UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Communication profiles of a group of young children (0 – 5 years) with Foetal Alcohol Spectrum Disorders

By

Maria Magdalena De Beer

Submitted in partial fulfilment of the requirements for the degree
M. Communication Pathology
Faculty of Humanities
Department of Communication Pathology
University of Pretoria.

Supervisor: Prof. A. M. Kritzinger

Co-supervisor: Mrs. U. Zsilavecz

November 2008

© University of Pretoria

Abstract:
Communication profiles of a small group of young children (0-5 years) with Foetal Alcohol Spectrum Disorders (FASD)

South Africa has the highest prevalence of Foetal Alcohol Spectrum Disorders (FASD) worldwide. Despite the high prevalence of FASD in children and the resulting need for services, appropriate identification and management of most genetic and congenital disorders are critically lacking in South Africa.

As a result of the established risk for communication delay from birth, young children with FASD need early communication intervention (ECI). There appears to be a dearth in research on the communication difficulties of local young children with FASD. Determining comprehensive communication profiles of young children may serve to emphasize their need for ECI.

The main aim of the study was to present the distinctive communication profiles of a group of young children with FASD. The sub-aims entailed the description of their developmental histories, family/care-giving contexts, communication functioning and identifying developmental trends across the participants.

A collective case study design following a quantitative approach was selected. The study was cross-sectional and descriptive statistics was used to describe the participants' communication skills. A purposive sampling procedure was utilized as a limited number of participants could be found with a diagnosis of FASD. Five participants diagnosed with FASD, living in the Gauteng area, between the ages of 4 to 58 months took part in the study.

The empirical study comprised of two phases. Phase 1 entailed the development of the Interview Schedule, the Assessment Protocol and the conduction of a pilot study. Phase 2 comprised the data collection, analysis and interpretation of results.

The results of the study indicated that all five participants presented with incomplete case histories obtained from the foster parents and general developmental delays. According to the Four-Level Early Communication Assessment Framework the greatest delays included all aspects of communication skills. A developmental trend of the combined communication profiles of the participants indicated an increase in delay with an increase in chronological age. The participants presented with complex multiple neuro-developmental needs to be viewed within a developmental systems and ecological framework.

Based on the results of this study the diverse roles of the speech-language therapist working with young children with FASD and their families were identified. A framework for interdisciplinary service delivery to this population was suggested.

The study succeeded in the attempt to provide a comprehensive, in-depth description of a group of the five participants' unique communication skills. In addition the study also highlighted the shortage of services, e.g. limited early identification and services dedicated to families affected by alcohol related problems. The study is of value to the speech-language therapist in the clinical and research domain. Future research is recommended to expand and support the findings.

Opsomming:
Kommunikasie profiele van ‘n groep jong kinders (0 – 5 jaar) met Fetale Alkohol Spektrumafykings (FAS)

Suid-Afrika vertoon die hoogste prevalensie van Fetale Alkohol Spektrumafwykings (FAS) wêreldwyd. Ten spyte van die hoë prevalensie van FAS in kinders en die voortspruitende behoefte aan dienste, is toepaslike identifikasie en hantering van die meeste genetiese en kongenitale afwykings in Suid-Afrika krities ontoereikend.

As ‘n resultaat van die bevestigde risiko vir kommunikasie agterstand vanaf geboorte, benodig jong kinders met FAS vroëe kommunikasie intervensie (VKI). Daar blyk ‘n gaping in die navorsing aangaande die kommunikasie probleme van plaaslike jong kinders met FAS te wees. Omvattende kommunikasie profiele van jong kinders met FAS kan die behoefte aan VKI dienste beklemtoon.

Die hoofdoel van die studie was om die kommunikasie profiele van ‘n groep jong kinders met FAS voor te lê. Die sub-doelwitte het die beskrywing van hulle ontwikkelings geskiedenis, gesin/sorggewer konteks, kommunikasie funksionering en die identifisering van ontwikkelings neigings in al die deelnemers behels.

‘n Saamgestelde gevallestudie is geselekteer volgens ‘n kwantitatiewe navorsings benadering. Die studie is ‘n kruisdeursnee ontwerp en beskrywende statistieke is gebruik om die deelnemers se kommunikasie vaardighede te beskryf. ‘n Doelgerigte steekproef prosedure is gebruik omdat ‘n beperkte aantal deelnemers met ‘n diagnose van FAS gevind kon word. Die vyf deelnemers wat geselekteer was vir die steekproef was gediagnoseer met FAS, woonagtig in die Gauteng area en het binne die 0 – 5 jaar ouderdomsgroep geval.

Die empiriese studie het uit twee fases bestaan. Fase 1 het die ontwikkeling van die onderhoud skedule, die assesserings protokol en die uitvoering van ‘n loodsstudie ingesluit. Fase 2 het die data insameling, analise en interpretasie van resultate behels.

Die resultate van die studie het aangedui dat al die deelnemers gepresenteer het met onvolledige gevalsgeskiedenisse wat van hul pleegouers verkry is en ‘n algemene ontwikkelings agterstand. Volgens die Vier-Vlak Vroëe Kommunikasie Assesserings Raamwerk het die grootste agterstande alle aspekte van kommunikasie vaardighede behels. ‘n Ontwikkelings neiging vanuit die gekombineerde kommunikasie profiele van die deelnemers het ‘n toename in agterstand met ‘n toename in kronologiese ouderdom aangedui. Die deelnemers presenteer met veelvuldige neuro-ontwikkelings behoeftes wat binne die ontwikkelings sisteem en ekologiese raamwerk beskou moet word.

Gebasseer op die resultate is die diverse rolle van die spraak-taalterapeut wat met jong kinders met FAS en hulle families werk, geïdentifiseer. ‘n Raamwerk vir interdissiplinêre dienslewering aan hierdie populasie word voorgestel.

Die studie het geslaag in die poging om ‘n omvattende, in-diepte beskrywing van die deelnemers se unieke kommunikasie vaardighede te verskaf. Addisioneel het die studie ook die tekort aan dienste, naamlik beperkte vroëe identifikasie en dienste toegewy aan families geaffekteer deur alkohol verwante probleme, uitgelig. Die studie is van waarde vir die spraak-taalterapeut in die kliniese en navorsings domein. Toekomstige navorsing vir die uitbreiding en ondersteuning van die studie se bevindinge word aanbeveel.

List of abbreviations

ABR	**:**	**Auditory brainstem response**
ADHD	**:**	**Attention-Deficit/Hyperactivity Disorder**
ARWT	**:**	**Afrikaanse Reseptiewe Woordeskat Toets**
CAPD	**:**	**Central auditory processing disorders**
CHRIB	**:**	**Clinic For High Risk Infants and Babies**
CNS	**:**	**Central nervous system**
CIX	**:**	**Cranial nerve Glossopharyngeus**
CX	**:**	**Cranial nerve Vagus**
CV-CV-CV	**:**	**Consonant Vowel combinations**
DAS	**:**	**Developmental Assessment Schema**
EC	**:**	**Early communication**
ECI	**:**	**Early communication intervention**
EI	**:**	**Early intervention**
EOWPVT	**:**	**Expressive One-Word Picture Vocabulary Test**
FASD	**:**	**Foetal Alcohol Spectrum Disorders**
FAE	**:**	**Foetal Alcohol Effects**
GERD	**:**	**Gastro-esophageal Reflux Disease**
NGO	**:**	**Non-governmental organisation**
OAE	**:**	**Oto-acoustic emissions**
OCI	**:**	**Observation of Communicative Interaction**
RITLS	**:**	**Rossetti Infant-Toddler Language Scale**
ROWPVT	**:**	**Receptive One-Word Picture Vocabulary Test**
SLT	**:**	**Speech language therapist**
VRA	**:**	**Visual Reinforcement Audiometry**

Table of Contents

1. **Chapter 1 – Introduction to Foetal Alcohol Spectrum Disorders**

1.1. Introduction 1
1.2. Research question and rationale 21
1.3. Description of terminology and abbreviations 22
1.4. Chapter outlay 24
1.5. Conclusion 25
1.6. Summary 26

2. Chapter 2 – Early communication assessment of infants and young children with Foetal Alcohol Spectrum Disorders and their families

2.1. Introduction 27
2.2. Principles of early communication assessment applied to families with children with FASD 29
2.2.1. Family centred and asset-based approach to assessment of infants and young children with FASD 30
2.2.2. Ecological approach to the assessment of families and their infant or young child with FASD 34
2.2.3. Assessment should be individualized and incorporate multiple sources and instruments to gather information 37
2.2.4. Culturally sensitive and non-discriminatory approach to assessment 38
2.2.5. Assessment should be comprehensive 39
2.2.6. Interdisciplinary team approach to assessment 52
2.3. Suggested EC Assessment Framework 55
2.4. Conclusion 57
2.5. Summary 58

3. Chapter 3 – Methodology

3.1. Introduction 59
3.2. Aims of the study 59

3.2.1. Main-aim of the study 59
3.2.2. Sub-aims of the study 59
3.3. Research design 60
3.4. Research ethics 62
3.5. Phases of the empirical study 63
3.5.1. Phase 1 64
3.5.2. Phase 2 64
3.6. Sample 64
3.6.1. Sampling method 64
3.6.2. Participant selection criteria 64
3.6.3. Sample size 65
3.6.4. Participant selection procedures 66
3.6.5. Participant characteristics 67
3.7. Material and apparatus 68
3.7.1. Parent/Care-giver information leaflet and informed consent 69
3.7.2. Interview schedule 70
3.7.3. Communication assessment protocol 73
3.8. Procedures 78
3.8.1. Pilot study 78
3.8.2. General procedures followed for the main study 82
3.8.3. Data analysis 82
3.9. Reliability and Validity 84
3.10. Conclusion 85
3.11. Summary 86

4. Chapter 4 – Results and discussion

4.1. Introduction 87
4.2. Sub-aim 1 & 2: To describe the developmental histories of the five participants with FASD and their family/care-giving contexts 87
4.3. Sub-aim 3: Communication profiles of participants 96
4.3.1. Participant 1: Presentation and discussion of results 96
4.3.2. Participant 2: Presentation and discussion of results 103
4.3.3. Participant 3: Presentation and discussion of results 110
4.3.4. Participant 4: Presentation and discussion of results 117
4.3.5. Participant 5: Presentation and discussion of results 123
4.4. Conclusion 131
4.5.Summary 135

5. Chapter 5 – Conclusions and recommendations

5.1. Introduction 136

5.2. Conclusions and implications 139

5.2.1 Conclusion of sub aim 1: Description of developmental histories of the infants and young children with FASD 139

5.2.2 Conclusion of sub aim 2: Description of child participants' family/care-giving contexts 143

5.2.3 Conclusion of sub aim 3: Description of the communication functioning of each participant with FASD in order to present communication profiles of the child participants 144

5.3. Critical evaluation of the study 148

5.4. Recommendations 150

5.4.1 Recommendations regarding clinical practice 151

5.4.2 Recommendations regarding future research 154

5.5. Final conclusion 155

5.6. Summary 156

6. **References** 157

7. Appendices

7.1. Appendix A: Copies of ethical clearance letters 181

7.2. Appendix B: Parent/Caregiver information leaflet and Informed consent 184

7.3. Appendix C: Interview Schedule 191

7.4. Appendix D: Communication Assessment Protocol Form 197

7.5. Appendix E: Example of assessment report 203

7.6. Appendix F: Transcription of the "Bus story"-test 209

7.7. Appendix G: Declaration form 212

List of Figures

Figure 1.1 Factors influencing developmental outcomes for children with FASD …… 20

Figure 2.1 Key principles of EC assessment to be applied to families with infants and young children with FASD ……. 30

Figure 2.2 Four-level assessment framework for infants and young children with FASD and their families …… 56

Figure 4.1 Participant 1: Comparison between chronological age and developmental level of functioning …… 98

Figure 4.2 Participant 2: Comparison between chronological age and developmental level of functioning …… 105

Figure 4.3 Participant 3: Comparison between chronological age and developmental level of functioning …… 111

Figure 4.4 Participant 4: Comparison between chronological age and developmental level of functioning ……. 119

Figure 4.5 Participant 5: Comparison between chronological age and developmental level of functioning …….. 129

Figure 4.6 Collective developmental trend emerging from the five participants …… 133

Figure 5.1 Systems perspective on FASD in the South African Context…….. 138

Figure 5.2 Role of the Speech-language therapist working with children with FASD and their families…… 148

Figure 5.3 Suggested interdisciplinary management of FASD ……... 152

List of Tables

Table 1.1	Diagnostic criteria of FASD ……..	2
Table 1.2	Physical, medical and general developmental characteristics of children with FASD ……	6 - 7
Table 1.3	Characteristics of communication impairments of young children with FASD ……	10 - 11
Table 1.4	Protective and risk factors to be considered when providing ECI to families affected by FASD …….	16
Table 2.1	The role of team involvement in EC assessment using the Four-level Early Communication Assessment Framework ……..	53
Table 3.1	Description of interview participants (n=7) …….	66
Table 3.2	Description of child participants (n=5) ……	66
Table 3.3	Content of interview schedule …….	71
Table 3.4	Data-collection instruments included in the Communication Assessment Protocol ……	72
Table 3.5	Data analysis procedures applied to the research study……	81
Table 4.1	Summary of the participants' case histories as reported by the foster families (n=5) ……..	88
Table 4.2	Developmental functioning of Participant 1, 4 months old …	96
Table 4.3	Summary of participant 1's developmental functioning, 4 months old …….	99
Table 4.4	Developmental functioning of Participant 2, 18 months old …	103
Table 4.5	Summary of Participant 2's developmental functioning ……..	105
Table 4.6	Developmental functioning of Participant 3, 35 months old …	110
Table 4.7	Summary of Participant 3's developmental functioning ……..	112
Table 4.8	Developmental functioning of Participant 4, 51 months old …	117
Table 4.9	Summary of Participant 4's developmental functioning ……	120
Table 4.10	Developmental functioning of Participant 5, 58 months old ..…	123
Table 4.11	Summary of Participant 5's developmental functioning ……	129

Table 4.12 Individual participants' developmental domains presenting with greatest impairment (n=5) ……. 132

CHAPTER 1

Introduction to Foetal Alcohol Spectrum Disorders

Aim: An introduction to Foetal Alcohol Spectrum Disorders is provided as orientation to the context of the study. The related environmental factors are discussed in order to illustrate how risk factors can affect the communication developmental outcome of affected infants and young children. The high prevalence of FASD in South Africa and the subsequent need for research on the early communication development of children with FASD is presented as the rationale for the study. The problem statement is formulated and described. Important concepts are defined and a summary of the chapters is presented.

1.1. INTRODUCTION

Foetal Alcohol Spectrum Disorders (FASD) has been identified as the leading cause of preventable mental disability in the United States (Antoniadis & Daulton, 1992; Batshaw & Conlon, 1997; Sparks, 1993). Among countries where prevalence figures are known, South Africa has the highest prevalence of FASD worldwide (Pienaar, 2003; Viljoen, Craig, Hymbaugh, Boyle & Blount, 2001a). Despite the high prevalence of FASD in children and the resulting need for services, appropriate identification and management of genetic and congenital disorders are critically lacking in South Africa (Ntsabula, 2001). Although listed as one of the priority conditions targeted for prevention, early detection and the provision of appropriate intervention in the *Human Genetics Policy Document for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities* (Ntsabula, 2001), FASD has not yet been addressed on all these service levels. Services for families and communities with children with FASD are still insufficient. Consequently, the high prevalence of FASD in South Africa provides impetus to healthcare providers to be competent in the areas of prevention of FASD, the early identification and assessment of young children who have this condition, and subsequent intervention.

Since speech-language therapy forms part of the services that should be provided to the families of children with genetic and congenital disorders, and considering the high prevalence of FASD in South Africa, it can be expected that the number of children with

FASD in the case-load of speech-language therapists will increase as professionals become more proficient in identifying FASD. It appears, however, that only a limited description of the communication developmental characteristics of young children with FASD is available in the literature (Schoenbrodt & Smith, 1995; Sparks, 2000; Sparks, 1993).

Studies conducted in the Western Cape region of South Africa indicate that the identification of children with FASD occurs mainly at school entry (Viljoen & Krause, 2001; Viljoen, Croxford, Gossage, Kodituwakku & May, 2001b). An investigation into the early communication development of children diagnosed with FASD may therefore provide additional guidelines for the early detection and appropriate early management of communication disorders in this population of young children. If detected early, infants and young children with FASD may enjoy the full benefits of early communication intervention (ECI), which implies caregiver training and support. However, for ECI to be successful, a comprehensive understanding of FASD and the diagnostic criteria of this condition are essential.

The diagnostic criteria formulated by Carmichael Olson, Jirikowic, Kartin and Astley (2007) for identifying FASD in a child are depicted in Table 1.1.

Table 1.1: Diagnostic criteria of FASD

Diagnostic terminology	Diagnostic characteristics	Description
1. Foetal Alcohol Syndrome (FAS)	• Prenatal and/or postnatal growth deficiency	• Height or weight less than the 10th percentile for gestational age at birth or later in life
	• Central nervous system (CNS) impairment	• Evidence of structural, functional or neurologic brain impairment
	• Cluster of cranio-facial dysmorphology	• Small palpebral fissures (eye slits), thin upper lip, smooth philtrum
	• Confirmed prenatal alcohol exposure	• Reliable evidence of maternal alcohol consumption. If evidence not obtained, it is not deemed necessary if the cluster of facial features is fully present.

2. Partial Foetal Alcohol Syndrome (PFAS)	• Growth deficiency • Cluster of cranio-facial dysmorphology • CNS impairment	
3. Alcohol-related Neurodevelopmental Disorder (ARND)	• CNS impairment • Confirmed prenatal alcohol exposure	

(Source: Carmichael Olson, Jirikowic, Kartin & Astley, 2007)

The process of diagnosing FASD in a child therefore requires a visual examination of the physical features of the child, obtaining a case history, and conducting a developmental assessment of the child. The visual examination is done by a medical specialist (i.e. dysmorphologist, geneticist, or paediatrician), who usually also obtains the case history in order to make the diagnosis. Different multi-disciplinary team members who may include a clinical psychologist, social worker, speech-language therapist, an occupational- or a physiotherapist can conduct the developmental assessment (Clarren & Astley, 1997).

Once the assessments have been conducted, a diagnosis of FASD on the continuum can be made. An infant or young child may then be diagnosed with FAS (Foetal Alcohol Syndrome), PFAS (Partial Foetal Alcohol Syndrome) or ARND (Alcohol-related Neurodevelopmental Disorder) (Carmichael Olson et al., 2007). Children with FASD therefore display great variability in symptoms on a continuum ranging from mild to severe (Carmichael Olson & Burgess, 1997).

According to Dittmer and Lentz (2004), the foetal pathophysiology brought about by the consumption of alcohol by the mother can be summarized as follows: Alcohol crosses the placenta and rapidly reaches the foetus. Unimpeded bidirectional movement of the alcohol between the mother and the foetus takes place. The foetus is dependent on maternal hepatic detoxification, because the activity of alcohol dehydrogenasis in the foetal liver is less than 10% of that in the adult liver. Furthermore, the amniotic fluid acts as a reservoir for alcohol, resulting in prolonged foetal exposure and the alteration of foetal development in the following ways:

- Disruption of cellular differentiation and growth
- Disruption of DNA and protein synthesis
- Inhibition of neuronal and glial cell migration

- Deprivation of intrauterine nutrients which has a direct effect on foetal growth
- Causation of a chronic state of foetal hypoxia, an oxygen shortage in the tissue

Prenatal exposure to alcohol may therefore have pervasive effects on the developing foetus, and the visible features of these effects can already be diagnosed at birth.

Although the literature provides specific diagnostic criteria and information on related characteristics regarding FASD (Carmichael Olson et al., 2007), the facial characteristics and growth deficiency in children with FASD are not predictive of definitive brain impairments or a specific level of developmental delay (Clarren, Carmichael Olson, Clarren & Astley, 2000). Therefore, a positive diagnosis of the presence of FASD alone does not provide an adequate basis for a prognosis regarding the level of cognitive impairment and the degree of developmental delay in a specific child. A comprehensive individual communication assessment may assist in determining each child's profile of strengths and weaknesses, as well as protective and risk factors in the family environment before prognostic predictions can be ventured.

According to Rossetti (2001), young children with FASD may be identified and diagnosed early as a result of their recognizable physical appearance, which is more pronounced during infancy (Abkarian, 1992). However, a conclusive diagnosis of FASD cannot always be established in this young population (Clarren et al., 2000) owing to later manifestation of deficits or impairments in the cognitive and other developmental domains that are not as apparent early in life. The accurate prognosis of FASD is further complicated by the variable effects of alcohol, the degree of FASD present and the effect of intervention on the individual (Clarren et al., 2000).

Table 1.2 provides an overview of symptoms additional to those described in the diagnostic criteria, which children with FASD may display. The summary of physical, medical and developmental characteristics in Table 1.2 is based on information gathered during an extensive study of relevant literature. Since the present study focuses on the nature of communication impairments in children with FASD, the developmental characteristics in Table 1.2 contains information on the cognitive and motor

development, sensory abilities and behaviour of children with FASD only. Communication skills of children with FASD will be indicated in a separate table – Table 1.3.

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Table 1.2: Physical, medical and general developmental characteristics of children with FASD

Physical characteristics	Medical characteristics	Developmental characteristics
Cranio-facial characteristics • Cleft lip and/or palate • Poor development of dentition • Microcephaly • Flat mid-face (hypoplasia) • Indistinct philtrum (smooth and/or long) • Thin upper lip and small lips • Thinned upper vermillion • Small teeth with faulty enamel • Prominent lateral palatine ridges in the mouth • Epicanthal folds • Low nasal bridge • Anteverted nostrils • Minor ear anomalies e.g. posterior rotation of the ears, poorly formed concha • Short, upturned nose • Micrognathia (small mandible) • Pre- or postnatal growth deficiency regarding head circumference • Hypoplasia of the maxilla • Ptosis (downward displacement of the upper eyelid) • Blepharophimosis (reduced space between the eyelids) • Strabismus, myopia and clinical micropthalmia	***Brain and Systemic defects*** • Musculo-skeletal defects • Genito-urinary defects • Immune deficiency • Increased risk for seizures • Muscular hypotonia • Disturbance in brain neuro-chemistry in the following systems: dopaminergic, noradrenergic, serotonergic, cholinergic, glutamatergic, GABAergic and histaminergic systems	***Cognitive impairments*** • Mild to moderate cognitive impairment • Attention impairment • Memory impairment • Complex learning impairment • Central processing disorders, slower, less efficient information processing • Working memory problems • Problems regarding social cognition • Deficits in story memory • Executive-function deficit in deductive reasoning • Inconsistent problem-solving strategies • Visual-spatial processing deficits
Height and weight • Low birth weight • Small stature • Pre- or postnatal growth deficiency regarding height and weight	***Organ defects*** • Cardiac (i.e. atrial or ventrical septal defect, occasionally tetralogy of Fallot) • Liver • Kidney • Morphological changes in brain structure (especially in the corpus callosum)	***Motor impairments*** • Visual-motor integration delay • Sensory motor integration problems • Psychomotor maturation delay • Fine motor dysfunction • Gross motor dysfunction
Physical characteristics	**Medical characteristics**	**Developmental characteristics**
Other physical characteristics • Brachyclinodactyly (shortened finger - 5th finger) • Anomalous palmar creases • Sacral dimple	***Increased risk of infections*** • Upper respiratory tract infections • Otitis media	***Sensory impairments*** • Auditory disorders, e.g. increased risk of sensori-neural and conductive hearing loss, auditory filtering

Table 1.2 provides a clinical picture of the variety of symptoms that children with FASD may reveal, excluding their communication difficulties. The clinical value of categorizing the symptoms is that it provides a comprehensive description of all the possible symptoms to aid clinicians in their identification and assessment of young children with FASD.

