2	1	0
E	10. Joins in with a group when verbal cues indicate that he/she is welcome.	Q1	When asked to join a group, does he/she usually join?	2	1	0
		Q2	How often does he/she join a group when verbal cues indicate that he/she is welcome?	2	1	0
B	11. Plays interactively with one or more children for at least 30 minutes with someone older supervising.	Q1	Has he/she ever played with one or more children for at least 30 minutes with someone older supervising?	2	1	0
		Q2	How long does it take to play interactively with one or more children when someone older is supervising?	2	1	0
B	12. Protects self by moving away from those who try to hurt others or destroy things (those who bite, hit, throw things, smash things, etc.).	Q1	Has he/she ever moved away from someone who is trying to hurt or destroy things?	2	1	0
		Q2	When he/she moves away, does he/she usually move away from the person who is trying to hurt or destroy things?	2	1	0
C	13. Plays simple make-believe activities with other children (for example, plays "dress-up," pretends to be superheroes).	Q1	Has he/she ever played simple make-believe activities with other children?	2	1	0
		Q2	How often does he/she play simple make-believe activities with other children?	2	1	0
G	14. Plays with others at simple outdoor games with no score (for example, tag, jump rope, catch).	Q1	Has he/she ever played simple outdoor games with no score?	2	1	0
		Q2	How often does he/she play simple outdoor games with no score?	2	1	0
B	15. Seeks out others for play or companionship (for example, asks others to play or spend time together).	Q1	Has he/she ever asked others to play or spend time together?	2	1	0
		Q2	How often does he/she seek out others for play or companionship?	2	1	0
B	16. Plays with other children with minimal supervision.	Q1	Has he/she ever played with other children with minimal supervision?	2	1	0
		Q2	How often does he/she play with other children with minimal supervision?	2	1	0
F	17. Takes turns when asked while playing games or sports.	Q1	Has he/she ever taken turns when asked to do so?	2	1	0
		Q2	How often does he/she take turns when asked to do so?	2	1	0
C	18. Engages with other children in elaborate make-believe activities involving more than one role (for example, plays "school" or "restaurant," enacts a TV show or movie).	Q1	Has he/she ever engaged in elaborate make-believe activities with other children?	2	1	0
		Q2	How often does he/she engage in elaborate make-believe activities with other children?	2	1	0