Furthermore, the symptoms described in Table 1.2 also demonstrate the possible far-reaching effects of prenatal alcohol exposure on foetuses (Clarren et al., 2000) and young children. Owing to variations in alcohol intake by mothers and the varied susceptibility of foetuses, a broad spectrum of symptom combinations may be found in children with FASD (Colangelo & Jones, 1982). Different variables also interact with one another in FASD. Variables such as dose exposure, duration of exposure, gestational timing, genetic background, drinking pattern, type of beverage, individual variation in alcohol metabolism, and nutritional status of the mother all contribute to the severity of symptoms that a child prenatally exposed to alcohol may display (Colangelo & Jones, 1982). The symptoms or characteristics are present on a continuum ranging from clearly within the normal range to distinctly displaying the features of FASD (Clarren et al., 2000). As can be seen in Table 1.2, and according to Steinhausen et al. (2003), children with FASD display a behavioural phenotype that has a characteristic pattern of motor, cognitive, linguistic and social deficits that can be consistently associated with FASD as a biological disorder.

Research has also shown that many children with FASD also display unusual and varied language impairments, but this area has received limited attention among researchers (Carmichael Olson & Burgess, 1997). To facilitate early identification of and intervention for children with FASD by a speech-language therapist, a comprehensive communication profile outlining the peculiar speech and language deficits of these children would be helpful to clinicians to guide them in appropriate assessment and intervention. Appropriate assessment and intervention will enable clinicians to endorse the *Convention on the Rights of the Child* which, in Article 23, states that ‘a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure

dignity, promote self-reliance and facilitate the child's active participation in the community' (McConkey, 1995:63). This study will therefore aim to contribute to the description of the unique communication skills of infants and young children with FASD since, compared with other symptoms, their speech, language and hearing impairments are not sufficiently described in the literature. The availability of such information may then enhance opportunities for these children to receive appropriate ECI services. Early intervention commencing as soon as possible after birth is regarded as evidence-based practice for families with infants at risk for developmental disorders (Rossetti, 2001).

The communication development of infants and young children with FASD is an area of intense research interest (Carmichael Olson et al., 2007). Despite interest in this developmental domain, limited clinical or longitudinal studies of communication in infants and young children prenatally exposed to alcohol have been conducted (Carmichael Olson et al., 2007).

Since this study focuses in particular on the communication abilities of young children with FASD, an overview of the known communication impairments that could be found in the literature is provided in Table 1.3. The characteristics are described according to the two developmental stages encompassed in ECI, i.e. infancy and early childhood.

Table 1.3: Characteristics of communication impairments of young children with FASD

Developmental Stage: Infancy 0 – 24 months				
Expressive language	***Receptive language***	***Pragmatics***	***Oral-motor development***	***Auditory abilities***
• High-pitched cry • Decreased vocalization • Delayed onset of first words • Limited lexicons • Delayed imitations of interactional partner's language production • Frequent use of gestures • Phonological skills may be age-appropriate or limited	• No descriptions found in the literature	• Poor mother-child attachment leading to a negative environment for the development of communication skills • Inappropriate use of gestures • Limited social interaction • Autistic-like behaviours	• Feeding difficulties • Difficulty with sucking accompanied by low muscle tone • Weak sucking reflex • Long latency to suck – lengthened time to initiate successful sucking • Difficulty to regulate the basic feeding cycle • If cleft palate is present, associated feeding difficulties can be expected • Delayed achievement of feeding milestones • Poor appetite and disinterest in food • Deficiency in one or more of the eight major valves along the vocal tract	• Abnormalities in orientation to auditory stimuli • 93% of infants with FASD present with recurrent otitis media with effusion during the first 6 years of life; this is the highest reported otitis media with effusion rate of any group of children with disabilities in the literature • Difficulty regarding speech-sound discrimination • Involuntary response to noises due to lack of habituation • Increased incidence of sensori-neural and conductive hearing loss

The information provided in Table 1.3 indicates that the typical communication impairments of infants and young children with FASD are numerous and encompasses auditory impairments, feeding difficulties and impairments affecting all aspects of language and communication. It is apparent from the literature and Table 1.3 that delays or impairments in the development of receptive language in children with FASD are not well described in the literature. Receptive language abilities are closely related to the child's level of cognitive impairment and may therefore not receive sufficient attention as a separate impairment. Furthermore, it is clear that a variety of communication impairments associated with FASD already manifest in infancy. The need for ECI is therefore clearly indicated.

Research conducted by Janzen, Nanson and Block (1995) indicates the presence of verbal and comprehension deficits in children with FASD at an age of three and a half years. The risk for communication impairment is present in infants with FASD from birth onwards. Therefore, deficits in the area of communication development should be expected and the subtle accompanying signs should be noted (Rossetti, 2001; Sparks, 1993).

During infancy, it is the areas of oral-motor development and expressive language that appear to be the most severely affected in children with FASD. According to Table 1.3, oral-motor difficulties resulting in feeding difficulties may be resolved during the early childhood period, and the areas of expressive language and pragmatics are most severely affected later in life. Young children with FASD have unique pragmatic impairments, such as a lack of communication repair, difficulty with meta-linguistic ability and verbosity, which are not usually associated with children with specific language impairments (SLI) (Owens, 1999a; Plante & Beeson, 1999). Based on available literature, it can therefore be concluded that expressive language abilities and pragmatics, inter-related with social communication interaction, are the areas of greatest concern on the spectrum of communication impairments that may occur in children with FASD. The high incidence of otitis media with effusion documented in children with FASD and the risk for sensori-neural hearing loss can be seen as factors contributing to the

manifestation of expressive and receptive language impairments (Olswang, Rodriguez & Timler, 1998).

According to Paul (2001:131), communication impairments in children with FASD are indicative of problems occurring across the lifespan, and there is a 'predictable progression of maladaptive behaviours and communication problems'. It is also suggested that these children reach their academic ceiling during adolescence and that problems regarding memory, learning, attention, judgement and pragmatics persist (Paul, 2001). Since FASD is particularly prevalent in South Africa and diagnosis may be late, speech-language therapists may encounter the unique communication impairments associated with this spectrum disorder in their caseloads. Speech-language therapists must be able to identify the distinctive symptoms in young children in order to assist in an early diagnosis of FASD.

In order to accurately diagnose a young child with FASD, a comprehensive assessment of all related factors must be conducted. According to a literature description the variability of communication and other impairments in children with FASD can be associated with the timing of alcohol consumption by the mother during pregnancy, the quantity of alcohol consumed during pregnancy, other substances used during the pregnancy, and the home environment (Gentry, Griffith & Dancer, 1998). Research by Colangelo and Jones (1982) focused on prenatal factors relating to the severity of symptoms in FASD. It is apparent that the quantity of alcohol consumption, the use of other substances and the home environment can contribute to the language impairment that is evident in the young child with FASD.

Gentry et al. (1998) take the research a step further, adding the home environment as a contributing factor to the severity of symptoms in children with FASD. These authors also mention the abuse of substances other than alcohol by the mother, which indicates a progression in research regarding FASD and prior to the publication of research findings (Colangelo & Jones, 1982) a limited awareness existed of the effect of the use of other drugs, such as marijuana and cocaine, on the foetus.

The effects of substance abuse on the care-giving environment of young children with FASD, as pointed out by Gentry et al. (1998), also have a significant influence on the development of their communication skills. According to Paul (2001), a mother with an alcohol abuse problem cannot devote optimal energy to the infant or young child's upbringing. Sparks (2000) adds that these mothers find it difficult to understand and relate to their children's communicative needs and may often reject and criticize communicative attempts of the child with FASD. Such an abusive and neglectful environment has a confounding negative impact on the child's development (Paul, 2001; Sparks, 2000), and especially on the domain of communication development.

Children with communicative and other developmental impairments are more likely to experience abuse than children that develop normally (Hyter, 2007; Paul, 2001). The presence of FASD in infants and young children is therefore a risk factor that is likely to expose them to abuse in their immediate environments (Hyter, 2007). The abusive behaviour towards children with communication impairment could be explained as the result of the children's inability to meet the parents' expectations of rewarding interaction, which leads to a less satisfying care-giving experience by the parents (Paul, 2001). A further risk for language impairment is present in maltreatment itself, due to the disruption of social interaction between the parent and the child (Hyter & Way, 2007; Westby, 2007). As a consequence of maltreatment many young children with FASD are placed in foster care (Hyter, 2007).

It is thus clear that the sources of risk for language and cognitive impairment in young children with FASD can also be found in several areas relating to the abusive and neglecting mother or primary caregiver (Hyter & Way, 2007; Sparks, 2003). An unsatisfactory care-giving environment may lead to disorganized attachment patterns in infants and young children. Attachment security is thus also compromised contributing to increased levels of depression in young children with FASD (Carmichael Olson et al., 2007). Attachment to a primary caregiver is also significantly related to language development (Paul, 2001). In contrast with the aforementioned factors, optimal

attachment has a positive effect on a young child's language, emotional and cognitive development (Sparks & Gushurst, 1997).

Young children affected by FASD do not display the negative sequelae of prenatal exposure to alcohol only, but may also demonstrate certain positive characteristics (Carmichael Olson & Burgess, 1997). The current perspective in ECI service delivery is to emphasize an asset-based approach (Billeaud, 2003). Every individual has a profile of strengths and weaknesses and appropriate ECI services can capitalize on the strengths and may improve some of the weaknesses in children with FASD. Despite numerous expressive language problems, positive characteristics such as being socially engaging, interested in others, very talkative and overtly affectionate, is also present in young children with FASD (Carmichael Olson & Burgess, 1997).

According to Werner (2000:116), protective factors are 'moderators of risk and adversity that enhance developmentally appropriate outcomes' in children. These moderators include the absence of serious learning problems and serious behavioural problems in children and the mastery of those developmental tasks and psychosocial stages that are considered to be appropriate for a given age and culture (Werner, 2000). The learning and behavioural problems associated with FASD can be serious and contribute to a high likelihood of secondary disabilities of lifestyle and daily functioning in adolescence and adulthood (Streissguth, Bookstein, Barr, Sampson, O'Malley & Young, 2004). The goal of ECI is to increase protective factors in the lives of children and families affected by FASD, and to decrease risks (Billeaud, 2003).

Effective ECI tailored to the unique developmental profile of young children with FASD will attempt to ameliorate the negative impact of some of the risk factors present in the young child's life and family context. Rossetti (2001) reports that the efficacy of ECI services has been well documented through research. If ECI services are provided early and appropriately, young children with FASD and their families may display not only risk factors, but also protective factors in their lives, as depicted in Table 1.4.

Table 1.4: Protective and risk factors to be considered when providing ECI to families affected by FASD

Protective factors *(Enhance positive developmental outcomes)*	**Risk factors** *(Decrease positive developmental outcomes)*
• Sociability of family • Religiosity of family • Mother with higher educational attainment • Being diagnosed before the age of 6 years • Early diagnosis of FASD • Having basic needs met in the family • Living in a stable and nurturing home • No violence experienced against child or in family • Affectionate nature of child • Appropriate early diagnosis of child and family problems • Non-judgmental attitudes on the part of professionals • Realistic expectations for the child and parent • Early success at improving infant self-regulation and mutual regulation between the caregiver and infant with FASD • Specialized support for parents and professionals • A case manager for service provision and the establishment of a partnership between service-delivery systems	• Continued parental substance abuse • Poverty • Child neglect • Child abuse • Adolescent mother • Difficult temperament of infant • Poor self-regulation abilities of the infant • Poor attachment to primary caregiver • Maladaptive parenting • Parental mental illness • Inconsistent interactions with caregivers • Frequent shifts in foster families • Low parental education • Violence • Social disruption

(*Sources:* Adnams, Kodituwakku, Hay, Molteno, Viljoen & May, 2001; Carmichael Olson & Burgess, 1997; Kim et al., 1999; Osofsky & Thompson, 2000; Streissguth et al., 1997; Viljoen et al., 2001b; Werner, 2000)

A crucial protective factor, as indicated in Table 1.4, in the life of a young child with FASD is early diagnosis (Streissguth et al., 1997). Research has indicated that an early diagnosis of FASD can be associated with more positive outcomes in adolescence and adulthood (Streissguth et al., 2004). According to the risk factors listed in Table 1.4, inadequate attachment with the primary caregiver is of great concern, owing to the cascading effect that poor attachment introduces into communication interaction between the mother and infant (Klein & Briggs, 1987; Lesar 1992). Often underscored in the literature, poor mother-child attachment adds to communication impairment, since the required developmental stimulation is not provided. Appropriate attachment with the primary caregiver is viewed as a foundation for optimal language, cognitive and emotional development (Sparks & Gushurst, 1997).

Therefore, poor attachment or ambivalent attachment of the mother to the infant (Sparks, 1993) may cause a negative cascading effect from infancy into early childhood, e.g. an infant experiencing feeding difficulties makes it difficult for the mother or primary caregiver to cope with the infant. Alcohol abuse can contribute to the impairment of physical, mental and social health of the biological mother affecting pregnancy and parenting skills negatively (Sparks, 1993). Giving birth to an infant with FASD can have a potentially destabilizing effect on the biological mother. The compromised psychological profile of the mother, usually characterized by depression, anxiety, powerlessness, decreased self-confidence and self-esteem, further jeopardizes the infant-parent relationship (Carmichael Olson et al., 2007). Osofsky and Thompson (2000) furthermore indicate that FASD characteristics could increase the risk of maladaptive parenting. Mothers who abuse substances display a profile characteristic of substance abuse where their primary focus is not their infant's needs, but their drug of choice (Hyter & Way, 2007; Osofsky & Thompson, 2000). The shifted focus in the mother leads to decreased positive interaction in the mother-child dyad. Furthermore, the lack of reciprocity in the mother-infant dyad may also be influenced by the negative cascading effect, introduced by the developmental impairment and the infant with FASD's labile states and moods. The infant's developmental impairment and lability may lead to a further compromise of the mother's neuro-psychological functioning which increases the risk of maladaptive parenting even further (Osofsky & Thompson, 2000).

Studies of typical language development suggest that children build their need to communicate on interaction with a responsive caregiver (Sparks, 1993). Responsive interaction patterns enable the child to develop an internal working model of a human relationship (Owens, 1999b). This internal representation developed by infants enables them to learn and use language appropriately. When the parent/caregiver is drug-dependent, the care-giving in the first few months of the infant's life is unpredictable (Lesar, 1992). As a result this unpredictability, the infant could develop an atypical representation of interaction in a human relationship, which could have a negative effect on language learning and use.

It has also been found that the feeding practices of a substance-dependent caregiver show little sensitivity to the needs of the infant and that interactions with toys are self-directed towards the mother's own needs and do not take the child's needs into account (Sparks, 1993). When the infant has FASD and the mother continues to abuse alcohol, both the infant and the mother enter the communication dyad facing a high risk of dysfunctional interaction. As the risk of dysfunction increases exponentially, the prognosis for the recovery of the developmental delays or impairments of the child with FASD becomes poorer (Paul, 2001; Sparks, 1993). As a result of maladaptive parenting, children with FASD are often removed from their biological parents and placed in homes of safety or foster care (Hyter, 2007; Westby, 2007).

It has been reported that children with FASD who are raised in foster care from early infancy do not necessarily display more satisfactory growth or functioning than those raised by their chronically alcoholic mothers (Kaemingk & Paquette, 1999). However, children who remain in families where continued alcohol-related problems exist have an added risk of experiencing more psychosocial problems in later life (Aronson, 1997). Studies involving children with FASD suggest that an environment conducive to emotional and social development may be related to a more stable home environment than could even be provided by foster care (Streissguth, Aase, Clarren, Randels, LaDue & Smith, 1991). One study reported that children with FASD had very unstable family environments even in foster care, as over time these children were living in an average of five foster homes (Streissguth et al., 1991). The acquisition of language in the context of the family is a dynamic interaction between the language development abilities of the child on the one hand, and the cultural beliefs, family values and child-rearing practices of the family on the other (Louw & Avenant, 2002). The unstable home environments of children with FASD are therefore high-risk family patterns that may have a negative effect on those children's developmental outcomes.

The *Conceptual Model of Early Development and Risk Factors* of Guralnick (1997), provides insight into how child development proceeds in the presence of certain positive and/or negative family characteristics and patterns, combined with the potential stressors

created by a child's disabilities (see Figure 1.1). In the case of children with FASD, the personal characteristics of a substance-abusing parent, as well as those of another present or absent parent/caregiver, will influence the family patterns. Family patterns will be influenced in respect of the quality of parent-child transactions, family-orchestrated child experiences and the health care and safety provided by the family to the child. The diagnosis of FASD in a child further creates stressors regarding information needs, interpersonal and family distress, resource needs and confidence threats (Guralnick, 1997).

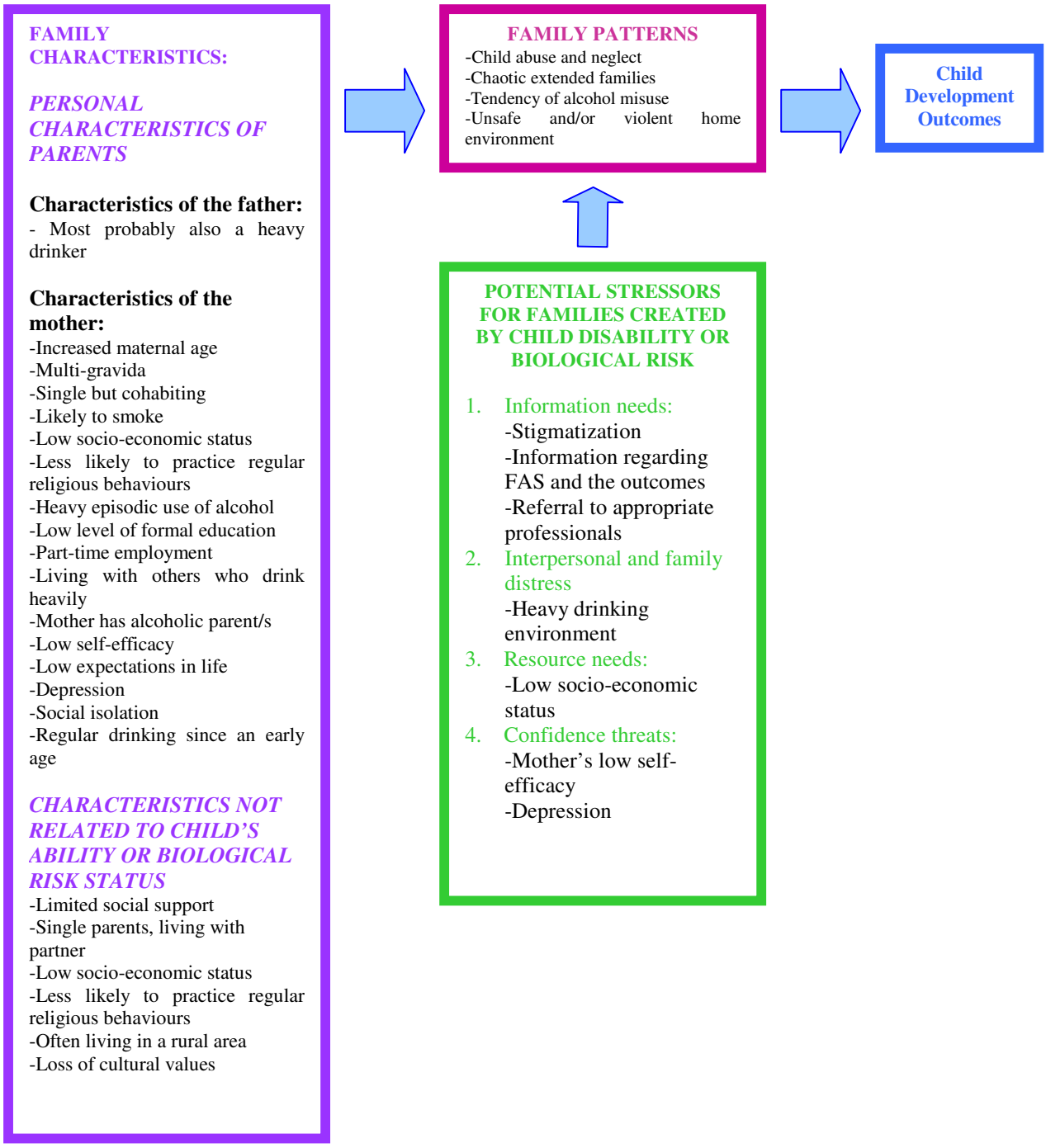


Figure 1.1: Factors influencing developmental outcomes for children with FASD
(Based on: Guralnick, 1997; Markel, 2005; May, Brooke, Gossage, Croxford, Adnams, Jones, Robinson & Viljoen, 2000; Viljoen, 1999)

The *Conceptual Model* of Guralnick (1997), as applied to FASD in Figure 1.1, could be linked to the ecological model, which recognizes the multitude of factors likely to impinge on the development of the child with FASD. These models are founded on the understanding that social units such as a family do not act in isolation, but interact both between and within systems. A strong interplay is present between aspects relating to nature and nurture, where interaction takes place between the characteristics of the child with FASD and the environment in which the child is raised (Garbarino & Ganzel, 2000). The environment of a young child with FASD is often characterized by cumulative risk. Such an environment is usually coupled with health and safety concerns, relational problems and chaotic lifestyles further negatively affecting the young child's developmental outcome (Carmichael Olson et al., 2007).

Reverberations of environmental impact occur across all the areas of the child's development. ECI should therefore, focus on caregiver training, information giving and support. ECI will aim to develop the children's stronger abilities to their best extent to compensate for the impairments that are present. Furthermore, empowering young children with FASD and their families with coping strategies that may facilitate improved caregiver-child interaction and child development, as well as may reduce the impact of disabling child characteristics and cumulative environmental risk (Carmichael Olson et al., 2007).

1.2. RESEARCH QUESTION AND RATIONALE

It is clear that a need exists for the investigation of the communication skills of young children with FASD in South Africa. The research may contribute to the description of the unique characteristics and care-giving environments that may exist locally in order to compile a comprehensive communication profile of young children with FASD and their needs. Local data is required due to the high prevalence of FASD (Viljoen et al., 2001a) and the unique environmental risks, i.e. extreme poverty, continued substance abuse by parents and the high incidence of HIV and AIDS (Swanepoel, 2004), which may contribute to the profile of young South African children with FASD. Multicultural- and multilingual communities characterize the South African context. Although the diversity of cultures as such is not a risk, diversity poses challenges to the delivery of culturally appropriate services. Most

speech-language therapists and audiologists in South Africa are not able to provide services in languages other than English and Afrikaans, and even in these languages limited services are available (Pickering, McAllister, Hagler, Whitehill, Penn, Robertson & McCready, 1998). The urgent need for services for infants and young children with FASD has already been described in the *Human Genetics Policy Document for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities* (Ntsabula, 2001), but these services have not yet been extensively implemented (Viljoen, 1999) and local data may emphasize the importance of speech-language therapy and audiology services. The intended study may be used as a guideline to compile an appropriate and culturally valid assessment protocol that would yield insight regarding the early communication development and care-giving environments of young children with FASD.

The prevalence of FASD in South Africa is the highest known in the world (Viljoen et al., 2001b). It should therefore be clear that a comprehensive communication profile of infants and young children with FASD may contribute to provide best practice in the field of ECI to this special population of children and their families.

The rationale for this study is clearly outlined in the need that exists for local data and the compilation of a communication profile of infants and young children with FASD. The research question that emerges from the rationale is: What is the nature of the communication abilities and impairments, as well as the environmental circumstances of a group of infants and young children with FASD in South Africa?

1.3. DESCRIPTION OF TERMINOLOGY AND ABBREVIATIONS

The terms and abbreviations used in this study are clarified below by means of brief descriptions.

CHRIB: Clinic for High-Risk Babies – This clinic at the Department of Communication Pathology at the University of Pretoria provides comprehensive ECI services to families and their children, predominantly younger than three years. Furthermore, it serves to provide clinical training for students in the field of ECI and to promote research. The main educational goal of CHRIB is to provide a model of ECI service delivery in South Africa (Kritzinger & Louw, 2002).

ECI: Early communication intervention – 'Intervention, including both assessment and treatment provided to families and their children below the age of three years, who demonstrate, or are at risk of demonstrating, either a disability or delay involving communication, language, speech or prerequisite oral-motor behaviour' (American Speech and Hearing Association, 1989). In this study the age range was extended up to 5 years of age, due to the late identification of young children with FASD, the decreased availability of services and a lack of legislation guiding ECI in South Africa. Furthermore, Fair and Louw (1999) indicate that infants and toddlers with special needs within the developing context of South Africa do not receive adequate ECI services. ECI focuses on enhancing early communication skills in infants and caregivers, and may be provided by speech-language therapists, as well as by other professionals collaborating in a transdisciplinary manner with speech-language therapists (Rossetti, 2001).

EI: Early intervention – The primary goal of early intervention is to prevent the occurrence of developmental delays and disorders as early as possible (Rossetti, 2001). In this study specifically with regard to the communication disorders associated with FASD. Early intervention is the broad term used to indicate services by various professionals to infants and young children below the age of three years and their families.

FASD: Foetal Alcohol Spectrum Disorders – This syndrome is the most common preventable cause of mental retardation worldwide. The teratogenic effects of alcohol on the foetus *in utero* are the sole cause. The features of FASD are growth retardation, central nervous system abnormalities, characteristic facial dysmorphology and a positive history of maternal alcohol abuse during the pregnancy, as well as malformations of other organ systems (Carmichael Olson et al., 2007). New terminology was discovered in the literature during the course of this study, regarding the diagnostic term Foetal Alcohol Spectrum Disorders. The new clinical descriptive term currently used, is Foetal Alcohol Spectrum Disorders (FASD) (Carmichael Olson et al., 2007). The significant developmental disabilities that arise from prenatal alcohol exposure are now recognized under the umbrella term of FASD (Carmichael Olson et al., 2007). This new term is indicative of the broad spectrum of disorders that may accompany prenatal alcohol exposure and the variation of the degree of severity of developmental disorder with which young children with FASD may present.

SLI: Specific language impairment – This impairment refers to a category of language impairment that has no obvious cause and seems not to affect or be affected by anatomical, physical, or intellectual problems. Specific language impairment reflects a significant limitation in language functioning involving receptive or expressive language or both (Owens, 1999a). Whereas, communication impairment with FASD can be related to a causative factor of prenatal alcohol exposure and is characterized by accompanying cognitive impairment. Furthermore, all areas of communication and related functions are affected not only expressive and receptive language (Carmichael Olson et al., 2007).

1.4. CHAPTER LAYOUT

The thesis comprises five chapters. A brief description of the contents of each chapter follows.

1.4.1. Chapter 1*: Introduction to Foetal Alcohol Spectrum Disorders*

A general introduction to the diagnostic characteristics of FASD and the risk and protective factors present in the lives of children living with this condition, and their families. The physical, medical, general developmental and communicative characteristics of children with FASD are discussed. The influence of numerous environmental risk factors on the communication development of children with FASD is also discussed. The need for a description of the unique communication characteristics of children with FASD in South Africa serves as the rationale for the study. The problem statement and research question are also posited. Terminology used in the thesis is explained and a chapter layout is provided.

1.4.2. Chapter 2: *Early communication assessment of young children with FASD and their families*

The chapter provides a description of an early communication assessment framework that can be implemented for the comprehensive evaluation of infants and young children with FASD and their families with a view to gain insight into the unique communication characteristics of this special population. The theoretical discussion provides the basis for the communication assessment protocol to be used during the empirical research on infants and young children with FASD.

1.4.3. Chapter 3: *Research method*

The research methodology used in the study is discussed. The study is divided into two phases: the first phase comprises the theoretical development of the assessment protocol and a pilot study, whereas the second phase is the conduction of the research. The research aims, design and criteria used for the selection of the participants are discussed. The reliability and validity of this study are also described. Furthermore, a review of the material and apparatus used is included, and details are provided of the data collection and analysis procedures used to execute the study. Due to the sensitive nature of the research, ethical considerations are also comprehensively covered.

1.4.4. Chapter 4: *Results and discussion*

The results of the study and the discussion thereof are presented. Figures and tables were used to illustrate the results. The results are discussed according to the aims of the study and with reference to the relevant literature.

1.4.5. Chapter 5: *Conclusions and implications for future research*

The implications of the results for theory, clinical practice and further research are discussed. Conclusions are drawn, a critical evaluation of the study is done and recommendations are made for future research in the field.

1.5. CONCLUSION

Infants and young children with FASD may display diverse physical, medical and developmental disabilities, as well as unique communication impairments, and may grow up in maladaptive care-giving environments. Since their communication impairments are comprehensive and include all the different areas of communication development – expressive language, receptive language, pragmatics, oral-motor skills and auditory abilities – a thorough understanding of the unique communication characteristics and language learning environments that can influence the functioning of infants and young children with FASD is vital to the effective early management of their communication problems.

Based on the literature review, it is concluded that a need exists for additional description of the communication characteristics of infants and young children with

FASD. Furthermore, a need was identified for a comprehensive assessment protocol for young children with FASD in order to describe their communication abilities in a holistic way.

A comprehensive communication assessment protocol for infants and young children with FASD must therefore include a case history of the medical aspects and development, an assessment of physical characteristics, general development communication functioning and care-giving environment, either as data collected by way of a structured interview or from direct assessment of the infant or young child. Appropriate guidelines for ECI can only be provided once a thorough investigation of all these aspects has been carried out and the unique communication developmental characteristics of the research participants have been elucidated.

1.6. SUMMARY

Chapter 1 describes the characteristics of children with FASD and the related environmental conditions. The high prevalence of FASD in South Africa coupled with the late identification of these children is described. In addition the characteristics of communication abilities of infants and young children with FASD in terms of their expressive language, receptive language, pragmatics, oral-motor skills and auditory abilities were discussed. The effect of FASD and resulting non-optimal care-giving environments on the communication development of this population is also reviewed. The lack of availability of services in South Africa is highlighted together with issues such as the lack of information regarding FASD in infants and young children.

The need for a comprehensive communication profile was highlighted in order to enable speech-language therapists and audiologists to provide accountable and effective ECI to young children with FASD and their families. The problem statement, rationale and research question were motivated and described. A description of the terminology used in the study is provided, as well as a description of the arrangement of the chapters. In the next chapter, early communication assessment within the framework of the family context will be reviewed.

CHAPTER 2

Early Communication Assessment of Children with Foetal Alcohol Spectrum Disorders and their Families

Aim: To provide a theoretical framework for early communication assessment of infants and young children with FASD and their family environments. The functions and principles of early communication assessment are described and applied to young children with FASD and their families. A four-level framework for assessment is used to provide the theoretical basis for the compilation of the Structured Parent Interview Guide and the Early Communication Assessment Protocol to be used in the research study is discussed.

2.1. Introduction

The theoretical perspectives that serve as foundation for assessment in the study, are two-pronged, namely a descriptive-developmental orientation (Coggins & Timler, 2000), as well as the transactional theory of development (Billeaud, 2003).

The approach to assessment assumed by a descriptive-developmental orientation implies that the communication functioning of typically developing infants and young children serves as a frame of reference to which to compare the functioning of infants and young children with FASD. It is important to draw a comparison in order to establish the attainment of specific communication skills of an infant or young child with FASD's achievement of specific communication skills. Criterion-referenced assessment instruments allow the speech-language therapist to assess the performance of the infant or young child relative to well-defined developmental expectations, further indicating to the therapist the acquisition of a particular communication skill (Rossetti, 2001). Criterion-referenced assessment instruments do not compare the child with a specific group of children that acts as the standard or norm of comparison. In the field of ECI the use of criterion-referenced assessment instruments are preferable over the use of standardized instruments. According to Rossetti (2001), the benefits of criterion-referenced assessment instruments over norm-referenced instruments are to determine a young child's mastery of desired behaviours based on whatever manner in which the behaviour is observed. The criteria function as a developmental profile of mastered behaviours, and based on the

results indicated by the suggested developmental profile, appropriate intervention strategies and suggestions to implement can be deducted.

The transactional theory of development serves as the second theoretical perspective of assessment in the current study. According to the transactional theory of development, there is an interdependency of the biological make-up of the child, the maturation of the central nervous system and environmental processes in the developing child (Billeaud, 2003). Therefore, a logical deduction is that "both typical and atypical language development occurs in conjunction with simultaneous maturation and development across many parameters. Anything that disturbs development in one area has the potential to affect development in other areas" (Billeaud, 2003:9). The transactional theory of development can be applied to early communication assessment of infants and young children with FASD, since environmental factors, such as substance abuse, domestic violence and poor socio-economic circumstances (Adnams et al., 2001), play a major role in the communication development of children with FASD in communities in South Africa. The different risk and protective factors in the environment identified in Table 1.3, and the communication development of infants or young children with FASD are interdependent. In chapter 1, Table 1.2, the presence of cognitive impairments and in Table 1.3 communication disorders, in infants and young children with FASD is indicated. Furthermore, physical and medical impairments in young children with FASD are interdependent, and contribute to the level of developmental functioning of these young children.

The researcher used the descriptive-developmental orientation together with the transactional theory of development to fulfil the functions of early communication (EC) assessment of infants and young children with FASD.

The first function of EC assessment of families with infants and young children with FASD will be to identify the communication impairment as early as possible, preferably before 3 years of age (Rossetti, 2001). In the current South African context, however, the population of infants and young children from zero to five years of age are included in the early intervention group. The rationale for including the preschool population as part of ECI is the late identification of children at risk for

developmental delays, limited ECI service provision and a lack of legislation regarding EC assessment and intervention in South Africa (Fair & Louw, 1999). The earlier communication impairment is identified and treated, the greater the success of the intervention efforts will be (Billeaud, 2003). After the identification of the presence of communication impairment, the description of the communication functioning of the infant or young child with FASD is important.

Lastly, the function of EC assessment would be to facilitate future intervention planning in an ecologically valid manner, i.e. to view the child in his/her context (Coggins & Timler, 2000; Weitzner-Lin, 2004).

It is therefore important to use a detailed EC assessment framework that will delineate specific content areas or domains of communication behaviour and related abilities that, when considered in a holistic manner, provide theoretical guidelines to assessment. Furthermore, the researcher needs to adhere to principles of EC assessment, which may be applied to families with infants and young children with FASD. The application of generally accepted EC assessment principles may provide a valid and theoretically justified frame of reference to conduct assessment in this special population.

2.2. Principles of EC assessment applied to families with children with FASD

The principles of EC assessment are criteria, or theoretically established precepts (Butterfield, 2002), that guide the researcher in conducting ethically valid research regarding the communication abilities of infants and young children with FASD.

Based on Weitzner-Lin (2004) and Rossetti (2001) the following principles of communication assessment used in the field of ECI and depicted in Figure 2.1, are proposed for application in the assessment of infants and young children with FASD. These principles are applied to EC assessment in order to describe the communication functioning of infants and young children with FASD, and the characteristics of their families:

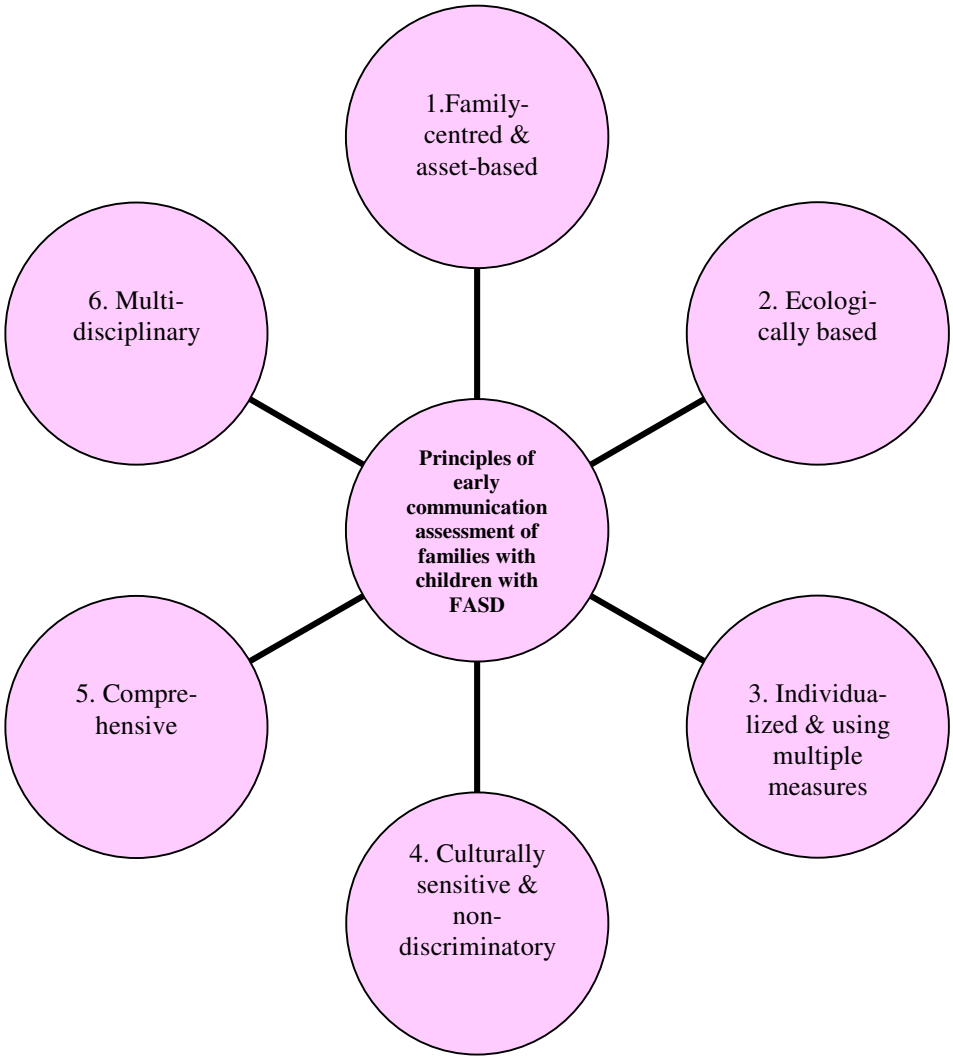


Figure 2.1: Key principles of EC assessment to be applied to families with infants and young children with FASD

2.2.1. Family-centred and asset-based approach to assessment of infants and young children with FASD

A family-centred approach to assessment reflects the paradigm shift that had taken place in EC assessment from focusing on the strengths and needs of the child to assessing the needs and strengths of both the child and the family (Tiegerman-Farber, 1995). This provides the speech-language therapist with a magnified view of the child as part of a family system (Tiegerman-Farber, 1995).

To implement a family-centred approach to communication assessment, the parents/caregivers should be involved as informants and partners in the assessment process (Bailey & Simeonson, 1988; Rossetti, 2001; Weitzner-Lin, 2004). It is,

however, a challenge when a young child is suspected to suffer from FASD, to involve biological parents both as informants and partners, since they may not want to provide sensitive information regarding alcohol or drug use during the pregnancy, or problematic home circumstances (Viljoen et al., 2001b).

Furthermore, the biological parents of a child with FASD may not want to participate actively as partners and may require much support to make decisions. The speech-language therapist has to respect parental autonomy and willing participation, and should be supportive and not act in a patronizing manner towards parents or foster parents (Rivers, 2000). To encourage parents or foster parents to be involved in decision-making and to fully participate in the assessment, the researcher will use a sensitive approach, build a warm, open relationship and let the parents feel valued (Roth & Worthington, 2001).

Following a family-centred approach, it is important to remember that substance abuse is often multigenerational (Belcher et al., 2005), affecting different family members e.g., grandparents, mother, uncles and siblings. Parents themselves may have the impairments associated with FASD. Furthermore, substance abuse usually results from a complex interplay between the individual, the environment and the drug of choice, which in this case is most often alcohol (Belcher et al., 2005). The interplay reflects back to different systems as if nested in one another (Garbarino & Ganzel, 2000), as well as the transactional theory of development where aspects are interrelated. The transactional theory implies that interrelated systems influence the child with FASD, as well as the parents. Therefore, the use of the family-centred approach in EC assessment is important to understand the interrelated systems of each family to develop an individualized approach to assessment.

The researcher needs to keep in mind that the person abusing substances is subjected to considerable social stigma and rejection that could lead to problematic family interactions (Crites et al., 1992). The responsibility of the speech-language therapist is thus to have a clear understanding of and a sensitivity to the complex web of stressors and problems associated with substance use and abuse in families (Crites et al., 1992).

Another aspect that cannot be overlooked in the family-centred approach is foster care. Children with FASD are often placed in foster care, due to unstable and risky home environments (Kaemingk & Paquette, 1999) in the hope of providing a more stable home and care-giving environment and minimizing risk to optimize their developmental outcome (Streissguth et al., 1991; Vig, Chinitz & Schulman, 2005). According to Vig et al. (2005) one of the principal reasons for foster placement in 30-75% of cases in the USA, is parental incapacity due to substance abuse. Further statistics provided by the U.S. General Accounting Office 1994 (Vig et al., 2005), is an estimation that at least 80% of children in foster care in the USA have had prenatal exposure to maternal drug use, including alcohol abuse.

According to Vig et al. (2005:147), "young children who have been removed from their biological families and placed in foster care are at a significant risk of poor developmental outcomes". These young children most likely did not receive optimal nurturing or attachment opportunities and developmentally appropriate stimulation in their biological family set-up, and the foster system was also not adequately geared to provide optimal attachment and developmentally appropriate stimulation on an individual basis. Placement in foster care in itself is therefore an added risk factor in addition to the presence of FASD in an infant or young child.

Foster care may limit the foster family's participation in assessment since foster parents may lack sufficient information to provide detailed answers regarding the child's prenatal exposure to alcohol and other substances, the perinatal and postnatal medical history, as well as the child's achievement of developmental milestones. Therefore, a foster family's role as informants may be limited due to their lack of knowledge about the child's history before foster care.

In the dysfunctional biological family context, exacerbated by substance abuse, neglect is rife and has been linked to children's language problems and even intellectual limitations (Vig et al., 2005). Neglect thus compounds the biological predisposition children with FASD display for receptive and expressive language impairments as well as cognitive impairment, and clearly demonstrates the interrelatedness of areas of developmental delay in children with FASD.

Despite substance abuse and the concomitant contextual factors, such as poor socio-economic status as well as social and family problems; parents of children with FASD are potentially able to provide the speech-language therapist with information of language use and communication interaction of the infant or young child in their home environment. In addition, information regarding communication that takes place in other settings where the speech-language therapist cannot be present can also be provided. The biological or foster parents provide valuable information regarding the child's communication strategies and language abilities when he/she is interacting with other significant communication partners (Rossetti, 2001; Weitzner-Lin, 2004). It is therefore important that the researcher listens carefully during data collection to what caregivers/parents report.

It has also been found that young children with impairments do not respond optimally to assessment that is conducted where only strangers are present (Rossetti, 2001; Sandall, 1997; Weitzner-Lin, 2004). The speech-language therapist thus assesses the child in the presence of parents, and allows them the opportunity to interact naturally with the child to involve the parents fully in the assessment process. Trust should be built from the beginning of contact with the parents so that they feel safe to participate in the assessment process.

During the data collection of the assessment process, the speech-language therapist has to identify protective factors and individual resilience in the infant or young child with FASD and his/her family as assets (Werner, 2000). Protective factors, as identified in Table 1.3, and resulting resilience are the factors to be prioritised for intervention, as these factors have the greatest potential to bring about positive change in the family context (Werner, 2000). Furthermore, an asset-based approach (Ammerman & Parks, 1998) will allow for a more representative description of the young child with FASD's communication impairment. The young child's communication functioning will then be described according to strengths and weaknesses. The strengths and protective factors will be viewed as potential sources of change. Following an asset-based approach is thus essential to valid EC assessment due to the fact that there are numerous risk factors exacerbating FASD in communities in South Africa.

Therefore, family involvement, whether of the biological or foster family, is essential to successful EC assessment. Since family involvement is a challenge in the presence of FASD, using a family-centred approach can be viewed as beneficial to the process of valid assessment. Family involvement can be promoted by enhancing family/caregiver participation. Certain guidelines to promote family involvement derived from Rivers (2000) can be implemented during the parent interview and assessment process. The speech-language therapist must recognize the culture of the family, and emphasize the importance of the parents/caregivers as team members. Furthermore, to ensure ethical conduct during the assessment the speech-language therapist must respect the parents/caregivers' right to privacy and anonymity. During the interview the parents/caregivers must be encouraged to express their needs, concerns and priorities. During the assessment of the infant or young child with FASD the speech-language therapist must aim to ensure optimal infant/child performance by using culturally and linguistically sensitive assessment tools and activities (Rivers, 2000).

If the speech-language therapist uses skills and behaviours that are culturally and linguistically sensitive, successful assessment of families and their infants or young children with FASD may be achieved. To further enhance the assessment process, the ecological context within which the infant or young child with FASD exist, should be considered. The next principle of importance in EC assessment is integrating an ecological approach in the assessment process.