Calculation of Raw Score

Raw Score = (Number of correct answers) x 2

Raw Score =  x 2 =

Raw Score =  x 100 =

C	5. Shows at least three different emotions (for example, happiness, sadness, surprise, fear).	2	1	0		
A	6. Tries to interact with others (for example, smiles or makes noises at someone, reaches for someone).	Q1	Has he/she ever tried to interact with others?	2	1	0
		Q2	How often does he/she try to interact with others?	2	1	0
B	7. Reaches for familiar person when that person holds out arms to him/her.	Q1	Has he/she ever reached for a familiar person when they hold out their arms?	2	1	0
		Q2	How often does he/she reach for a familiar person when they hold out their arms?	2	1	0
B	8. Shows affection to familiar people (for example, hugs, kisses, cuddles).	Q1	Has he/she ever shown affection to familiar people?	2	1	0
		Q2	How often does he/she show affection to familiar people?	2	1	0
A	9. Shows interest in children the same age, other than brothers or sisters (for example, watches them, smiles at them).	Q1	Has he/she ever shown interest in children the same age, other than brothers or sisters?	2	1	0
		Q2	How often does he/she show interest in children the same age, other than brothers or sisters?	2	1	0
B	10. Looks around from time to time to check that parents, caregivers, or other familiar persons is nearby.	Q1	Has he/she ever looked around to check if familiar people are nearby?	2	1	0
		Q2	How often does he/she look around to check if familiar people are nearby?	2	1	0
D	11. Identifies self while looking at own tongue in mirror or photo.	Q1	Has he/she ever identified himself/herself in a mirror or photo?	2	1	0
		Q2	How often does he/she identify himself/herself in a mirror or photo?	2	1	0
C	12. Smiles in response to praise or compliments (for example, "Good job," "That's a nice shirt").	Q1	Has he/she ever smiled in response to praise or compliments?	2	1	0
		Q2	How often does he/she smile in response to praise or compliments?	2	1	0
E	13. Initiates or tries to initiate parent's or caregiver's facial expressions (for example, when parent or caregiver makes a happy, sad, or surprised face).	Q1	Has he/she ever initiated or tried to initiate parent's or caregiver's facial expressions?	2	1	0
		Q2	How often does he/she initiate or try to initiate parent's or caregiver's facial expressions?	2	1	0
C	14. Recognizes emotions in others (for example, might say "You look sad" or "Rachel is happy").	Q1	Has he/she ever recognized emotions in others?	2	1	0
		Q2	How often does he/she recognize emotions in others?	2	1	0
E	15. Initiates relatively complex actions as they are being performed by another person (for example, allowing, putting on makeup, vacuuming, hammering nails).	Q1	Has he/she ever initiated relatively complex actions as they are being performed by another person?	2	1	0
		Q2	How often does he/she initiate relatively complex actions as they are being performed by another person?	2	1	0
H	16. Uses actions or words to show happiness, sympathy, or concern for others on own initiative (for example, hugs, holds hands, asks "Are you okay?").	Q1	Has he/she ever used actions or words to show happiness, sympathy, or concern for others on own initiative?	2	1	0
		Q2	How often does he/she use actions or words to show happiness, sympathy, or concern for others on own initiative?	2	1	0
G	17. Tries to make friends with others his/her age (darts, shows particular interest in interacting with certain other children).	Q1	Has he/she ever tried to make friends with other children?	2	1	0
		Q2	How often does he/she try to make friends with other children?	2	1	0
B	18. Says the relationship of family members to self (for example, "That's my mom," "He's my brother"), simply calling parents Mom, Dad, or equivalent doesn't count.	Q1	Has he/she ever said "Mom" or "Dad" or equivalent for his/her mother or father?	2	1	0
		Q2	How often does he/she say the relationship of family members to self?	2	1	0
C	19. Uses words to express own emotions (for example, "I'm happy," "I'm scared," "I don't like him").	Q1	Has he/she ever used words to express his/her own emotions?	2	1	0
		Q2	How often does he/she use words to express his/her own emotions?	2	1	0
F	20. Maintains culturally appropriate eye contact during social interactions.	Q1	Has he/she ever maintained appropriate eye contact during social interactions?	2	1	0
		Q2	How often does he/she maintain appropriate eye contact during social interactions?	2	1	0
F	21. Answers politely when familiar adults make small talk (for example, if asked "How are you?" says "I'm fine," if told "You look nice," says "Thank you").	Q1	Has he/she ever answered politely when familiar adults make small talk?	2	1	0
		Q2	How often does he/she answer politely when familiar adults make small talk?	2	1	0
E	22. Initiates relatively complex actions several hours after watching someone else perform them (for example, shaving, putting on makeup, vacuuming, hammering nails).	Q1	Has he/she ever imitated someone else's actions several hours after watching them?	2	1	0
		Q2	How often does he/she imitate someone else's actions several hours after watching them?	2	1	0

Calculation of Raw Score

Raw Score = (Number of correct answers) x 2

Raw Score =  x 2 =

Raw Score =  x 100 =





## APPENDIX H: Data collection sheet

### DATA COLLECTION SHEET

Case History Form				For Office Use			
Infant Code:							
Assessment Date:							
Participant's contact number:							
<b>SECTION A: BACKGROUND INFORMATION</b>							
1. What is the <b>date of birth</b> of the infant? <i>(Please use dd/mm/yy)</i>							
dd	mm	yy		v1	dd	mm	yy
2. What is the <b>gender</b> of the infant?							
Male			1	v2			
Female			2				
3. What is your relation to the infant?							
Mother of the infant			1	v3			
Father of the infant			2				
Family member of the infant			3				
Non-family caregiver of the infant			4				
4. What is your <b>home language</b> <i>(Indicate those applicable)</i> ?							
Setswana			1	v4			
Sepedi			2				
IsiZulu			3				
Shangaan			4				
English			5				
Afrikaans			6				
Venda			7				
Ndebele			8				
Xhosa			9				
Southern Sotho			10				
SiSwati			11				
Tsonga			12				
<b>Other (specify):</b>			13				
5. What other <b>languages</b> do you <b>speak</b> ? <i>(Indicate those applicable)</i>							
Setswana			1	v5.1			
Sepedi			2	v5.2			
IsiZulu			3	v5.3			
Shangaan			4	v5.4			
English			5	v5.5			
Afrikaans			6	v5.6			

Venda		7	V5.7	
Ndebele		8	V5.8	
Xhosa		9	V5.9	
Southern Sotho		10	V5.10	
SiSwati		11	V5.12	
Tsonga		12	V5.12	
<b>Other (specify):</b>		13	V5.13	
<b>6. In terms of the Employment Equity Act, to which population group do you belong?</b>				
Black		1	V6	
Coloured		2		
White		3		
Asian		4		
<b>Other (specify):</b>		5		
<b>7. Who is the primary caregiver (person who physically takes care) of the infant?</b>				
Mother		1	V7	
Father		2		
Both parents		3		
Grandparents		4		
Extended family members		5		
Foster parents		6		
<b>Other (specify):</b>		7		
<b>8. What is the highest educational qualification of the Mother of the infant?</b>				
I do not know		1	V8	
No formal schooling		2		
Less than Grade 8		3		
Grade 8 to Grade 10		4		
Grade 11 to Grade 12		5		
Diploma/Degree		6		
Postgraduate		7		
<b>9. What is the highest educational qualification of the primary caregiver of the infant (if not the mother or father)?</b>				
I do not know		1	V9	
No formal schooling		2		
Less than Grade 8		3		
Grade 8 to Grade 10		4		
Grade 11 to Grade 12		5		
Diploma/Degree		6		
Postgraduate		7		