2.2.2. Ecological approach to the assessment of families and their infant or young child with FASD

The culture of the infant or young child with FASD and their family is part of the micro-system of the child and family (Garbarino & Ganzel, 2000). Recognition of the cultural practices in the family is consistent with the ecological approach and is depicted in Figure 2.1.

The researcher must take into account that the infant or young child with FASD exists in a family, a group of people who live together, help each other and have a special relationship (Hughes, 1992). The family is a system and the birth of an infant with FASD can disrupt the family's systemic interaction. The infant or young child with

FASD can be exposed to maladaptive parenting if a substance-abuse problem is present, which can give rise to deprived learning experiences and consequently delayed developmental outcomes (Hughes, 1992).

In an ecological approach to EC assessment the development of a young child with FASD, is emphasized within a certain context. Ecology reflects the relationship between people and their environments, which can represent different systems (Garbarino & Ganzel, 2000; Tiegerman-Farber, 1995). The ecological approach relates to the systems approach. The micro-system is the family's direct interactions with each other on a frequent basis (Garbarino & Ganzel, 2000). The biological, foster family or care-centre represents the micro-system. The micro-system provides interaction patterns to which the developing young child with FASD is exposed to on a frequent or daily basis.

The meso-systems are relationships between micro-systems in which the infant or child experiences reality (Garbarino & Ganzel, 2000; Tiegerman-Farber, 1995). An example of a meso-system could be the relationship between the family and the child's day-care centre. Following the meso-system is the exo-system. The exo-system represents settings that have a bearing on the development of children, but where children do not play a direct role (Garbarino & Ganzel, 2000). An example of an exosystem is the parent/caregiver's workplace and a community health clinic. Unemployment together with social problems, i.e. child neglect and abuse, that are rife in the South African context (Swanepoel, 2004) and related to FASD, can have a negative cascading impact on the child and family affected by alcohol abuse. The different systems are all nested in the macro-systems, which represent the broad ideas, philosophies, demographic and institutional patterns of a particular culture or sub-culture (Garbarino & Ganzel, 2000).

An example of a macro-system that had contributed to the problem of FASD in South Africa in the past was the DOP-system in the Cape wine lands. The DOP-system referred to a unique feature of agriculture in the Western Cape. It is historically categorized as the institutionalisation of alcohol as a medium of payment and social control over farm workers (London, Sanders & Te Water Naude, 1998). The DOP-system left behind an enormous legacy of widespread alcohol abuse. Legislation

implemented in 1928, has made the DOP-system illegal, however, research suggests that it is still in use on farms in the Western Cape region (Te Water Naude, London, Pitt & Mahomed, 1998). The consequences of excessive alcohol use linked to the DOP-system may still be substantial and poses dire problems for effective health-service delivery in the rural areas in this region (Te Water Naude et al., 1998).

Another example of a macro-system effect on families affected by FASD (Garbarino & Ganzel, 2000) is the governmental health, educational, and social grant policies presenting with a lack of appropriate service delivery regarding grant allocation and distribution in rural areas and at government departments in South Africa.

The systems approach embedded in an ecological perspective of child development, therefore adds to the speech-language therapist's perspective, insight and methods of data collection during assessment. The systems approach provides a comprehensive view of the layers of the context surrounding the young child with FASD, which can contribute or detract from the child's developmental outcome.

The ecological approach furthermore aids the researcher in understanding early assessment and intervention within a broader context. This approach provides insight regarding relationships between contributing factors to impairments in an individual - in this case the communication impairment of an infant or young child with FASD.

An ecological approach enables the speech-language therapist to reflect on what is currently happening in the child's life and how to deal with the consequent developmental problems and social pathologies, such as substance abuse, that affect children (Garbarino & Ganzel, 2000). This approach thus aids the speech-language therapist in executing a logical and sensitive action plan to collect data during the assessment process in children and families with FASD. Tiegerman-Farber (1995) also supports the use of an ecological approach in viewing the communication development of the child in a nested system situated in a broader communication system.

Another principle to consider in EC assessment is an individualized approach integrating multiple information sources.

2.2.3. Assessment should be individualized and incorporate multiple sources and instruments to gather information

When the researcher observes the young child with FASD during the assessment, a well-developed picture of the child's communication abilities may be established. This will be achieved by using multiple sources in order to gather rich information to obtain a comprehensive individual communication profile of the young child with FASD.

Multiple sources of information should be utilized during EC assessment to obtain valid information regarding the communication abilities of the infant or young child with FASD (Rossetti, 2001; Sandall, 1997; Weitzner-Lin, 2004). According to Weitzner-Lin (2004), a thoroughly developed overview of a young child's communication abilities cannot be based on one perspective of the child only. The speech-language therapist cannot use one criterion-referenced instrument or test to assess the child's communication strengths and weaknesses.

Billeaud (2003) refers to the professional's toolbox to utilize multiple sources of information, since master craftsmen use an array of different tools to do a job efficiently. The speech-language therapist needs different methods and procedures to assess young children with FASD and their families. Billeaud's (2003) view regarding the utilization of multiple sources, relates to Rossetti (2001), who emphasizes that one source of information regarding socio-communicative competence of the young child, in this case with FASD, is not more important than another.

According to Clarren et al. (2000), a comprehensive evaluation of FASD necessitates multiple measurements, which typically consist of norm-referenced and criterion-referenced measurements (McCauley, 2001), as well as caregiver/parent information. Although criterion-referenced assessment tools are preferred in EC assessment (Rossetti, 2001), norm-referenced instruments are useful with the child older than 36 months (McCauley, 2001). Norm-referenced assessment tools have to be administered in a consistent manner in which test items are to be presented and the young child's performance is summarized meaningfully through the use of percentiles or standard scores (McCauley, 2001; Owens, 1999a). On the other hand, criterion-referenced

assessment tools provide a summary of performance according to developmental levels indicated in ages (McCauley, 2001; Owens, 1999a). An individualized strategy to assessment is very important since children with FASD can vary greatly. The goal of assessment is therefore to describe the unique characteristics of each family and infant or young child with FASD. An individualized approach to EC assessment will entail that the developmental domains remain the same for each child, but assessment instruments and procedures may vary according to the age of the child and the presence of specific disorders, e.g. FASD, which requires specific assessment procedures.

In EC assessment, parents/caregivers and other professionals can be used as different sources of information (Sandall, 1997). It is thus important to follow an interdisciplinary collaborative approach to assessment in FASD (Clarren et al., 2000), to ensure the optimal utilization of all appropriate resources.

According to the literature regarding the EC assessment, (Billeaud, 2003; Owens, 1999a; Rossetti, 2001; Sandall, 1997, Weitzner-Lin, 2004), selecting assessment strategies that will yield the desired information about the communication development of the infant or young child with FASD should be mindfully implemented to obtain valid assessment results. One of the principles, as depicted in Figure 2.1 that can contribute to a valid assessment is to follow a culturally sensitive and non-discriminatory approach.

2.2.4. Culturally sensitive and non-discriminatory approach to assessment

The assessment process should not penalize the child because of race, gender, cultural background, socio-economic status, dysfunctional family interactions and substance abuse present in the family. To adhere to the principle of providing non-discriminatory services, the assessment should as far as possible also be conducted in the child's first language, with a variety of materials using multiple methods to elicit or facilitate communication behaviours (Rossetti, 2001; Louw, 1997; Weitzner-Lin, 2004).

An interview with the family provides further insight for the speech-language therapist into the world of the infant or young child and his/her family. It allows the

speech-language therapist to determine the cultural and environmental influences on the child's communication development in the home, as well as the dimensions of communicative competence that emerge as important to the family and their culture (Rossetti, 2001; Weitzner-Lin, 2004).

The incidence of FASD among certain racial and cultural groups in South Africa is higher than among other groups (Viljoen et al., 2001a). Cultural sensitivity is, therefore, essential when working with young children with FASD and their families. An estimated 7.5 % of children are being affected by FASD in socio-economically disadvantaged areas in the Western Cape. In the Northern Cape, FASD occurs in 10 % of the poor communities. At-risk areas identified in Gauteng province are Soweto (2.2 % incidence), Lenasia South (1.2 % incidence), Westbury (3.7 %), as well as other poor communities in Johannesburg. It is therefore important not to stigmatise these communities even though the high incidence of FASD in their midst has been proven (Department of Health, 2001). While adhering to a non-discriminatory approach, the assessment should also be comprehensive, as indicated in Figure 2.1.

2.2.5. Assessment should be comprehensive

The assessor's responsibility is to ensure that all the important developmental and behavioural dimensions of language and communication are covered during the assessment. The child's performance should be considered in as natural as possible a setting (Weitzner-Lin, 2004). This approach is also advocated by the ecological approach described by Garbarino and Ganzel (2000) and Tiegerman-Farber (1995).

The principle of comprehensiveness thus means, that all developmental areas should be included in FASD assessment. The assessment framework of Kritzinger and Steenkamp (2006) includes all the developmental areas for a comprehensive EC assessment. The comprehensive Four-level EC assessment framework (Kritzinger & Steenkamp, 2006), as used by the Clinic for High Risk Infants and Babies (CHRIB) EC assessment team at the University of Pretoria can provide a theoretical basis for assessing a child and family affected by FASD. This framework was proven effective in providing a comprehensive description of young children's communication abilities. This early communication assessment framework was also used

successfully in research for the comprehensive description of a young child with a genetic syndrome (Kritzinger & Steenkamp, 2006).

The first level of the Four-level Early Communication Assessment Framework, describes physical appearances that may relate to genetic anomalies and determines the child's sensory abilities. According to Kritzinger and Steenkamp (2006) it is important to first gather information regarding the physical appearance and sensory abilities of a child, as it assists in the identification of a genetic syndrome or sensory impairment. The presence of a sensory impairment or genetic syndrome will determine the outcome of the following three levels of the assessment framework (Kritzinger & Steenkamp, 2006).

The second level describes communication functioning and feeding skills of the child. This level provides the speech-language therapist perspective on assessment. Since the main goal of the present study was to present individual distinctive profiles of a small number of infants and young children with FASD's communication skills, this focus was considered appropriate.

Level 3 of the Four-level Early Communication Assessment Framework involved the screening of general developmental domains, such as cognitive and fine motor development. This description can be useful in determining the extent of the participant's developmental difficulties in other areas and the interactions thereof with communication difficulties (Kritzinger & Steenkamp, 2006). The function of screening general developmental areas is also to determine the need for referral to specialized assessment by other disciplines such as occupational therapy.

The last level of the Four-level Early Communication Assessment Framework of Kritzinger and Steenkamp (2006) renders a description of all risk and resilient factors within the child as well as in his/her environment. This Four-level Early Communication Assessment Framework forms part of the CHRIB Assessment Protocol (Louw & Kritzinger, 2002).

The CHRIB assessment protocol was used, because it is a comprehensive EC assessment instrument developed for the South African context and has been

successfully used in the local context (Kritzinger & Louw, 2002) of a highly acclaimed ECI service provider.

In order to provide a theoretical basis for assessing a young child with FASD and their family, the different levels comprising the Four-level EC assessment framework will now be discussed.

Level 1 – Physical appearance & Sensory abilities

- **Visible genetic features**

Communication disorders, feeding difficulties and physical appearance may often be the first indicators of the presence of a syndrome or genetic disorder (Louw & Kritzinger, 1998). Therefore, genetic screening is an additional function of the speech-language therapist during assessment (Louw & Kritzinger, 1998). The speech-language therapist can provide important information regarding the syndrome delineation and the diagnostic process involved (Louw & Kritzinger, 1998). According to Shprintzen (1997) an accurate description of infants and young children with syndromes, such as FASD, can contribute knowledge regarding the phenotypical spectrum of FASD.

A clinical tool to describe a child's genetic features in EC assessment has been compiled by Louw and Kritzinger (1998). This screening tool can assist the speech-language therapist to accurately describe the visible genetic features of infants and young children suspected of FASD and aid in referral for a genetic diagnosis.

- **Hearing ability & vision**

This area investigates the hearing and the visual status of the infant or young child with FASD. A complete diagnostic hearing battery should be performed as a result of the presence of cranio-facial abnormalities such as posterior rotation of the ears and abnormalities of the concha, (Joint Committee of Infant Hearing, 2000) in children with FASD.

According to Madell (1999) the following areas should be investigated: Anatomy of the external meatus, minimum response level for narrow band noise for infants and pure tones for young children. Furthermore, minimum response level for speech, and the

mobility of the middle ear system, the lowest intensity required to elicit contraction of the middle ear muscle, functioning of the outer hair cells of the cochlea, as well as the electrical activity along the auditory pathway should be investigated (Plante & Beeson, 1999).

Children with FASD present with visual abnormalities such as strabismus and myopia - see Table 1.2. Visual status is assessed by observation of eye movements during tracking activities in a play-based setting and through parental report.

Level 2 – Communication functioning & Related skills

A comprehensive assessment of a young child with FASD's communication functioning and related skills will include the assessment of listening skills, oral-motor and feeding skills, as well as receptive language, expressive language, articulation, pragmatics, caregiver-child interaction and emergent literacy skills.

- **Listening skills**

According to Prizant and Wetherby (1993), informal observation may contribute information about a child's functional hearing. The CHRIB Listening Scale is a very useful instrument to utilize during observation (Hugo & Pottas, 1997). The CHRIB Listening Scale was shown to be effective to distinguish between listening skills of different young children with disabilities (Hugo, Louw, Kritzinger & Smit, 2000). It is important that listening skills are evaluated, since many infants and young children present with normal peripheral hearing, but with discernible auditory processing problems (Hugo & Pottas, 1997). Since poor listening skills at an early age as a possible result of chronic otitis media may contribute to later auditory processing problems (Hugo & Pottas, 1997), the evaluation of listening skills in children with FASD is considered very important.

- **Oral-motor & Feeding skills**

Oral motor skills are essential for the child to achieve adequate abilities for eating and drinking by mouth (Swigert, 1998), as well as speech. The birth to two-year level is considered a critical learning period for the development of oral motor skills for eating, drinking and speech production. A critical learning period is a fairly well delineated time when a specific developmental stimulus must be applied to produce a particular action. It

is therefore more difficult to learn a particular behaviour pattern after a critical learning period has passed. Oral motor development has a critical learning period from birth to 2-3 years of age, but many refinements and changes occur in this system until 16-18 years of age (Chapman Bahr, 2001).

From an EC assessment perspective it is thus important to examine the oral mechanism for integrity of structure and function (Billeaud, 2003), especially in children with FASD where the middle third of the face is associated with anomalies. Special attention should be paid to uncoordinated motor sequences in swallowing, biting and chewing (Billeaud, 2003). During assessment the following activities should be observed: eating and drinking, imitative oral movement (toddlers of 24 months and older) and speech production (Chapman Bahr, 2001; Jelm, 1993).

According to literature (Abkarian,1994; Batshaw & Conlon,1997; Carmichael Olson, 1995; Crites et al., 1992; Gerber, 1998; Rivers & Hedrick, 1992; Schoenbrodt & Smith, 1995; Sparks, 1993, 2000), the infancy period in FASD, is characterized by feeding difficulties such as a weak sucking reflex that can be associated with oral-motor dysfunction, lengthened time to initiate sucking, and difficulty regulating the basic feeding cycle due to central nervous system (CNS) impairments. If a cleft palate is present additional feeding difficulties may be expected in an infant with FASD. Infants with FASD display delayed achievement of developmental feeding milestones (Arvedson & Brodsky, 2002). According to Swigert (1998), hospitalised infants with FASD may need naso-gastric feeding because of poor sucking skills, increased fatigue and distractibility. According to Swigert (1998) infants with FASD may not reach complete oral feeding until after one year of age, considering the severity of their cranio-facial disorders and neurodevelopmental disorders (Carmichael Olson et al., 2007). Infants and young children with FASD display an array of symptoms that may delay the development of feeding skills: growth retardation, possible cleft palate, midfacial hypoplasia, thin upper lip, developmental delay, CNS dysfunction and hearing loss (Hall, 2001).

The presence of feeding difficulties may place additional stress on the child and parent/caregiver, which may affect their interaction style, leading to maladaptive interaction patterns (Evens, Louw & Kritzinger, 2004). In FASD there are already other maladaptive parenting practices present due to continued substance abuse. Therefore,

maladaptive interaction patterns may develop due to decreased tolerance by the parent/caregiver to cope with the feeding difficulties of the infant and may compound negative parent-child interaction.

Children with developmental disabilities or severe developmental deprivation such as abuse, neglect and poverty are at an increased risk of experiencing significant feeding disorders and nutritional compromise (Evens et al., 2004; Kedesdy & Budd, 1998). According to Hyter and Way (2007) abuse, neglect and poverty are rife in most biological caregiving contexts of young children with FASD. Kim et al. (1999) noted that poor nutrition is a common experience for children whose mothers are abusing alcohol and/or other illicit drugs. The presence of feeding difficulties can lead to nutritional deficiencies and growth delays. Nutritional deficiencies can lead to increased risk of and susceptibility to infection, especially for otitis media (Kedesdy & Budd, 1998). Infants and young children with FASD already display a high risk for otitis media, as identified in Table 1.2, which can then be further compounded by nutritional deficiencies. Nutritional deficiencies may further affect the neurodevelopmental disorders that are already present (Evens et al., 2004), in infants and young children with FASD.

It is thus evident that there is a transactional effect of the vast array of factors discussed, impacting on the development of children with FASD. A comprehensive assessment, considering the multiple factors influencing oral-motor skill and feeding skill development, is thus of utmost importance in an EC assessment protocol.

- **Receptive language**

This area investigates the infant or young child with FASD's comprehension of language. It is an important domain to assess due to the interrelatedness of comprehension, cognition and language production (Rossetti, 2001). As indicated in Table 1.3 this area has not been well researched, however, children with FASD present with difficulties in following instructions and comprehending semantics.

Receptive language can be assessed during observation of play, parent/caregiver-child interaction and during the parent interview. A criterion-referenced assessment scale, such as the Rossetti Infant-Toddler Language Scale (Rossetti, 1990) can be used. With older

participants (>3 years) a norm-referenced receptive vocabulary test can be used to indicate baseline functioning regarding single-word understanding.

- **Expressive language & Articulation**

Language production involves the combination of linguistic symbols to form meaningful messages (Roth & Worthington, 2004). This area investigates language and speech production regarding, phonology, morphology, and syntax of the young child with FASD. Expressive language reflects the young child's world knowledge (Prizant & Wetherby, 1993).

The expressive language of children with FASD is characterized by verbosity, echolalia, dysfluency, poor narrative skills, difficulty with sequencing of events, short mean length of utterance for their age, syntactical errors, word-finding difficulties and overuse of nouns – see Table 1.3. Expressive language in children with FASD is also reported to be more affected than receptive language – see Table 1.3.

Different means of assessment could be employed to evaluate children with FASD's expressive language skills (Clarren et al., 2000), i.e. age and developmentally appropriate standardized measures, story retelling with the use of picture books or a narrative test for children older than 3 years. Another means of assessment is observation during free play. The structured parent interview also provides added information regarding the development of speech production and the current level of expressive skills of the young child with FASD.

- **Pragmatics**

In infants this area investigates communication functions in terms of means and ways of communication (Prizant & Wetherby, 1993). In older children this area investigates the use of language in social contexts. Different areas are taken into consideration and determined: conversational discourse, appropriate role taking, how information is communicated, communication functions and the purposes of communication (Prizant & Wetherby, 1993; Rossetti, 2001).

According to Table 1.3 – chapter 1 - pragmatics is a domain characterized by several difficulties in young children with FASD. The latter's language use is characterized by

inappropriate topic maintenance and shifting, lack of communication repair, inappropriate use of language to initiate and maintain social discourse, poor eye contact, verbosity and a lack of theory of mind together with struggling to take a communication partner's perspective into consideration.

An EC assessment instrument of pragmatic skills is thus a useful instrument in the information gathering process to aid in providing insight into this developmental domain (Rossetti, 2001). The Rossetti Infant-Toddler Language Scale (Rossetti, 1990) is an example of an instrument, including a subcomponent to assess pragmatics, used in the EC assessment protocol of this study.

- **Infant/child-caregiver interaction**

Synchronous parent/caregiver-child interaction holds positive long-term effects on the development of cognitive, social and linguistic skills in children (Rossetti, 2001). The assessment scale of Klein and Briggs (1987), can be used by the speech-language therapist to describe interaction strategies used by the parent/caregiver regarding their communication interaction strengths and weaknesses. The primary purpose of assessing parental interaction style is to help the parent/caregiver develop an awareness of strategies that they are using that may facilitate successful and positive interactions (Prizant & Wetherby, 1993).

The observation of a match between a parent/caregiver's style and an infant or young child's ability to participate actively and successfully is an important part of the communication assessment (Prizant & Wetherby, 1993). A qualitative description of the parent-child interaction aids understanding of the child in the context of the family (Rossetti, 2001).

As no research studies on mother-child communication interaction between children with FASD and their parent could be found in the literature, it reflects a need for the description of this aspect of communication. The description of mother-child communication interaction in this study may therefore provide new information.

According to Harty (2004) parental beliefs also influence the structure of the early physical environment, the amount of stimulation or opportunities provided, as well as the

parents' general expectations of their child. Furthermore, parental beliefs can also influence parents' sensitivity to their child's needs.

As further stated by Harty (2004), if the communication interaction is perceived as successful the mother's competence increases. However, in the presence of FASD and the resulting neurodevelopmental disorders of the child, interaction can be perceived as unsuccessful, in which case it may lead to feelings of increased stress and decreased competence in the mother. The risk of unsuccessful interaction between infants and young children with FASD and their parent may negatively impact on the acquisition of communication skills, as well as other developmental skills.

It is clear that the process of mother-child communication interaction is embedded within a broader context in which ecological factors, such as socio-economic status, family structure and cultural values, may all contribute towards the maintenance or adjustment of parental perceptions, beliefs and behaviours (Harty, 2004). The mother's beliefs and perceptions influence the formation of parent-child communication interaction and child development over time. When interaction is taking place with a child with disabilities, such as FASD and its concomitant impairments, adults tend to produce a high percentage of questions, commands, and requests for clarification, whereas the children tend to produce yes/no answers and only provide information when requested (Harty, 2004). It can thus be expected that the parent or caregiver interacting with the young child with FASD, may adopt a more directive style, due to the fact that they may not be able to accurately perceive the communication development needs of their infant or young child with FASD.

- **Emergent literacy skills**

Children with specific speech and language impairment often have associated literacy problems (Stackhouse, 2000). Research suggests that children who have early language delays are at risk of reading difficulties in the elementary school (Kaderavek & Sulzby, 1998).

It is therefore important to assess emergent literacy skills as part of the child's communication abilities (level 2). A valid method to assess this skill is through joint picture- or storybook reading (Anderson-Yockel & Haynes, 1994). Joint book reading is

a caretaker-child interaction activity reported cross-culturally (Anderson-Yockel & Haynes, 1994) and appears to be a highly revered and widely practised routine within and across cultures (Kaderavek & Sulzby, 1998).

During this activity important components to potential language development are embodied, namely to establish routines for predictability, to focus the child's attention which is an important skill for the development of joint attention, and to provide semantic contingency, structure and scaffolding opportunities (Anderson-Yockel & Haynes, 1994; Kritzinger & Louw, 1997). The advantages of joint book-reading activities are that children with limited vocabularies and children with language delays benefit from it (Anderson-Yockel & Haynes, 1994). Furthermore, being read to aloud is considered to be the single most important factor in preparing a child to learn to read (Kritzinger & Louw, 1997).

Kritzinger and Louw (1997) also suggested that joint book reading could be used as an early intervention strategy to help prevent or minimize the effects of language disorders and learning disabilities in the South African context. In the context of FASD, family poverty and low levels of literacy among parents emphasizes the need to enhance school readiness in children with FASD. Therefore the facilitation of emergent literacy skills through appropriate early intervention activities is needed in the population of children with FASD to enhance their future success at school.

Therefore, adding the context of parent-child joint book-reading interaction to the EC assessment protocol will offer another ecologically valid family-level interaction situation to observe during assessment (Kaderavek & Sulzby, 1998).

Communication assessment in a young child with FASD should thus consist of a comprehensive approach to assess all the various interrelated aspects contributing to a young child's communication profile. It is thus evident that the different areas of communication skills comprising level 2 of the EC assessment framework, lend themselves to provide a valid and comprehensive description of the child's communication abilities and weaknesses. To establish an insightful profile of a young child with FASD's functioning it is important to include the screening of general developmental abilities of the young child.

Level 3 – General development

General development is screened, as in-depth assessment of social interaction, cognition, perception, play, self-help skills and motor skills, is not part of a communication assessment. The aim of screening is to detect difficulties and refer to the appropriate team members. According to Kritzinger and Steenkamp (2006), this level of general development can be utilized as comparison to the communication assessment results to provide a clearer view regarding the extent of the infant or young child's developmental difficulties.

Screening of all the developmental domains under the umbrella of general development is conducted through the gathering of information from a variety of sources. Information is gathered from the structured parent interview, completion of a general development assessment instrument, and observation during the entire assessment session. A number of areas are to be screened to obtain a clear view of the interrelatedness of different developmental domains as described in the transactional model of development (Billeaud, 2003).

- **Social interaction skills**

Social interaction skills refer to the interaction of a young child with other people. These skills play a role in parent-child attachment, the modelling of others behaviour and the establishment of relationships (Louw, Van Ede & Louw, 1999).

Young children with FASD present with problems in the area of social interaction skills (Carmichael Olson et al., 2007; Henry, Sloane & Blackpond, 2007). Their social interaction is characterized by poor pragmatic skills contributing to less successful interaction with peers (Coggins et al., 2007; Henry et al., 2007) in conversational, educational and play contexts.

- **Cognition & Perception**

Cognition refers to the way in which the infant or young child gathers information regarding his/her world, and then utilizes this knowledge to guide behaviour. Examples of cognitive behaviours are attention, memory, conceptualisation, thinking

and association. Cognitive development thus refers to the refinement of cognitive processes and products (Louw et al., 1999).

The inclusion of the screening of cognitive and perceptual skills is justified by the presence of cognitive impairments and perceptual difficulties in young children with FASD as indicated in Table 1.1.

- **Play**

In the case of young children with FASD, they may struggle to progress to symbolic play stages due to the presence of cognitive impairments, and their play may also reflect more simple play schemata. Change in play complexity is generally accompanied by changes in communication status (Rossetti, 2001).

Knowledge of the level of a child's play development provides the speech-language therapist with a functional baseline of the child's overall developmental level. The relationship between symbolic play and communication is well established, and the quality of play stages reflects early cognitive development (Rossetti, 2001). Play is therefore a window to gain insight into a child's cognitive abilities, temperament, receptive communication, expressive communication and socialization (Billeaud, 2003). Furthermore, underlying abilities such as joint-attention, sustained attention, manner and form of manipulation of objects and bids for interaction in play activities can be judged through skillful construction of opportunities to observe the child at play (Billeaud, 2003).

Young children with FASD may have difficulties with joint and sustained attention, due to possible attention impairments, as indicated in Table 1.1. They may also experience difficulty with bids for interaction in play activities, since the children struggle with appropriate initiation and turn-taking, as also indicated in Table 1.1. Cognition and play therefore are important skills for the speech-language therapist to screen in FASD, as they will provide additional information of a child's communication development. Environmental deprivation such as decreased exposure to developmentally appropriate toys due to poverty or neglect should also be taken into consideration during assessment of play skills.

- **Independence & Self-help skills**

Independence refers to the acquisition of skills to master certain tasks independently, without the help of an adult (Louw et al., 1999). The mastery of skills promotes self-confidence in the young child's belief in his own abilities. Since children with FASD present with impulsive behaviour, poor self-confidence, feelings of insecurity and being easily frustrated (Carmichael Olson, 1995; Colangelo & Jones, 1982; Jacobson et al., 1993; Steinhausen et al., 2003), these difficulties can have a negative impact on their mastery of self-help skills. Long-term effects of poor self-help skills contribute to difficulty in independent living as adults (Williams, 2001).

- **Motor skills**

A certain level of nerve, muscle and skeletal development is required to facilitate appropriate motor development for fine and gross motor movement (Louw et al., 1999). The developmental attainment of motor milestones will enable the young child to gradually master total body movement.

Although this is the domain of the physiotherapist and occupational therapist with in-depth expertise regarding early motor development, a general indication of the level of motor skill development is an important contribution to a holistic view of an infant or young child with FASD' developmental functioning. Due to the interrelatedness of communication and general developmental skills the inclusion of all indicated domains on level 3 of the EC assessment protocol will enable the speech-language therapist to integrate all developmental findings. To establish a perspective of the young child with FASD's general developmental functioning, the influence of the risk and resilience factors present in the young child's life should also be considered.

Level 4 – Risk & Resilient factors

To aid the researcher in a consistent asset-based and family-centred approach to valid EC assessment a clear view of the unique risk and protective factors present in the infant or young child with FASD and their family is required. A profile of these factors can then be compiled with information obtained during the structured interview. According to Kritzinger and Steenkamp (2006), level 4 allows the speech-language therapist a current realistic view of the young child. On this level of

assessment risks are identified and resilient factors are utilized for intervention planning and guiding parent support.

The CHRIB Assessment Protocol (Kritzinger & Louw, 2002) provides a list of areas and instruments to utilize during the assessment of a young child with FASD. The Four-level framework (Kritzinger & Steenkamp, 2006) organizes all the areas in four descriptive categories or levels.

To allow for holistic assessment of the young child with FASD, the speech-language therapist should thus pay attention to all four levels of the assessment framework (Kritzinger & Steenkamp, 2006). Since the assessment of children with FASD comprises such a wide range of assessment areas a team approach to assessment is required.

2.2.6 Interdisciplinary team approach to assessment

Guralnick (2000) advocates an interdisciplinary team approach to the assessment of infants and young children with disabilities. A cooperative and systematic effort among different professionals that move toward more cohesion among team members is required (Rossetti, 2001). Due to the complexity and sensitivity of the presence of FASD in a young child and therefore the family, an interdisciplinary approach to assessment is essential. An interdisciplinary team approach assists the speech-language therapist to gather rich information regarding the child with FASD's history and development to expand the comprehensive EC assessment. A variety of different team members should thus be utilized – see Table 2.1.

Table 2.1 The role of team involvement in EC assessment using the Four-level Early Communication Assessment Framework

Team member	*Level of involvement*	*Function*
Paediatric neurologist	**Level 1**	Diagnosis of FASD
	Level 3	Assessment of neuro-developmental status
Geneticist/Dysmorphologist	**Level 1**	Diagnosis of FASD
Opthalmologist	**Level 1**	Assessment of visual status
Audiologist	**Level 1**	• Determine hearing status • Determine presence of central auditory processing disorders (CAPD)
	Level 2	Assessment of listening skills
Speech-language therapist	**Level 2**	• Assessment of communication and related skills • Determine impact of impairment on communication interaction
	Level 3	• Screening of general developmental domains
	Level 4	• Determining the presence of risk and resilient factors
Dietician	**Level 2**	• Determine nutritional status • Address nutritional deficiencies and concerns
Occupational therapist	**Level 1**	• Assessment of sensory integration • Assessment of visual perception
	Level 3	• Assessment of cognition and motor skills • Determine impact of impairment on participation in activities of daily living (ADL) and learning
Physiotherapist	**Level 3**	• Assessment of gross motor movement • Determine impact of impairment on mobility
Clinical or educational psychologist	**Level 4**	• Assessment of family interaction, coping mechanisms and support structures
Social worker	**Level 4**	• In-depth analysis of family context • Description of socio-emotional and financial status of the family

According to Table 2.1 each professional has a function or role to play in the interdisciplinary assessment process of young children with FASD and their family context. The speech-language therapist should be competent in sourcing information from the parent/caregiver regarding other professionals' involvement with the young child with FASD and contacting team members to discuss findings in a collaborative interdisciplinary meeting.

Although Rossetti (2001) advocates transdisciplinary teamwork in EI, it is deemed by the researcher that interdisciplinary teamwork is more realistic in South Africa, due to the lack of policy guidelines to form professional teams. The speech-language therapist in South Africa must therefore work within existing structures.

The assessment information collected by the interdisciplinary team can aid the speech-language therapist to establish a holistic picture of the child's functioning across all developmental domains and provide further information regarding the family/caregiver context. Guralnick (2000) also recommends interdisciplinary assessment when working in the field of EI.

The transactional approach (Billeaud, 2003) together with the descriptive developmental orientation (Coggins & Timler, 2000) should also be incorporated in the interdisciplinary assessment approach as justified earlier in this chapter.

An interdisciplinary team approach will aid all team members to choose appropriate assessment strategies, discuss and refine treatment goals as a team after the completion of the assessment process. The specific model of teamwork recommended for families affected by FASD is not often indicated in current literature, however Atchison (2007) stated that the general consensus is that teamwork is deemed as important for facilitating optimal developmental outcomes. Further in-depth research regarding the most appropriate teamwork model for interacting with infants and young children with FASD and their families in the South African context is thus necessary.

In conclusion, all the principles of EC assessment discussed should be utilized for the optimal benefit of each young child with FASD and the family. These principles, as depicted in Figure 2.1 can guide the speech-language therapist to provide more appropriate assessment and treatment services for this unique population.

All the principles of EC assessment should be implemented by the speech-language therapist to provide a valid profile of the infant or young child with FASD's communication skills and developmental abilities. These principles were integrated in the Four-level EC assessment framework that can be used in the empirical study.

2.3. Suggested integrative EC assessment for young children with FASD

To integrate the principles of EC assessment, the Four-level framework was incorporated in the CHRIB Assessment Protocol to meet the unique assessment needs of FASD. An integrative summary of the assessment framework is presented in

Figure 2.2 to assist the speech-language therapist with research-based assessment procedures. In order to delineate specific content areas of a child's communicative behaviour and related abilities that are to be assessed, an integrative assessment framework is required, to provide a comprehensive and valid portrait of a young child (Prizant & Wetherby, 1993) with FASD's distinctive communication profile and family/care-giving context. An integrative summary of the suggested Four-level EC assessment framework is depicted below in Figure 2.2.

As is evident in Figure 2.2 the suggested EC assessment framework aims to provide guidelines for the research assessment protocol and furthermore, to provide clinical guidelines to speech-language therapists working in the field of ECI. When encountering children with FASD in their caseload, this integrative assessment approach may aid the speech-language therapist to deliver valid assessment services to the population of infants and young children with FASD and their families.

2.4. CONCLUSION

Families with infants and young children affected by FASD are a unique population with complex needs. Currently there is a growing body of researchers describing data regarding the teratogenic effects of alcohol on central nervous system function and physical development, the diversity of children with prenatal alcohol exposure and their families, as well as the developmental and behavioural characteristics of this clinical population (Carmichael Olson et al., 2007). Therefore the professional working in the field of EI should implement research findings in order to provide appropriate assessment and intervention to infants with FASD and their families.

The EC assessment principles gleaned from a thorough review of ECI literature, Kritzinger and Steenkamp (2006)'s four-level EC assessment framework and the CHRIB Assessment Protocol (Louw & Kritzinger, 2002) with the added context of the environment (See Figure 2.2) were integrated to guide the empirical research of the study. By increasing the understanding of all EI team members regarding risk factors, vulnerabilities and complex service needs of infants and young children with FASD and their families, EI professionals can become effective advocates and provide services that ameliorate risk and optimise outcomes for these children and their families (Vig et al., 2005). The aim of this chapter, to provide a theoretical framework for EC assessment of young children with FASD and their family environments, was successfully achieved. A further aim was to provide a theoretical foundation for the compilation of the Interview Schedule and the Early Communication Assessment Protocol through use of a two-pronged theoretical foundation obtained from the transactional approach to development (Billeaud, 2003) together with a descriptive-developmental orientation (Coggins & Timler, 2000). The use of the Interview Schedule and the Early Communication Assessment Protocol in

the empirical research of the study, were justified and motivated comprehensively with reference to the abovementioned theoretical foundation.

2.5. SUMMARY

EC assessment principles were discussed, and an integrative EC assessment approach for FASD was proposed. In the following chapter on the methodology of the research study the researcher based the data collection instruments on the theoretical perspectives and application of EC assessment principles derived from the comprehensive literature review presented in Chapters 1 and 2.

CHAPTER 3

Research Method

Aim: To provide an overview of the research methodology followed in the investigation of the unique communication characteristics of a small group of infants and young children with FASD. The aim and objectives of the research project, the research design, ethical issues, selection criteria, participants, materials, data collection, procedures, analysis procedures, validity and reliability are described in this chapter.

3.1. INTRODUCTION

The methodology of a research study demonstrates the process followed in planning the study, executing the research to obtain data and the steps followed to analyze and interpret the data (Leedy & Ormrod, 2005). The methodology therefore provides a window into the researcher's mind to view the planning and procedures implemented during the research process (Leedy & Ormrod, 2005). According to Strydom (2002b), the comprehensive description of the methodology helps the researcher to develop confidence in the methods that will be utilized. Furthermore, the methodology aims to elucidate, in a clear and precise manner, the relationship between the research question and the data being collected (Strydom, 2002a).

3.2. AIMS OF THE STUDY

3.2.1. Main-aim

The main aim of the study is to present the distinctive communication profiles of a small group of infants and young children diagnosed with FASD.

3.2.2. Sub-aims

- To describe the developmental histories of the infants and young children with FASD.
- To provide a description of their family/care-giving contexts.
- To describe the communication functioning of each participant with FASD in order to present communication profiles of the children.
- To describe the developmental trend of communication skills emerging from the group of participants.

3.3. RESEARCH DESIGN

A collective case study design was selected. A collective case study enabled the researcher to focus on multiple cases in-depth, in this instance, five young children with FAS. A collective case study design is thus the in-depth study of a small number of individuals to gain more understanding regarding certain characteristics (Leedy & Ormrod, 2005). Due to the limited number of participants that could be selected, the participants were too heterogenous to describe as a group. Fouche (2002) furthermore describes the collective case study as the examination of a group of cases in order to compare the characteristics of the individual participants with one another to describe the differences and similarities. The collective case study can also be utilized to indicate changes over time (Leedy & Ormrod, 2005), therefore it allowed the researcher to indicate a developmental trend across the five participants developmental ages.

The advantages of utilizing a collective case study design were that it enabled the researcher to learn more about individuals in a poorly understood population (Leedy & Ormrod, 2005). The in-depth exploration of a small group of participants allowed the researcher to use multiple sources of information that are rich in context, and enabled the researcher to situate these cases in its larger applicable context (Fouche & Delport, 2002). A weakness of a collective case study is that the findings of a small sample cannot be generalized (Leedy & Ormrod, 2005). This was the case in the present research study.

To suit the aims of the study an additional method was utilized. A cross-sectional method was used because the researcher collected all the data at a single point in time (Leedy & Ormrod, 2005). Child participants from different age groups were only studied once in the course of the research process (Leedy & Ormrod, 2005). The composite data of each child were then plotted on a single graph in order to indicate the trend in development over time (Leedy & Ormrod, 2005). This developmental trend graph enabled the researcher to identify a possible underlying pattern that characterize the collective case more broadly than a single case study could reveal (Leedy & Ormrod, 2005).

The advantages of a cross-sectional survey were that results could be obtained relatively quickly during a face-to-face interview with the caregiver and an individual assessment of the child. The structured interview instead of a self-completed questionnaire was selected because of the possible expected low literacy level of some of the parent/caregiver participants, as well as the low rate of postal returns of questionnaires (Leedy & Ormrod, 2005). The survey method was also cost-effective since a single meeting was scheduled for the interview and the assessment session, which took place at the same location on the same day. Transport costs were therefore limited. The design rendered large volumes of descriptive data that enabled the researcher to compile a comprehensive communication profile of each young child with FASD. Another advantage of the cross-sectional method was the decreased intrusion in the lives of the research participants since the data gathering took place only once (De Vaus, 2001; Leedy & Ormrod, 2005).

A quantitative descriptive approach was used, since the number of participants was only five, no correlations could be computed between the participants' characteristics (De Vaus, 2001; Leedy & Ormrod, 2005). A descriptive research design is the most widely used design in the field of social research (De Vaus, 2001). The descriptive nature of the approach enabled the researcher to compile a characteristic profile of each of the participants, through the use of in-depth case studies. A disadvantage of a descriptive research design is that causation cannot be determined. Therefore, specific characteristics of the young children could not be ascribed to the child's care giving environment or to the child's constitution (Leedy & Ormrod, 2005).

To increase the trustworthiness of the results triangulation of data (De Vos, 2002a) was used. In order to aid the internal validity of a study triangulation of multiple sources are used to answer the research question and to identify common themes gleaned from different sources of data (Leedy & Ormrod, 2005). The following sources of data were used for triangulation: parental report, researcher observation (direct and video recording), as well as a second rater of parent-child interaction. The description of the care-giving context enabled the researcher to follow an ecological approach and place the participants in their environments with all the contributing variables in order to understand the family systems and their interactions (Billeaud, 2003; Garbarino & Ganzel, 2000).

A purposive sampling procedure was selected (Strydom & Delport, 2002), due to the limited availability of infants and young children diagnosed with FASD and their accessibility for research.

As there were more advantages attributed to the selected research design than disadvantages, a collective case study following a quantitative research strategy, deemed appropriate to describe the distinctive communication functioning of a small number of young children with FASD. Since observational assessments of behaviour and structured interviews are the preferred methods of data collection in descriptive research (Leedy & Ormrod, 2005; Robson, 2000), these two methods were thus used in order to present an integrated description of the child participants' communication functioning and their families.

3.4. RESEARCH ETHICS

The approval of the Research Proposal and Ethics Committee of the Faculty of Humanities, University of Pretoria, as well as the approval of the Medical Research Ethics Committee Gauteng Department of Health, was obtained prior to the commencement of the study (see Appendix A). The approval of the Medical Research Ethics Committee was sought since the public health system was identified as a possible source of research participants.

A researcher has an obligation to research participants to maintain the highest possible level of confidentiality regarding their personal information (Leedy & Ormrod, 2005). Due to the sensitive nature of this study, relating to parental abuse of alcohol and the effect thereof on children, participants' identities were to be kept confidential. However, confidentiality applies to all studies irrespective of the sensitive nature thereof. Since names were attached to the interview schedules and video recordings of the data-collection sessions, it was important that the interview schedules were read only by the researcher and the study leaders, and that the video recordings were only viewed by the researcher, a second rater and the study leaders. The information obtained from the interview schedules and video recordings was only used for the purposes of the present study. During analysis of the interview data, as well as the

assessment data, numbers were allocated to each participant (Participant 1 – P5). The discussion of the results did not contain any names. In this manner confidentiality of the research participants was ensured, and the sensitive nature of the presence of FASD in families was considered.

Parents/caregivers gave informed consent to participate in the study, as this is a very important ethical principle (Strydom, 2002b). According to recommendations by Leedy and Ormrod (2005), a letter of informed consent together with an information leaflet (Appendix C) were given and explained to the caregiver/parent of the research participants. This was done to ensure voluntary participation and to confirm that the caregiver/parent understood the nature, purpose and methods of the study as well as their role and the level of involvement. The caregiver/parent could contact the researcher to access the results of the study. The right of the caregivers/parents to withhold information or to withdraw the research participant from the study at any stage without negative consequences to them was made known to them (Leedy & Ormrod, 2005).

During the study care was taken not to deceive participants. Full disclosure regarding the assessment results was provided to the parents/caregivers of the participant regarding the child's developmental levels after the assessment (Strydom, 2002b) as to ensure truthfulness. The parents/caregivers were able to contact the researcher at all times for the duration of the study. All data collected during the assessment session were compiled into an assessment report that was given to the parent/caregiver if requested. Recommendations were included in the report and referrals to appropriate services were made if requested by parents. The researcher was available to answer any arising questions.

3.5. PHASES OF THE EMPIRICAL STUDY

These phases, as utilized by Uys (2000), clearly outline the different stages of the empirical study.

3.5.1. Phase 1

This phase entailed the development of the Interview Schedule and the Assessment Protocol. A literature study was conducted and on the basis thereof the compilation

of the Interview Schedule and Assessment Protocol was carried out. To conclude phase 1 a pilot study was conducted.

3.5.2. Phase 2

This phase comprised the collection and recording of data, followed by the analysis of the data, the interpretation of the data and the implications drawn from the research. The phase culminated in a description of the distinctive communication abilities of each case and a comparison between the cases, as well as the indication of a developmental trend across the participants.

3.6. SAMPLE

3.6.1. Sampling method

The sampling method selected for the study was non-probability sampling, since there was no way of guaranteeing that each element of the FASD population would be represented in the sample (Leedy & Ormrod, 2005). Non-probability sampling is a purposive sampling method where the participants are chosen with a particular purpose in mind (Leedy & Ormrod, 2005). As a result of the difficulty experienced to recruit young research participants with a diagnosis of FASD non-probability sampling was appropriate. Recruitment of infants and young children with a medical diagnosis of FASD appeared to be problematic, possibly due to the late identification of this population, which usually only takes place at school-going age in South Africa (Viljoen & Krause, 2001).

3.6.2. Participant selection criteria

The selection criteria for research participants in the study were as follows:

- The research participants had to have a diagnosis of FASD on the continuum of the spectrum, which include a spectrum of diagnostic characteristics. Characteristics such as a height or weight less than the 10th percentile for gestational age at birth or later in life, evidence of structural, functional or neurologic brain impairment, small palpebral fissures (eye slits), a thin upper lip and a smooth philtrum, reliable evidence of maternal alcohol consumption, but if

evidence not obtained, it is not deemed necessary if the cluster of facial features is fully present. (Carmichael Olson et al., 2007).