10. What is the <b>age</b> of the infant's mother?				
			V10	
11. How many <b>children</b> has the Mother <b>given birth</b> to?				
			V11	
12. How many people are <b>living</b> in the household?				
			V12	
13. Does the infant attend day-care?				
Yes		1	V13	
No		2		
<b>INFORMATION OBTAINED FROM THE ROAD TO HEALTH BOOKLET:</b>				
14.1 How did the infant feed from 0-6 months?				
Only breastfeeding		1	V14	
Only formula feeding		2		
Both breastfeeding and formula		3		
Solids		4		
Other		5		
14.2 What was the duration of the feeding type?				
Only breastfeeding		1	V15.1	
Only formula feeding		2	V15.2	
Both breastfeeding and formula		3	V15.3	
Solids		4	V15.4	
Other		5	V15.5	
15. What is the mother's latest HIV test result?				
Positive		1	V16	
Negative		2		
To be done		3		
16. When did the mother have the last test?				
Before pregnancy		1	V17	
During pregnancy		2		
At delivery		3		
After pregnancy		4		
17. Is the mother on lifelong ART?				
Yes		1	V18	
No		2		

18. If yes, what was the duration of lifelong ART at time of delivery of the infant?				
Less than 4 weeks at the time of delivery of the infant		1	V19	
More than 4 weeks at the time of delivery of the infant		2		
Received lifelong ART before pregnancy		3		
19. Was Nevirapine given to the infant?				
Yes		1	V20	
No		2		
20. What is the infant's latest PCR result?				
Positive		1	V21	
Negative		2		
21. Is the infant currently receiving ARTs?				
Yes		1	V22	
No		2		
<b>SECTION B: ADAPTED RISK ASSESSMENT CHECKLIST (Kritzinger, 2012)</b>				
1. What is the birth order of the infant?				
1st		1	V23	
2nd		2		
3rd		3		
4th		4		
5th		5		
2. Did the mother smoke during pregnancy?				
Yes		1	V24	
No		2		
3. Did the mother abuse alcohol or drugs during pregnancy?				
Yes		1	V25	
No		2		
4. Is there a family member with a history of any of the following problems?				
Hearing problems		1	V26	
Speaking problems		2		
Learning problems		3		
Movement problems		4		

Other		5		
5. How many postnatal clinic visits did you have?				
			V27	
6. Were there any difficulties during pregnancy? If yes, please specify.				
No		1	V28	
Yes		2		
Specify:				
7. What was the duration of the pregnancy?				
38-41w		1	V29	
<38w		2		
>41w		3		
8. If applicable, what was the reason for premature birth?				
			V30	
9. What was the birth weight of the infant?				
			V31	
10. Was the infant well after birth?				
Yes		1	V32	
No		2		
11. Did the infant need hospitalisation and why?				
No		1	V33	
Yes		2		
Reason:				

## **APPENDIX I: Proof of submission of article**

11/19/2019

Gmail - Child: Care, Health & Development - Manuscript ID CCH-2019-0468



Carmen de Beer <carmen.vaneck@gmail.com>

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## Child: Care, Health & Development - Manuscript ID CCH-2019-0468

1 message

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**Nikki Veä Orong** <onbehalf@manuscriptcentral.com>  
Reply-To: CCHadmin@wiley.com  
To: carmen.vaneck@gmail.com

Tue, Nov 19, 2019 at 3:22 PM

19-Nov-2019

Dear Mrs. de Beer,

Your manuscript entitled "Developmental outcomes of HIV-exposed infants in a low-income South African context" has been successfully submitted online and is presently being given full consideration for publication in Child: Care, Health & Development.

Your manuscript ID is CCH-2019-0468.

Please mention the above manuscript ID in all future correspondence or when calling the Editorial Office with queries. If there are any changes to your mailing address or e-mail address, please log in to Manuscript Central at <https://mc.manuscriptcentral.com/cch> and edit your user information accordingly.

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Please note: the average turnaround time for papers submitted to the journal is currently 3 months, but a paper may take as long as 6 months to receive a decision. In exceptional cases, this can take even longer, but papers older than 6 months are made our top priority.

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Thank you very much for submitting your manuscript to Child: Care, Health & Development.

Kind regards,

Nikki Veä Orong  
Managing Editor  
Child: Care, Health & Development