- The age of the research participants had to be between 0 – 5 years to comply with the aims of the study to investigate a group of infants and young children eligible for EI.
- The research participants had to be geographically located in the greater Pretoria, Gauteng area. A study by Viljoen et al. (2001a) indicates that at-risk communities in Gauteng are reported to have a high prevalence of children with FASD. This would make access to participants possible and more time and cost effective for the researcher.
- Caregivers/parents of the research participants had to provide informed consent (verbal or written) to participate in the research study.
- The first or second language of the caregivers/parents and children had to be Afrikaans or English, since the researcher is competent in these two languages only.

3.6.3. Sample size

The sample size utilized in the study was dependent on the availability of participants complying with the selection criteria. Recommendations from the statisticians who had been consulted before data gathering ensued, suggested that the largest possible sample size should be selected to render as much data as possible to analyze. The implication was that the smaller the sample size, the fewer statistical analysis procedures could be applied. In this study the sample size was small and non-representative, therefore no statistical analyses could be performed. The data gathered from each participant was first presented individually in the form of five single case studies and then as a collective case study design (Fouche, 2002; Leedy & Ormrod, 2005). According to Doehring (2002), case studies are used to provide evidence about individuals, such as the parents/caregivers and infants and young children with FASD, that are not usually intended to be generalized to a population. Therefore, inferential statistical analyses were not possible (Doehring, 2002) and results were presented as descriptive statistics.

3.6.4. Participant selection procedures

The particular purpose of the study was to describe the communication profiles of young children prenatally exposed to alcohol. Participants in the study had to be infants or young children already diagnosed with FASD by a medical specialist. The sample in the study was therefore based on the researcher selecting young children already diagnosed with FASD.

Several institutions and professionals were contacted to recruit possible participants: the Department of Genetics at a university in Gauteng, a paediatric neurologist at an academic hospital, the Facial Deformities Clinic at a leading academic hospital in Pretoria, an occupational therapist working at a Child Therapy Centre at the academic hospital, a community nurse involved in a local community with a high prevalence of FASD, a community clinic and the preschools in the same community, as well as two places of safety for children in Pretoria. Only the paediatric neurologist and one place of safety were able and willing to provide names of children diagnosed with FASD.

The paediatric neurologist identified a possible suitable research participant who also complied with the selection criteria of the study. The participant was utilized for the pilot study and the main study. The other four participants in the study were all recruited from the one place of safety where the centre administrator provided information regarding suitable participants. Due to the limited availability of participants conforming to all the selection criteria, as well as the sensitive nature of FASD, only five participants could be selected. However, there were many possible participants with FASD symptoms who came to the researcher's attention, but they had not yet been diagnosed with FASD. Due to the lack of a FASD diagnosis in these possible participants, they could not be included in the study. Therefore, the participant recruitment process confirmed the late diagnosis of children with FASD in South Africa, as was found by Viljoen and Krause (2001).

3.6.5. Participant characteristics

The characteristics of the interview participants are summarized in Table 3.1.

Table 3.1: Description of interview participants (n=7)

Characteristics	Value
Gender of participants taking part in the interview:	Male : 2 Female : 5
Parental status	Foster parents: 5 Adoptive parents: 2
Educational level of foster parents:	Mothers : 3 degree level, 2 matric Fathers: 1 degree level, 1 matric
Occupations:	Mother: kindergarten teacher, 2 housewives, librarian, joint shop owner and manager Father: joint shop owner and manager, mechanic

According to Table 3.1, the interview participants in the study were either foster or adoptive parents. Two fathers participated with their wives. No biological parent of the child participants took part in the study. One couple were adoptive parents, another couple were busy adopting one of the child participants and the other interview participants were temporary foster parents. The temporary home situation indicated that there were uncertainties present in the lives of families and child participants (Vig et al., 2005).

Other characteristics of the interview participants indicated that all were educated and employed. The interview participants reported that the social workers did not provide detailed background information of the biological parents to them.

Table 3.2: Description of child participants (n=5)

Characteristic	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5
Chronological age	4 months	18 months	35 months	51 months	58 months
Age at diagnosis of FASD	At birth	15 months	28 months	48 months	At birth
Age placed in foster care system	5 weeks	12 months	26 months	24 months	From birth
Number of placements in foster care	1	2	2	3	1
Age of adoption	Not yet	In process	Not yet	Not yet	7 months
Gender	Male	Male	Female	Female	Male

According to Table 3.2 all the participants spent various periods in the foster care system. During the participants stay in the foster care system some of the participants spent time in various care centres as well as with multiple foster families. According to Table 3.2 the participants had a variety of number of placements in foster care from one placement up to three placements in foster care. It is further evident from Table 3.2 that the participants had a wide age range. Four of the five participants had only been diagnosed with FASD after being placed in foster care. The foster parents were unaware of the children's condition when taken into foster care. It is thus admirable that they all plan to adopt the child, despite the diagnosis of FASD. Table 3.2 indicated that the earlier the child participants were placed in foster care the earlier the diagnosis of FASD was made. Thus it can be inferred that foster placement could possibly facilitate earlier identification and diagnosis of the child's condition. According to Vig et al. (2005), children placed in the foster care system in the USA are usually thoroughly examined by medical specialists and referred to related team members such as therapists, when necessary. Failure to attend to medical or developmental needs in the child participants' biological family could have been present due to poverty, lack of accessible services and alcohol abuse in the family (Vig et al., 2005).

The early diagnoses of participant 1, 2 and 5 indicated that very early diagnosis of FASD is possible in South Africa, although not prevalent according to Viljoen et al. (2001a). Additional characteristics of the participants indicated that gender was not equally divided between participants, and could be viewed as an incidental distribution.

3.7. MATERIAL AND APPARATUS

The material used during data collection for the study was:

- Parent/Caregiver Information Leaflet and Informed Consent – Appendix B
- Interview Schedule – see Table 3.3 and Appendix C
- Communication Assessment Protocol – See Table 3.4 and Appendix D

The apparatus used during data collection and analysis were as follows:

- Video camera - Panasonic VZ10 VHS-C Movie Camera
- Video cassettes – 45 minute TDK VHS-C HS

- Audio cassettes – TDK 60 minute
- Audio tape recorder – Sony TCM-343 Cassette-Recorder
- VCR – Sansui Video Cassette Recorder VC-R250EI
- Colour monitor to view and analyze video recordings - AIM TV S21 54 cm
- Developmentally appropriate toys and children's books to elicit communication behaviours from the participants (Rossetti, 1990; Roth & Worthington, 2001).

3.7.1. Parent/Caregiver Information Leaflet and Informed Consent

The content of the leaflet included a description of the:

- *Nature of the study:* The parents/caregivers would be informed that the research would include a structured interview with them and an assessment session to investigate the communication skills of the young child prenatally exposed to alcohol and/or other substances and their care-giving environments.

- *Purpose of the study:* The parents/caregivers would be informed that the purpose of the study is to describe the communication skills of young children who were prenatally exposed to alcohol and/or other substances, in order to provide clinical guidelines to speech-language therapists and audiologists to assist them in the assessment and therapy of the children and their caregivers.

- *Procedures of the study:* The investigator would interview the parents/care-givers for 30 – 45 minutes regarding their child's developmental and medical history as well as the care-giving situation. The information required about their child is of such a nature that they will be able to answer the questions. The investigator would assess their child for approximately 60 minutes during which they will participate in some play and book-reading activities. The investigator would play with their child during the assessment and their child would not be forced to do something. The investigator was trained to work with young children and their parents. The parent/caregiver and child would not be separated at any time during the assessment. The interview would be taped on a recorder and certain parts of the assessment session would be video recorded for later analysis by the investigator. The interview and assessment would be scheduled at their convenience.

- *Rights of the participants:* The parents/caregivers would be fully informed of their rights as participants in the research study. Their participation in the study is

entirely voluntary (they decide if they want to take part in the study or not) and they can refuse to participate or stop at any time without giving any reason. The investigator retains the right to withdraw them from the study if it is considered to be in their best interest.

- *Risks and benefits involved in the study:* The parents/caregivers would be informed of any risks or benefits that can be present in the study. They would be informed that no harm to them or their child will result if they decide to participate in the study. The assessment results would be discussed with them if they are interested in the information. Their child would be referred to appropriate therapy services if they want to involve them in an ECI programme. They would further be informed that the information gained from the research will help speech-language therapists and audiologists in the future to provide better services to children, who were prenatally exposed to alcohol and/or other substances and their mothers/primary caregivers.

- *Confidentiality:* The parents/caregivers would also be informed that all information obtained during the course of the study is strictly confidential. They and their child's names would not be written down anywhere. Information that may be reported in any publication would not include any information that would identify them or their child.

To further adhere to ethical principles this information leaflet and consent forms were provided to the foster and adoptive parents before conducting the data-collection. After ensuring that they understood the content of the information brochure, they were requested to sign a written consent form to indicate consent for the children with FASD to participate in the research study.

3.7.2. Interview Schedule

Within the ECI framework the involvement of families is essential (Rossetti, 2001). Providing a case history gives parents/caregivers the opportunity to be part of the assessment process from the onset of involvement with a speech-language therapist (Kritzinger & Louw, 2000). The inclusion of a case history in a comprehensive data collection approach may uncover valuable sources of information about the child and

family to be used for the research (Kritzinger & Louw, 2000). A case history also allows the researcher to compile a more comprehensive profile of the participants' characteristics and facilitates parental/caregiver involvement in the research process. Furthermore, certain data can only be obtained from parents/caregivers. The interview data also assisted the researcher to familiarize herself with the child's developmental history and family context within a systems framework (Garbarino & Ganzel, 2000).

The Interview Schedule consisted of five categories: General information, prenatal and birth history, medical history, developmental history and parental concerns and needs and was based on Kritzinger and Louw (2000), and Shipley and McAfee (2004). Therefore, factual information as well as information regarding attitudes and perceptions of the parents/caregivers was collected (Billeaud, 2003; Kritzinger & Louw, 2000; Shipley & McAfee, 2004).

The content of the interview was compiled according to sub-aim one and two of the study using different sources from various fields. The Interview Schedule drew questions from the case history form (Kritzinger & Louw, 2000) used at the Clinic for High-Risk Babies (CHRIB), as well as parental questionnaires used by KOMMUNIKA, a clinic for pre-school children with communication difficulties, and the Cochlear Implant Team at the Department of Communication Pathology, University of Pretoria, as well as a case history questionnaire by Shipley and McAfee (2004). The questions and justification for including these questions were influenced by different sources in the field of ECI (Billeaud, 2003; Rossetti, 2001) and assessment in Speech-Language Pathology (Shipley & McAfee, 2004).

The structure of the interview schedule was compiled using sources in the fields of survey and social research (Leedy & Ormrod, 2005; Leedy & Ormrod, 2005; Robson, 2000). Other questionnaires used at Masters level research in ECI were consulted to aid the development of an appropriate format (Evens, 2002; Jessop, 2003).

Since the interview was expected to be rather lengthy, attempts were made to pose questions in a simple, participant-friendly format. A logical flow and order of questions was used, with unambiguous language and clarification of terminology (Leedy & Ormrod, 2005) (See Appendix C).

The different topics of the Interview Schedule, the justification for inclusion, and sources are outlined in Table 3.3.

Table 3.3: Content of Interview Schedule

Topic	Content and justification	Sources
Biographical Information	To obtain information pertaining to the child's biological and family/foster family circumstances, socio-economic status of the family, the level of education of the caregivers providing stimulation to the child, as well as the family structure. This information is important since the literature repeatedly states that children with FASD have unstable home environments marked by abuse, neglect and parental alcohol addiction. The main language spoken and the number of languages spoken in the home were included to enquire about the cultural and linguistic background of the family.	Dollaghan et al. (1999) Kritzinger & Louw (2000) Shipley & McAfee (2004) Sparks (2000) Zhang & Bennett (2001)
Prenatal and Birth History	This section was included since many causes of speech/language impairments, such as FASD, have their origin in the prenatal period. There is a dearth of information regarding perinatal histories of children with FASD in South Africa. Specific close-ended questions regarding the child's perinatal conditions were included to attempt to cover most of the known possible risk factors for communication impairment and developmental delay in this time period. This information was included to describe the early perinatal events that may be characteristic of neonates with FASD, since FASD is known to affect foetal growth and may cause resulting perinatal risk conditions.	Kritzinger & Louw (2000) Rossetti (2001) Shipley & McAfee (2004) Sparks (2000) Carmichael Olson et al. (2007)
Medical History	To obtain information regarding medical conditions that could place the child at risk of delayed communication development or that could have contributed to the etiology of the communication disorder. It is documented that children with FASD present with a wide array of medical problems and organ disorders (see Table 1.1, Chapter 1).	Kritzinger & Louw (2000) Shipley & McAfee (2004) Viljoen (1999)
Developmental History	To obtain information regarding the attainment of the child's developmental milestones and developmental progression to aid in the compilation of a distinctive profile of the communication functioning of the participants. It is clearly reported in the	Kritzinger & Louw (2000) Shipley & McAfee (2004) Sparks (2000)

	literature that children with FASD also present with an array of developmental delays and impairments (see Table 1.2, Chapter 1).	Steinhausen et al. (2003)
Parental Concerns and Needs	To obtain information regarding the parent/caregiver feelings and needs. It is documented that parents of children with FASD are at risk of maladaptive parenting. It is therefore essential to gather information regarding their specific concerns and needs in order to provide suggestions regarding specific and appropriate support. It is also important to describe the needs of the foster and adoptive parents, as they play a central care giving role in the future of the infant or young child with FASD.	Guralnick (1997) Garbarino & Ganzel (2000) Rossetti (2001) Sparks (2000) Vig et al. (2005)

3.7.3. Communication Assessment Protocol

The basic rationale for assessment was to collect data regarding the child's level of communicative functioning (Coggins & Timler, 2000). The orientation towards assessment followed in the protocol was a descriptive-developmental approach. According to Coggins and Timler (2000:48), "such an approach assumes that children developing language typically provide the best way to identify the ability of a child with a language impairment to comprehend and produce language". The assessment instruments used during the assessment were adapted from Louw and Kritzinger (2002) and Kritzinger and Steenkamp (2006) to cover specific characteristics of FASD. Furthermore, the instruments had to cover the range of four to 58 months, the age spectrum of participants. An outline of the data-collection instruments included in the Communication Assessment Protocol is provided in Table 3.4, structured according to the Four-level Early Communication Assessment Framework (Kritzinger & Steenkamp, 2006).

Table 3.4: Data-collection instruments included in the Communication Assessment Protocol

Name of instrument	Assessment area	Age range	Justification
Level 1 – Physical features and sensory integrity			

Genetic Screening Checklist (Louw & Kritzinger, 1998)	Visual examination of cranio-facial and other physical features: • Hair • Hard & soft palate • Facial features • Jaw & teeth • Lip appearance • Tongue appearance • Dental abnormalities • Proportion of midfacial structures • Hand crease patterns • Fingers • Toes & elbows • Feet • Smell of breath and urine	All ages	The examination enables the researcher to identify and describe FASD specific cranio-facial characteristics that may interfere with oral-motor skills development and speech-language development. It may assist in the early identification of FASD by a speech-language therapist (Louw & Kritzinger, 1998).
Otoscopic examination (Shipley & McAfee, 2004)	Visual inspection of the external meatus of the ear and the tympanic membrane.	All ages	To assess the anatomy of the external auditory meatus and the tympanic membrane to establish the presence of anomalies and excessive ear wax that, can interfere with the normal functioning of the auditory system and may be FASD specific (Church et al., 1997; Shipley & McAfee, 2004).
Hearing assessment: ▪ *Visual Reinforcement Audiometry (VRA)* ▪ *Immittance measurements* ▪ *Oto-acoustic emissions testing (OAE))* ▪ *Play audiometry*	Hearing function	▪ VRA for 6-36 months ▪ OAE for all ages ▪ Immittance measurements for all ages ▪ Play audiometry for 37–60 months	▪ To determine hearing sensitivity and functioning of the outer hair cells of the cochlea as well as middle ear functioning. ▪ Immittance measures were important due to the exceptionally high incidence of otitis media with effusion in this population (Church et al., 1997; Plante & Beeson, 1999).
Vision assessment	Visual function	All ages	To informally observe the child's visual response to objects and people.
Level 2 – Communication and related skills			
Oral-peripheral examination (Shipley & McAfee, 2004)	Oral-motor function	All ages	The assessment determines whether a disruption in oral-motor function is interfering with oral-motor skill and speech development (Shipley & McAfee, 2004; Sparks, 2000)
Oral-Motor/Feeding Rating Scale (Jelm, 1990)	Description of breast/bottle feeding, spoon and finger feeding, chewing and straw	0–12 months, but applicable to	Insight is gained regarding the participants' oral-motor skills and their feeding abilities. It

	drinking regarding: • Lip/cheek movement • Tongue movement • Jaw movement • Related areas of feeding function: *Self-feeding *Dietary adaptations *Feeding position *Sensitivity to food *Swallowing	older ages as well	is reported that children with FASD demonstrate delays/impairments regarding oral-motor skills and feeding (Abkarian, 1993; Sparks, 2000).
The Rossetti Infant-Toddler Language Scale (Rossetti, 1990)(RITLS) (Provides criterion-referenced outcome indicating the age level of the child's communication development)	Language and communication skill areas: • Interaction attachment • Pragmatics • Gesture • Play • Language comprehension • Language expression	0–36 months	This scale is reliable for the assessment of the child's communication abilities (Billeaud, 2003). According to Rossetti (1998), this scale is the most widely used in the world to assess infants and toddlers.
Expressive One-Word Picture Vocabulary Test (Revised)(Gardner, 1990)(EOWPVT) (Norm-referenced)	Expressive language vocabulary of single words which refers to the child's ability to name a picture	2 years – 11 years 11 months	▪ This is a thoroughly researched test that has been utilized in many research studies worldwide (Rivers & Hedrick, 1998). ▪ Provides a reliable measure of one word vocabulary (Gardner, 1990). ▪ The test material is also presented in a child-friendly manner with attractive pictures. ▪ No incompatible cultural specific pictures were found in the test material in the age range of 2 – 5 years.
CHRIB Assessment Protocol (Louw & Kritzinger, 2000)	Phonological repertoire: ▪ Place of articulation ▪ Method of articulation ▪ Babbling patterns	All ages	▪ This subsection of the CHRIB assessment protocol is reliable for the assessment of the child's phonological skills. ▪ According to Abkarian (1992) and Becker, Warr-Leeper & Leeper (1990) children with FASD tend to present with speech sound production errors.
Receptive One-Word Picture Vocabulary Test (Gardner, 1985) (ROWPVT) (Norm-referenced test to determine the child's comprehension of language at a one-word level)	Receptive language vocabulary of single words – referring to the child's ability to identify a named picture from among a group of pictures.	2 years – 11 years 11 months	▪ The test has been utilized in studies of language of children with FASD (Rivers & Hedrick, 1998). ▪ The stimulus pictures appeared culturally appropriate as test material.

Afrikaanse Reseptiewe Woordeskat Toets (Buitendag,1994) (ARWT) (This test is based on the same principles as the Peabody Picture Vocabulary Test and provides a standardized norm-referenced test in the Afrikaans language)	Receptive language vocabulary of single words in Afrikaans which refers to the child's ability to identify a named picture from among a group of pictures	2 years – 10 years 11 months	The test was included because the first language of some of the participants was anticipated to be Afrikaans.
The Bus Story – (a test of continuous speech) (Renfrew, 1972) (This is a norm-referenced test for story-retelling ability and conversational language ability)	Expressive language abilities regarding: ▪ Story retelling ▪ Child's mean length of utterance or sentence length ▪ Factual recall ▪ Grammatical sentence structure ▪ Use of tenses	3 years – 8 years	The test was included due to young children with FASD's difficulties with narrative tasks (Carmichael Olson et al., 2007; Thorne, Coggins, Carmichael Olson & Astley, 2007). The test provides rich information in a child friendly task for participants older than 36 months.
CHRIB Assessment Protocol: Subsection: Communication skills (Louw & Kritzinger, 2002; Wetherby & Prizant, 1989)	Communication abilities regarding the use of language: ▪ Topic maintenance ▪ Communication repair ▪ Communication intentions ▪ Turn-taking abilities ▪ Eye contact	0–5years	Children with FASD present with impairments in the area of language use and social language (Carmichael Olson et al., 2007). Verbosity is also a unique characteristic of their social language impairment (Clark, 2004). The information obtained from the checklist enables the researcher to describe the language use as appropriate or inappropriate.
Observation of Communicative Interaction (OCI)(Klein & Briggs, 1987) *Assessment of Parent-Child Communication Interaction (Kritzinger, 2005)*	Mother-child / Primary caregiver- communication Interaction: • Physical closeness • Interaction patterns • Language stimulation Detailed description of caregiver communication model when interacting with the child. 20 listed parent/caregiver actions, e.g.: • Attempts to establish eye contact • Responses to the child's verbal and non-verbal signals	0–12 months, but applicable to older ages > 12-60 months	This allows the researcher to determine the pattern of closeness of attachment and communication interaction that provides insight into the primary communication dyad where the child is learning language and how to communicate (Klein & Briggs, 1987; Rossetti, 2001).
Kaderavek-Sulzby Bookreading Observational Protocol (Kadevarek & Sulzby, 1998)	Facilitation of emergent literacy: • Appropriateness of storybook selection by the mother	> 12–60 months	▪ Insight is provided into the child's experience with literary socialization and emergent joint book reading. ▪ Assessment of joint book

	• Use of scaffolding behaviours by the mother • Social/emotional climate created by joint book-reading • Child's verbal responsiveness • Quality of joint book-reading between parent and young child		reading offers an ecologically valid family-level interactive situation (Armstrong 1998; Kadevarek & Sulzby, 1998).
CHRIB Listening Scale (Hugo, Louw, Kritzinger & Smit, 2000)	Listening skills: • Situation 1: During communication evaluation • Situation 2: During hearing testing	0–36 months	This scale is used to assess the child's listening skills in two contexts. Children with FASD display difficulty paying attention to sound and have an increased risk of sensori-neural and conductive hearing loss that can, have a negative effect on their listening skills (Plante & Beeson, 1999).
Level 3 – General development skills			
Developmental Assessment Schema (Anderson, Nelson & Fowler, 1978)(DAS)	General development: • Receptive language • Expressive language • Personal-social skills • Perceptuo-cognitive skills • Self-help skills • Gross motor skills • Fine motor skills	0–60 months	This instrument allows the researcher to: ▪ Obtain a holistic view of the child's different developmental areas. ▪ To take all areas and their interactions into consideration. ▪ To compare general development areas with communication development. The assessment of general development is important as children with FASD present with an array of developmental delays (Sparks, 2000).
Symbolic Play Scale Checklist (Westby, 2000)	Symbolic play: Levels corresponding with language developmental stages: • Presymbolic level I: 8 – 12 m • Presymbolic level II: 13 – 17 m • Symbolic level I: 17 – 19 m • Symbolic level II: 19 – 22 m • Symbolic level III: 2 y • Symbolic level IV: 2 y 6 m • Symbolic level V: 3 y • Symbolic level VI: 3 y to 3 y 6 m	8–60 months	The assessment of play provides information regarding how the child uses language (Rossetti, 2001). Studies indicated that children with FASD struggle with cooperative and socio-dramatic play, as well as initiating and organizing play (Beirne-Smith et al., 2002)

	• Symbolic level VII: 3 y 6 m to 4 y • Symbolic level VIII: 5 y		
Stages of play development (Roth & Worthington, 2001)	Stages of play development according to age: • 6 – 8 m: Non-meaningful manipulation of objects • 8 – 12 m: Purposeful exploration of objects. • 12 – 18 m: Self-related symbolic play. • 18 – 24 m: Other-related play. • 24 – 30 m: Planned symbolic play. • 3 – 5 years: Socio-dramatic play	6–60 months	The stages provide a general indication regarding the developmental level of the child's play skills. Play is closely linked to language development (Westby, 2000).

A number of norm-referenced tests were included in the Communication Assessment Protocol as depicted in Table 3.4. Although the focus of the study was early communication development where mostly criterion-referenced instrument use are advocated, norm-referenced standardized tests were also used due to the difference in the ages of the participants who were a few months old to 58 months. Although Rossetti (2001) still advocates the use of criterion-referenced instruments in EC assessment for children in the age range of 0 – 36 months, other views are now also present in the literature. According to Andersson (2004) the use of norm-referenced instruments combined with criterion-referenced instruments is frequently a critical component in the early intervention assessment process. Both types of instruments are commonly used in early intervention as seen in the research of Bagnato, Neisworth and Munson (1997) and McLean, Wolery and Bailey, (2004). Norm- and criterion-referenced tests can provide valuable information if the materials incorporate a developmentally contextualized approach (Andersson, 2004).

3.8. PROCEDURES

3.8.1. Pilot Study

The pilot study was the process whereby the researcher tested the selected combination of research materials and procedures for the prospective study of the communication skills of infants and young children with FASD (Strydom, 2002a).

- ***Aims of the pilot study:*** The aims of the pilot study were as follows:

1. Refinement and adjustment of the structure and content of the interview schedule, the assessment protocol and the information brochure for informed consent (Leedy & Ormrod, 2005).
2. The time and effort taken to complete the interview schedule, as well as the ease of understanding, use, clarity, consistency and relevancy of the questions were assessed (Leedy & Ormrod, 2005). Ambiguous language and unfamiliar terminology could be identified in the Interview Schedule.
3. The duration of the application of the assessment protocol as well as the sequential ordering of the various components of the assessment were determined. The applicability of the assessment instruments was determined.
4. To test the electronic equipment (video and audio recorders) during the interview and assessment session.
5. To determine the physical arrangement of the room and the assessment area.

A pilot study can therefore assist to increase the reliability and validity of the interview schedule and assessment protocol. Since the researcher is an experienced clinician in ECI, she was familiar with all the assessment instruments and procedures and further experience with the material was not deemed necessary during the pilot study.

- ***Participant in the pilot study:*** One participant, who complied with the selection criteria, was recruited with the assistance of a paediatric neurologist at an academic hospital in Gauteng. The participant had been diagnosed with FASD by the paediatric neurologist shortly after birth.

- ***Materials of the pilot study:*** The complete interview schedule, as well as the assessment protocol of the main study was applied on the participant and mother/caregiver. The information brochure for informed consent was also provided. Relevancy, consistency, brevity, clarity and appropriateness of questions, as well as the degree to which they could be answered based on parent/caregiver knowledge, were evaluated (Strydom, 2002a). The evaluation of the assessment protocol focused on: the length of time taken to complete assessment tasks, the appropriateness of assessment instruments, and the

comprehensiveness of data rendered by the assessment instruments. The assessment instruments were selected from the Communication Assessment Protocol according to the participant's age of 58 months. The information included in the brochure and the informed consent form was discussed with the adoptive parents.

- ***Procedures of the pilot study:*** The researcher telephonically contacted the parent/caregiver to schedule a date, time and venue for data collection for the pilot study. A Parent/Caregiver Information Leaflet was provided on the day of data collection. Written informed consent was obtained before proceeding with the assessment and the interview.

  The room selected for use during the interview was an office situated in a private paediatric speech-therapy practice. Prior to the data collection the researcher ensured that the room was child-friendly by creating a free play area, and a small table with appropriate books and stationery, and a second area with toys arranged to elicit more specific responses that the researcher wanted to observe. The video camera was placed on a tripod in a corner of the room and positioned to be the least intimidating for the parents/caregivers and child. The interview area had three comfortable chairs positioned in a semicircle to create an informal setting to conduct the interview in a non-intimidating and comfortable setting (Sandall, 1997). The audiocassette recorder was placed unobtrusively on a small side table next to the parent's/caregiver's chair.

  An audio recording was used to capture the information provided during the interview, as to not distract the parent/caregiver with the vigorous noting down of information. According to Strydom (2002a), the taking of notes may inhibit respondents' answers. The parent/caregiver had the undivided attention of the researcher, which contributed to good rapport. During the interview with the parent, the following techniques were used: reframing, counter questioning, open-ended questions and empathetic listening (Roth & Worthington, 2001).

The data collection procedure consisted of the following steps: 5-minute orientation period with the mother/caregiver, the assessment of the child and then the completion of the interview with the mother. In order to prevent fatigue the assessment of the child was conducted first. At the end of the interview a suitable time and date for hearing assessment was scheduled.

During the assessment of the child a video recording was made to gather data. Only the mother-child interaction and book-reading were interpreted by the second rater. According to Cole and St. Claire-Stokes (1984), a video recording is considered the method of choice for collecting a sample of communicative behaviours, since it provides both an auditory and a visual record of the ongoing events and also serves as a reliability check. Furthermore, the visual record is particularly important for gaining insight into the non-verbal characteristics of the participants' communication behaviours.

Upon completion of the assessment and interview a brief feedback session was held with the adoptive parents to provide information regarding their child's communication development. Appropriate recommendations and referrals were also provided (i.e. follow-up with a paediatric neurologist, speech-language therapy or an occupational therapy assessment). A report was also mailed to the adoptive parents a week after the evaluation containing the assessment results, the discussion thereof as well as the recommendations and referrals.

- ***Results of the pilot study:*** A comprehensive data set could be obtained and no changes needed to be made to the interview schedule, assessment protocol or the patient information leaflet. An interpretive summary of the information obtained during the Parent/Caregiver Interview was compiled.

  A detailed description of the participant's communication skills was obtained. FASD characteristics were clearly displayed by the participant upon completion of the assessment protocol. No terminology difficulties or irrelevant questions were identified. The interview schedule was deemed appropriate for use in the main

study. The interview time was established at 35 minutes. The duration of the assessment was an hour. The assessment instruments were deemed applicable and the sequential order was confirmed as appropriate. It was also established that the child required breaks during the assessment period. It was now possible to prepare the participants of the main study.

The pilot study was deemed successful, because sufficient data were collected on one participant and would therefore be sufficient for an in-depth description of the participants of the main study.

Due to the fact that there were no changes to the assessment protocol, and due to the shortage of research participants it was decided to include this participant's data in the main study (Leedy & Ormrod, 2005).

3.8.2. General procedures followed for the main study:

The parents of the research participants were contacted telephonically to schedule a date, time and venue for the data collection and to obtain informed consent for participation in the study. All the procedures implemented during the pilot study were followed during the main study.

3.8.3. Data analysis

Statisticians at the Department of Statistics, at the University of Pretoria provided guidelines regarding the most suitable methods to process and analyse the data meaningfully.

According to Leedy and Ormrod (2005) data analysis in a collective case study design typically involves specific steps. The steps and application thereof is depicted in Table 3.5.

Table 3.5 Application of data analysis steps to the research study

Steps of sequential analysis	Application
Step 1: Logical organization of details about the case	• Allocating participant numbers from the youngest (participant 1) to the oldest (participant 5). • Arranging interview schedules and assessment protocol sheets according to

	the participant numbers.
Step 2: Categorization of data	• Tabulation of case history data obtained from the interview schedules according to identified recurrent themes. • Tabulation of data obtained from the assessment protocol, according to the different assessment areas.
Step 3: Interpretation of single instances	• Interpretation of results obtained in each specific assessment area for each participant. • Interpretation of identified themes that have arised from the data obtained from the interview schedule.
Step 4: Identification of patterns	• Depicting developmental levels in relation to participant's chronological age on a graph. • Discussion of developmental level. Discussion of themes that characterize the collective case study more broadly as deducted from interview schedule data and developmental levels.
Step 5: Synthesis of data & generalization	• Indicating a developmental trend across all five participants to synthesize an aspect of development over time. • An overall view of the collective case study's results is discussed and conclusions are drawn.

According to Table 3.5, data from the assessment protocol of each participant were tabulated according to the assessment areas. Thereafter a graph was presented depicting developmental levels in relation to the participant's chronological age.

All the descriptive data gathered from each participant was analysed for congruent themes, patterns and characteristics. Because of the small, unrepresentative sample, no statistical analysis procedures were utilized and data was analysed (Leedy & Ormrod, 2005), according to age levels and scoring procedures of the different assessment instruments.

Data analysis was carried out manually. The data were summarized, tabulated and presented in graphs. Comparisons between the individual cases were indicated and discussed. The multifaceted communication skills of infants and young children with FASD were portrayed in the data that were analysed.

A second rater was used for analysing the excerpt video recordings of the mother-child communication interaction. The second rater was blind to the first rater's findings (Leedy & Ormrod, 2005) regarding communication interaction. The second rater was provided with the necessary assessment forms that were indicated in the communication assessment protocol, to evaluate informal mother-child interaction and the interaction during a book-reading activity. The second rater was a qualified and experienced speech-language therapist to increase the reliability of the data-analysis segment of the mother-child interaction. The results of the researcher and second rater were compared and found that similar observations and comments were made when analysing the video recordings. Minor differences were discussed until agreement was reached.

3.9. RELIABILITY AND VALIDITY

According to (Leedy & Ormrod, 2005), consistency is a characteristic of a reliable research instrument and accuracy is a characteristic of a valid instrument. The reliability and validity of the study were enhanced by the use of a pilot study (Strydom, 2002a). The different assessment instruments selected for the present study have already been used in previous ECI research studies and proven to be reliable (Bam, 2000; Höne, 1999; Kritzinger, Louw & Hugo, 1996; Kritzinger & Steenkamp, 2006). To increase the reliability of data collection and analysis, a second rater was used for the analysis of mother-child interaction.

The internal validity was addressed through triangulation (De Vos, 2002a). The researcher's observations were enhanced by the parental report, video and audio-recordings and a second rater for the analysis of mother-child interaction.

Appropriate selection criteria of participants further aided the internal validity of the study, as the selection criteria enabled the researcher to draw conclusions about FASD (Neuman, 2000). A possible threat to internal validity and credibility of a study is an interview schedule and assessment protocol that is not sufficiently grounded in the appropriate literature and that do not relate to the aims of the study (De Vos, 2002a; Neuman, 2000). To address these issues, a wide literature base was used to justify and compile a relevant and comprehensive interview schedule and assessment

protocol (Leedy & Ormrod, 2005; Neuman, 2000). The content validity was addressed by ensuring that the research materials corresponded with interview schedules, assessment protocols and theoretical frameworks in the field of ECI research and in agreement with the aims of the study.

Face validity was addressed by using a Patient/Caregiver Information Leaflet, structuring the interview schedule and assessment protocol in a logical way and using appropriate language and terminology - all of which was tested in a pilot study (Leedy & Ormrod, 2005; Neuman, 2000; Strydom, 2002a). Construct validity required that the interview schedule and assessment protocol contained only pertinent questions and assessment tasks that relate to the study's objectives (Leedy & Ormrod, 2005; Neuman, 2000).

The findings of the study could not be generalized or transferred to the entire FASD population because of the small, unrepresentative sample utilized in this study. (De Vos, 2002a).

The researcher strived for objectivity by asking the question whether the findings of this study could be confirmed by another study (De Vos, 2002a). The results of the study could be confirmed by other research findings. The procedures of the study were also described in a transparent manner so that the study can be replicated.

3.10. CONCLUSION

Despite the high prevalence of infants and young children with FASD in South Africa, only a small number of infants and young children diagnosed with FASD could be found to participate in the study. The participant of the pilot study was also utilized in the main study due to the limited number of participants. A comprehensive Interview Schedule and accompanying Assessment Protocol were compiled and used in five carefully selected cases to comprise a cross-sectional collective case study (Fouche, 2002). In an attempt to describe the unique communication profiles of each participant and family, a quantitative research approach was selected and successfully applied in the pilot study. The same methods were applied to the four other participants to present meaningful results.

3.11. SUMMARY

This chapter described the aims and the research methodology that directed the empirical study, which formed part of phase 1 (pilot study) and the second phase of the study. The researcher successfully accomplished phase 1 and phase 2 of the research study. The research design, ethical issues, research participants, the required materials, apparatus, data collection and analysis procedures were described and justified as comprehensively as possible, with the necessary attention to detail. This was done to provide scientific validity and reliability to the research study.

CHAPTER 4

Results and Discussion

Aim: To present and discuss the results of this study according to the formulated aims. The results are presented in tables and figures and are discussed with the view to identify each of the five participants' unique communication characteristics and indicate possible trends in the findings. The results are interpreted with reference to the literature.

4.1. INTRODUCTION

The **main aim** of the study was ***to present distinctive communication profiles of five infants and young children diagnosed with FASD***. In this chapter the results are presented according to the sub-aims set for this research. Individual profiles of the case histories and family contexts of infants and young children with FASD will be described. Thereafter, the results obtained from the assessment are presented in detail for each individual participant according to the collective case study design using the Four-level Early Communication Assessment Framework (Kritzinger & Steenkamp, 2006). The results of each participant are firstly presented in a summarized table, then according to a developmental graph and finally in a conclusive table with discussion. Conclusions are drawn, integrating all the results and emerging trends of the group of participants and their foster or adoptive parents. Developmental trends across the collective case study are indicated.

4.2. SUB-AIM 1 & 2: TO DESCRIBE THE DEVELOPMENTAL HISTORIES OF THE FIVE PARTICIPANTS WITH FASD AND THEIR FAMILY/CARE-GIVING CONTEXTS

The pertinent information gathered during the structured interview with each participant's foster parent/s is presented according to categories emerging from the gathered data. The results are presented in Table 4.1.

Table 4.1: Summary of the participants' case histories as reported by the foster and adoptive parents (n=5)

Categories	Participant 1 Age: 4 months Gender: Male	Participant 2 Age: 18 months Gender: Male	Participant 3 Age: 35 months Gender: Female	Participant 4 Age: 53 months Gender: Female	Participant 5 Age: 58 months Gender: Male
1.Biological family characteristics *Parental ages*	Mother: 25 Father: Not available	Not available	Mother: 27 Father: 28	Not available	Mother: 35 Father: Not available
Parental education	Not available	Not available	Mother & father: Special needs school	Not available	Not available
Parental occupations	Mother: Housewife Father: Gardener	Mother: Veterinary assistant	Mother: Shop assistant Father: Garden services	Not available	Not available
Community	Mamelodi	Pretoria West	Pretoria North	Danville	Roodepoort
Known sibling	Sister	Sister	Brother & sister presenting with FASD	Brother & sister presenting with FASD	Not available
Home language	Sotho	English	Afrikaans	Afrikaans	Afrikaans
Substance abuse	Alcohol abuse	Alcohol abuse Poly-drug use	Alcohol abuse	Alcohol abuse Cigarette use	Alcohol abuse Cigarette use
2. Foster family characteristics *Placement age*	5 weeks (single placement)	13 months (multiple placements)	2 years (multiple placements)	2 years (multiple placements)	At birth (single placement)
Family language	Afrikaans	Afrikaans & English	Afrikaans	Afrikaans & English	Afrikaans
Nursery school attendance	Double medium crèche, full day basis	At home full day with foster mom	Afrikaans nursery school on half day basis	Double medium nursery school on full day basis	Afrikaans nursery school on full day basis
3. Prenatal & Birth history *Term*	Full term	Not available	Not available	Not available	Full term
Type of delivery	Natural birth	Not available	Not available	Not available	Natural birth
Birth weight	2,4 kg	Not available	Not available	Not available	2,805 kg
Head circumference	Smaller than norm	Not available	Not available	Not available	Not available
Type of feed	1 week NICU stay, breastfed by biological mother	Not available	Not available	Bottle fed	Bottle fed
4.Early behavioural characteristics	• Irritable • Inconsolable • Very active	• Not available • Not available • Very active	• Not available • Not available • Not available	• Not available • Not available • Very active & friendly	• Irritable • Inconsolable • Very quiet
5.Professional person diagnosing FASD	Paediatrician working without a team in a public hospital	Paediatric neurologist working without a team in a public hospital	Paediatric neurologist working without a team in a public hospital	Paediatric neurologist working without a team in a public hospital	Paediatric neurologist working without a team in a public hospital
6. Medical history	• One episode of high temperature after inoculations • Bronchiolitis • Eczema	• Chronic middle ear infections, received grommets • Chronic tonsillitis • Gastro-enteritis	• Tonsillitis • Regular colds & flu	• High temperature during flu episodes • Chronic middle ear infections, received grommets before 3 years • Chronic tonsillitis • Tonsillectomy • Regular colds & flu • Sinusitis • Reconstruction of cleft- palate at 27 m • ADHD, on medication • Takes vitamin	• One episode of high temperature • Tonsillitis • Regular colds & flu • Colic

				supplements	
7.Early feeding behaviour *History of presence of feeding problem*	Yes	No	No	Yes	No
Current feeding status	Experiencing feeding problems Emesis after eating solids	Age appropriate	Not a fussy eater Healthy appetite	Not a fussy eater Healthy appetite	Age appropriate
Behaviour in peri- & postnatal period	Emesis during first few days after birth Transition from breast to bottle problematic	No information available	No information available	Bottle fed since birth Sucking, swallowing & drooling problems associated with cleft-palate	No information available
Allergies	Possible lactose intolerance	No	No	No	No
Current problems	Sucking problems Excessive drooling	None	None	None	None
Associated medical diagnosis	Reflux/GERD after feeds	None	None	Reconstructed cleft-palate	None
8.Current problems *Speech difficulties*	No	Yes	Yes	Yes	Delayed onset of first words, slow speech development before 2 years
Hearing difficulties	No	Yes	No	No	No
Behavioural difficulties	Yes	No	Yes, limited attention, easily distracted	Yes, limited attention	Yes
Sleep difficulties	Yes	No	No	No	No
Delayed achievement of developmental milestones	Not reported	Delayed motor development	General delayed development, limited functional abilities	Delayed mastery of self-help skills Delayed motor development	Delayed mastery of self-help skills Delayed motor development
Other	None	Strabismus	None	None	None
9.Current parental concerns and needs	• Hearing abilities • Feeding difficulties & transition to solid foods	• Hearing abilities • Functioning & vision of right eye	• Poor speech production skills • Information & guidance regarding stimulation of speech development	• Hearing abilities, slow speech development & language understanding • Information on handling of frustration when people do not understand child's speech	• No concerns • No needs

According to Table 4.1, no 1 the participants' biological families present with typical problems associated with alcohol abuse described in the literature. Four of the participants have biological siblings who may still be with their parents. Furthermore, the **biological parents** present with low educational levels, low income occupations and reside in lower income communities in and around Pretoria in Gauteng. According to Cone-Wesson (2005) the characteristic biological family context of children with FASD is usually rife with poverty, poor nutrition, substance abuse and a lack of prenatal care. When substance abuse co-occurs with poverty the teratogenic effects of addictive substances may be exacerbated (Cone-Wesson, 2005). O'Leary

(2004) also reports that there is a higher incidence of FASD in lower socio-economic groups.

Another aspect highlighted in the **biological family characteristics** is the different language and cultural groups that the participants represent, indicating that FASD was present across differing language and cultural groups in the five participants.

In comparison to the biological families the **foster parents** presented with higher educational levels and participated in higher income occupations (see Table 3.1). It is therefore clear that the foster care and the adoption brought positive changes to the participants' home environments.

Regarding the participants' **prenatal and birth history** limited information was made available to the foster and adoptive parents. According to Vig et al. (2005) the loss of records regarding the history of children in foster placement is of concern and occurs often. Furthermore, the lack of information regarding the child's early history may be a barrier to access appropriate early intervention services. Multiple foster care placements could also have contributed to the loss of records of these participants (see Table 4.1, no 2).

The foster family of participant 1 was the only family in the study who had some knowledge regarding birth history. Participant 1 presented with low birth weight (2.4 kg) and a small head circumference, indicating possible intra-uterine growth retardation and microcephaly. According to Cone-Wesson (2005), McGrath, Kenner and Amspacher (2004) and O'Leary (2004) features of FASD in infancy includes microcephaly and intra-uterine growth retardation, which results in low birth weight. Low birth weight in infants with FASD is associated with possible maternal malnutrition during pregnancy (Viljoen et al., 2002). The literature reports that good nutrition is not really of concern to biological mothers who consume alcohol during pregnancy. Poor socio-economic conditions in rural areas contribute to limited food choices and availability of food in South Africa (Viljoen et al., 2002), thus poor nutrition can be present in mothers with children diagnosed on the continuum of FASD.

Three of the participants were described as very active and two as irritable during infancy (see Table 4.1, no 4). According to McGrath et al. (2004) the early behaviour of infants with FASD is characterized by irritability, jitteriness and over activity. The foster parents reported that these typical regulatory difficulties of infants with FASD were present early on in their lives.

Four of the participants were **diagnosed** with FASD by a paediatric neurologist, and one participant by a paediatrician, who functioned without an established team in the public health sector (see Table 4.1, no 5). Knowledge regarding the management of FASD in the private health sector in South Africa is not known. According to literature guidelines a developmental paediatrician or a dysmorphologist usually diagnoses FASD (Streissguth et al., 1997). Clarren et al. (2002) recommend an interdisciplinary team assessment to assist in the diagnosis of FASD in young children. Guralnick (2000) emphasizes a comprehensive assessment within an interdisciplinary team as best practice guidelines for EI. It appears that there was a lack of teamwork in the diagnoses of the infants and young children with FAS who participated in this study. All these diagnoses were made by a single medical practitioner without a team. Although the results of this study cannot be generalized, a lack of a teamwork approach may be typical of the diagnostic process of FASD in Gauteng.

As discussed earlier the availability of comprehensive medical records of children in foster care is problematic (Vig et al., 2005). According to the five participants' available **medical histories,** it appears that they may present with a compromised immune system. Chronic tonsillitis was present in three of the participants, and chronic otitis media in two of the participants (Church et al., 1997). Otitis media may cause hearing difficulties that may be a contributing factor in language-learning difficulties (Church et al., 1997) described later in the participants.

According to research by Giberson and Weinberg (1992), as well as Johnson, Knight, Marmer and Steele (1981) a clear link between immune system abnormalities and prenatal exposure to alcohol has been established. Recent research by Zhang, Sliwowska and Weinberg (2005) indicates that prenatal alcohol exposure has an adverse effect on foetal programming of the hypothalamic-pituitary-adrenal (HPA)

axis during gestation. Prenatal alcohol exposure can reprogramme the HPA axis and increase HPA tone throughout life (Zhang et al., 2005). Increased HPA tone can be responsible for an increased vulnerability to illnesses in persons with FASD. The researchers further found that alterations in immune function may be one of the long-term consequences of foetal HPA programming contributing to immune incompetence and an increased vulnerability in young children prenatally exposed to alcohol. Children with FASD are therefore more vulnerable to the immunosuppressive effects of stress (Zhang et al., 2005). Foetal programming of HPA activity may underlie some of the long-term behavioural, cognitive and immune deficits in adults with FASD. The impairment of immunity may thus explain an increased susceptibility to infection in FASD. Alcohol may be an immunoteratogenic agent, disrupting the normal development and maturation of the immune system, which may also have been present in the participants of the present study.

In addition to FASD, one of the participants was also diagnosed with ADHD. Although not diagnosed with ADHD, four of the participants were reported as very active during their early years. It is described in the literature that ADHD can frequently be present in young children diagnosed with FASD (Atchison, 2007). FASD and ADHD can both contribute to sensory modulation difficulties experienced by infants and young children with FASD (Atchison, 2007). Coles et al. (1997) proposed that alcohol could be an etiological factor in ADHD, since the condition is frequently diagnosed in children with FASD. According to Coles et al. (1997) the condition may differ between children with FASD and those without, as those children without FASD do not present with the same neurocognitive and behavioural characteristics as children with a primary diagnosis of ADHD. It may be deducted that children with FASD could present with a different subtype of ADHD than children with the single diagnosis of ADHD without concomitant disorders.

According to Table 4.1, no 7 the known histories of the participants indicated that **early feeding difficulties** affected two participants. Sucking difficulties and excessive drooling was noted in these participants. Arvedson and Brodsky (2002) indicated that infants with FASD demonstrate delays in oral motor development, weak sucking patterns and tire easily during feedings. McGrath et al. (2004) describe weak sucking during infancy as a significant area of impaired function in infants with

FASD. Furthermore, one participant with early feeding difficulties was diagnosed with a cleft palate. In the literature a cleft palate is included in the multiple cranio-facial anomalies that infants with FASD present with (Arvedson & Brodsky, 2002; Church et al., 1997; Sparks, 2000). Appropriate adaptations for feeding were thus required early on for this participant before reconstructive surgery took place.

The youngest participant with feeding difficulties was also diagnosed with Gastro-esophageal reflux disease (GERD) (Hall, 2001; Swigert, 1999) that contributes to episodes of emesis after feeds. Possible lactose intolerance was suspected due to the allergic reactions to formula milk in one of the participants and difficulty in the transition from breast to bottle to solids was also present. It is clear that the participants presented with significant feeding difficulties, which according to Arvedson and Brodsky (2002), appear to be typical of infants with FASD.

The **current problems** of the participants as described by the foster and adoptive parents in Table 4.1, no 8, included delayed achievement of motor milestones, also described in the literature (Carmichael Olson & Burgess, 1997; Van der Leeden et al., 2001).

Speech, behavioural, attention problems and delayed development of self-help skills were also present in most of the participants. This area of development is of concern in children with FASD, as it may impact on their future independence in adulthood (Streissguth et al., 1997). The foster and adoptive parents viewed behavioural difficulties as having a negative impact on the participants' social interaction and family/caregiving environment. It is well known that cognitive impairment, learning disorders, behavioural disorders and speech-language deficits are characteristic of children with FASD (Cone-Wesson, 2005) – see also Table 1.2. Three of the five participants were described as "talkative" by their foster parents. The foster parents viewed the talkativeness of the participants as positive, suggesting that they viewed the participants' increased verbosity as appropriate speech and language skills. It appears that the foster and adoptive parents may not be well informed about all the characteristics of FASD. Abkarian (1992) and Clark (2004)'s research indicates that talkativeness is a characteristic of children with FASD.

The results of the **parental concerns and needs** indicate that four of the foster parents have concerns regarding the participants' communication development, even though they had stated no concerns about the children's talkativeness. For example, one of the adoptive parents reported that she was unsure how to address frustration in the participant when people outside of the immediate family do not understand the child's speech.

According to Table 4.1, no 9, three foster parents were concerned about the participants' hearing abilities. Despite all the concerns about the participants' communication and hearing, only one foster parent expressed the need for guidance regarding stimulation of the participant's speech and language development. Of all the concerns that the foster parents reported in the interview, concerns about the children's communication development was clearly the area of greatest concern – see Table 4.1, no 9.

It appears that the foster parents were not aware of ECI services (speech-language therapy and audiology services), again indicating the lack of a team approach in the management of FASD in the participants. The participants in the study were diagnosed early, but have not been referred to early intervention services by the time of data collection.

In conclusion the trends that emerged from the case histories of the five participants reported in Table 4.1 were as follows:

- All participants had a confirmed diagnosis of FASD, indicating that early diagnoses occurred despite reports by Viljoen (1999) that children were mostly identified at school entry level in South Africa. However, the results cannot be generalized as it was a selection criterion to include participants already diagnosed with FASD.
- All participants were living in foster care, one had already been adopted, and one adoption was in progress. Children with FASD in the foster care system in South Africa may be more accessible for research than those children living with their biological families.

- Placement in foster care resulted in improved circumstances for the participants, compared to their biological families.
- The participants were diagnosed by a single medical professional in a public hospital, without comprehensive team involvement, except for the social worker that was involved in follow-up and foster care placement.
- The foster and adoptive parents displayed a lack of information regarding early intervention services, specifically early communication intervention services.
- The unknown histories of perinatal and postnatal development were characteristic of the participants. The incomplete or lost histories of the period before placement in foster care may be a concern for the participants' sense of identity as they grow older. Furthermore, it can be of concern for ECI services when describing risks and resilience in young children with FASD.
- The participants displayed problems regarding early self-regulatory behaviour and feeding.
- The participants may have compromised immune systems, presenting in recurrent otitis media and tonsillitis.
- As reported by the foster and adoptive parents the participants displayed delayed achievement of developmental milestones in different developmental domains, but mostly in listening, speech, language and motor development.
- The participants were described as talkative and active children by the foster parents.

Each of these characteristics is also described in the literature as typical of children with FASD (Carmichael Olson et al., 2007). The trends observed in the case histories of the five participants may serve as guidelines for speech-language therapists in clinical practice to ensure obtaining a comprehensive case history if a child is suspected of FASD. This may, however, not be possible if a child is already placed in foster care. These observed trends may also be of value in the promotion of effective team management of young children with FASD.

Speech-language therapists should also not assume that foster parents have adequate knowledge regarding the diagnosis and prognosis of FASD. In the pursuit of best

practice in EI, speech-language therapists should disseminate information regarding the diagnosis of FASD and the associated communication and developmental sequelae, to the foster parents and other team members. Effective teamwork in EI will not allow professionals to assume that foster parents have the necessary knowledge regarding the implications of FASD when a diagnosis was made. Providing adequate information regarding the diagnosis, the implications and the necessity of EI is thus a joint responsibility of every EI team member. The dissemination of adequate information on FASD in a team context is therefore important as it highlights one of the benefits of a dedicated FASD team.

4.3. SUB-AIM 3: COMMUNICATION PROFILES OF PARTICIPANTS

The individual profiles of each participant in the research study will be presented, from the youngest to the oldest, in a table followed by a figure, a summarized table and a discussion.

4.3.1. Participant 1: Presentation and discussion of results

Table 4.2 Developmental functioning of Participant 1, 4 months old

Assessment Area	Results
Level 1 – Sensory integrity and physical features	
Oro-facial structures & genetic screening	• Face: mid-facial structures appear flattened • Lips: thin upper lip with an absent philtrum • Tongue and frenulum: surface colour and size were normal • Pharynx and tonsils: colour was normal • Hard and soft palate: colour, rugae, symmetry at rest were normal • Head size: appears small for age • Ears: low set • Eyes: wide set, epicanthal folds present • Nose: broad and flat
Hearing abilities and vision	• Hearing status could not be evaluated as the foster parent did not attend a second evaluation session during which hearing evaluation would have take place. • Vision appears normal
Level 2 – Communication and related skills	
Oral-motor abilities & feeding skills	• Jaw: normal range of motion, but some degree of dysfunction present due to difficulties with bottle feeding • Lips: struggles to pucker lips, struggle with optimal lip closure for bottle feeding • Tongue: normal protrusion of tongue with a slightly exaggerated tongue thrust during bottle feeding, normal strength, retraction, downward and lateral movements • Soft palate: gag reflex present
Listening skills	• Reaction to environmental sounds and toys: Good. • Reaction to speech and whispered speech: Good.
Receptive language	• 3 - 6 month level (DAS; RITLS)
Expressive language	• 3 - 6 month level (DAS; RITLS) • Phonetic repertoire: limited consonants - only /m/ and /b/, and vowel

	approximations, despite age appropriate levels on the DAS and RITLS
Pragmatic skills	• 3 – 6 months (RITLS)
Mother-child interaction	• Interaction attachment: 3 – 6 month level • Optimal interaction (Klein and Briggs, 1987)
Level 3 – General developmental skills	
Behaviour	• Friendly interactive infant
Personal social skills	• 0-3 month level (DAS) • Delay of 1 month present
Perceptuo-cognitive skills	• 3 - 6 month level (DAS)
Play development	• 3 – 6 month level (RITLS)
Self-help skills	• 0 - 3 month level (DAS) • Delay of 1 month present
Motor skills	• Fine motor: Age appropriate (DAS) • Gross motor: 3- 6 months level (DAS)
Level 4 – Risk factors & Resilience	
Risk factors	Before placement in foster care: • Diagnosis of FASD • Low birth weight and small-for-gestational age • Poor self regulatory behaviour • Continued parental substance abuse in biological family context • Poverty • Child neglect • Maladaptive parenting • Low parental education
Resilience	• Early foster care placement (5 weeks) • Early diagnosis of FASD • Foster mother with higher educational attainment • Basic needs are met in foster family
Areas of need	• Feeding therapy • Early communication intervention • Hearing assessment • Occupational therapy for regulatory difficulties • Dietician to provide dietary recommendations • Medical management of GERD and other illnesses

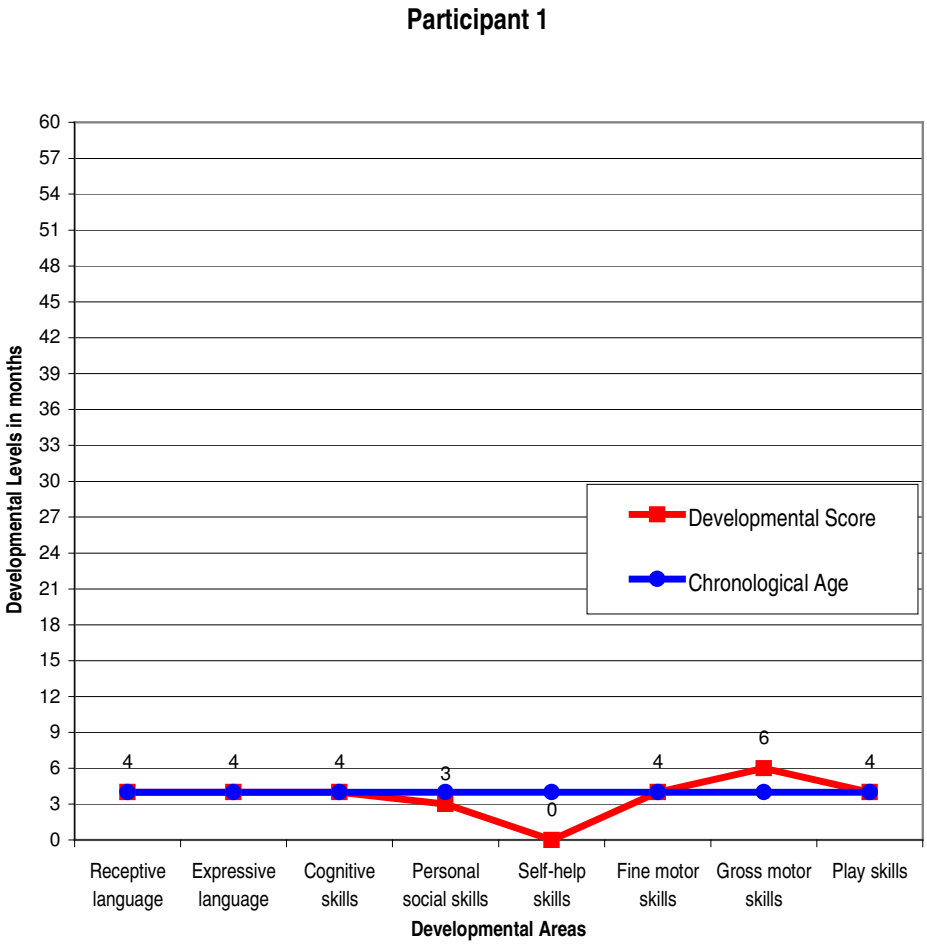


Figure 4.1. Participant 1: Comparison between chronological age and developmental level of functioning

According to Figure 4.1. Participant 1 is currently functioning at an age appropriate level, except for slightly delayed personal-social and self-help skills. Gross motor skills are currently well developed above his chronological age.

A classification of severity of delay was implemented to summarize each participant's results in table format. The severity classification was derived from Rossetti (2006) and the Arizona Revised Statutes 15 – 761. A mild developmental delay is defined as the child performing 6 months below chronological age expectations in developmental skill mastery. A moderate delay is considered when a child is performing more than 6 – 12 months below chronological age expectations. Lastly, a severe delay is present when a child is performing more than 15 months below chronological age expectations in developmental skill mastery.

Table 4.3: Summary of participant 1's developmental functioning, 4 months old

Assessment area	Age appropriate	Mild delay (6 month delay)	Moderate delay (> 6 – 12 month delay)	Severe delay or anomaly (> 15 month delay)
Level 1 – Sensory integrity and physical features				
Genetic screening				**Typical features of FASD present**
Hearing and vision	Yes			
Level 2 – Communication and related skills				
Oral-motor abilities		**Jaw and lip function**		
Listening skills	Adequate			
Receptive language	Yes			
Expressive language	Yes (on the DAS and RITLS)	**Limited vocalizations**		
Pragmatic skills	Yes			
Parent-child interaction	Optimal			
Level 3 – General developmental skills				
Behaviour		**Excessively active Regulatory problems**		
Personal social skills	0 – 3 m			
Perceptuo-cognitive skills	Yes			
Play development	Yes			
Self-help skills	0 – 3 m			
Motor skills	Adequate fine motor skills. Gross motor skills above age level.			

The participant was diagnosed with FASD at 4 months and clearly displayed the physical characteristics of the spectrum disorder. The outstanding physical characteristics in Participant 1 are the cranio-facial features related to FASD. At the early age of four months, anomalies that represented distinctive phenotypical characteristics of FASD were already present.

According to Table 4.3 the participant presented with mild difficulties regarding oral-motor skills, which were also indicated in the parental report in Table 4.1, no 7. The

participant especially struggled with appropriate grading of jaw movements and latching on to the nipple to create an adequate lip seal. Feeding difficulties can thus be associated with the presence of jaw and lip dysfunction, and regulatory problems (Arvedson & Brodsky, 2002) that had been reported by the foster parent.

Although participant 1 was already four months old, prenatal alcohol exposure and breastfeeding by his biological mother during the first week of life could still have contributed to his present feeding difficulties (Arvedson & Brodsky, 2002). Breastfeeding after birth could have contributed further to the participant's alcohol exposure and the detrimental effect thereof. According to Abate et al. (2002), foetuses that were exposed to alcohol during the last trimester can have specific feeding difficulties after birth. In utero conditioning of the foetus in response to alcohol could negatively affect nutritive suckling. The experience of alcohol exposure in utero could contribute to early alcohol dependency, as well as inadequate latching and sucking skills (Abate et al., 2002). Church et al. (1997) also described oral-motor impairments related to sucking in young children prenatally exposed to alcohol. Arvedson and Brodsky (2002) confirmed the presence of feeding problems, especially in the first 12 months of life of infants with FASD. The presence of early feeding difficulties poses a risk for future communication delay (Rossetti, 2001). Although no communication delay in the areas of receptive and expressive language was currently observed on assessment instruments, Participant 1 should be followed-up in ECI due to the fact that a diagnosis of FASD is an established risk factor for communicative delay. However, his expressive language was characterized by a limited phonetic repertoire of bilabial sounds and vowel approximations only.

In comparison, the expressive language development of a normally developing infant at 4-months-old is characterized by frequent CV-CV-CV babbling sequences more and larger consonant repertoire, which includes some glottal sounds. Vocalizing should occur in a variety of situations (Owens, 1999b).

According to Table 4.3 Participant 1 presented with developmental difficulty in the area of social interaction, but still falling with in the normal range and tended to interact with the primary caregiver only. During data collection the participant responded to the primary caregiver interaction and sought eye contact with her, vocalized in response to the caregiver's model, cried as the main mode of gaining

attention, attempted to imitate facial expression and laughed at amusing activities. The participant obtained age appropriate scores on the RITLS (Rossetti, 1990) and during interaction with the foster mother. However, as reported by the foster mother, interaction with other caregivers, i.e. day-care persons and foster family members was not optimal.

Research by O'Connor, Kogan and Findlay (2002) indicated that 70% infants with prenatal alcohol exposure exhibit insecure attachment behaviour with their biological mothers/primary caregivers. Rogers-Adkinson and Stuart (2007) described that avoidant interactional patterns with adults are often present, in order to evade a confrontational situation, especially if neglect is present. Insecure attachment may negatively affect the infant's development of personal-social and communication skills. The delay in socialization in Participant 1 may therefore be associated with insecure attachment behaviour.

In the current study the early impairment of social interaction skills, indicated by non-optimal interaction patterns, were already noted at the young age of 4 months. This may indicate that the presence of a social communication disorder may already be present from infancy in participant 1. This social communication impairment may contribute to later impaired social interactive competence (Henry et al., 2007) and undesired interactive behaviour.

Another factor of importance during development is the cultural and language differences between Participant 1's biological parents and the foster mother's. Cross-cultural adoptions are currently a trend in South Africa as white families often adopt black or coloured infants (LoBaido, 2005). Longitudinal research is required to determine the effects of cross-cultural adoptions on children's development of identity.

Participant 1 was therefore functioning mostly age appropriately, but displayed the established risk of FASD. A limited description of the characteristics of the different developmental areas of infants with FASD could be found in the literature (see Table 1.1). Comparison with other studies is therefore limited. According to Sparks (1993) the earliest observed symptoms of FASD in infants, which were also observed in Participant 1, were growth deficiency, dysmorphology, and early neurobehavioural

signs, namely tremulousness and hyperactivity. Participant 1 presented with low birth weight, small-for-gestational age and early excessive activity, as well as areas of minor developmental difficulty. Rossetti (2001) categorized infants with FASD in the established risk group, indicating that FASD has an expected pattern of developmental delay. However, there appears to be no typical profile, but rather a continuum of variable levels of impairment in children with FASD (Carmichael Olson et al., 2007). Therefore the use of the term Foetal Alcohol Spectrum Disorders (FASD) is deemed more appropriate, reflecting the continuum of impairment that is present.

The clinical implications of the physical characteristics and developmental difficulties observed in Participant 1 are as follows: The speech-language therapist working with infants suspected of FASD needs to assess oral-motor, feeding, communication and development skills in detail, identify and document growth retardation and refer to a paediatrician for monitoring of growth, refer to a paediatric neurologist for monitoring of neurodevelopment, inform the family of the established risk for developmental delay, provide them with information regarding FASD and the possibility of developmental delays that may emerge, provide ECI in an interdisciplinary team consisting of at least a speech-language therapist audiologist, occupational therapist, social worker and psychologist. In clinical practice the services of a dedicated team for diagnosis and follow-up of families affected by FASD is recommended (Carmichael-Olson et al., 2007; Coggins & Timler, 2000).

4.3.2 Participant 2: Presentation and discussion of results

Table 4.4 Developmental functioning of Participant 2, 18 months old

Assessment Area	Results
Level 1 – Sensory integrity and physical features	
Oro-facial structures & genetic screening	• Face: mid-facial structures appear flattened • Jaw: symmetrical • Teeth: normal dentition, good hygiene • Lips: thin upper lip with an absent philtrum • Tongue and frenulum: surface colour and size were normal • Pharynx and tonsils: colour appeared normal • Hard and soft palate: colour, rugae, symmetry at rest were normal • Head size: appeared small for age • Ears: bilateral narrow ear canals • Eyes: wide-set, epicanthal folds present, strabismus of the right eye • Nose: very broad and flat
Hearing abilities and vision	• Bilateral scarring on tympanic membranes due to grommets. • Right ear: Type B tympanogram, indicating a perforation of the tympanic membrane. Acoustic reflexes were elicited at increased intensities at 110 dB. • Left ear: Type As tympanogram, indicating low compliance of the middle ear system. No acoustic reflexes could be determined in the left ear, because the participant was non-compliant. • Normal hearing threshold for pure tones and speech were elicited in his best ear.
Level 2 – Communication and related skills	
Oral-motor abilities & feeding skills	• Jaw: normal range of motion and movement • Lips: struggles to pucker lips • Tongue: inadequate tongue range of motion. • Soft palate: gag reflex present
Listening skills	• Reaction to environmental and toy sounds: Adequate. • Reaction to whispered speech: Inadequate. • Reaction to speech: Adequate.
Receptive language	• 9 – 12 months level (RITLS; DAS) • Delay of 6 – 9 months
Expressive language	• 12 - 15 months level (RITLS; DAS) • Incomplete consonant repertoire - /m/, /b/, /p/, /t/, /g/, /d/, /j/, /h/ and /sh/, and produces all the vowels • One-word utterances, limited vocabulary of 20 recognisable words, phonological developmental impairment present • Delay of 3 – 6 months
Pragmatic skills	• 12 – 15 months (RITLS). • Requesting attention vocally and through touch • Inappropriate eye contact • Does not yet consistently use pointing for requesting • Struggles with turn-taking • Difficulty establishing joint attention at times • Delay of 3 – 6 months
Parent-child interaction	• Optimal interaction (Klein & Briggs, 1987)
Book reading/Emergent-literacy skills	• Mother chose an appropriate story, text was at an appropriate language level for the child • Appropriate scaffolding behaviours displayed by the mother • Mother displayed enjoyment during book reading interaction • Inappropriate strategies used by the mother, i.e. too much direct questioning • Participant responded to some questions but was mostly unoesponsive, displayed some enjoyment of the storybook interaction
Level 3 – General developmental skills	
Behaviour	• Short attention span

	• Moves rapidly from one activity to the next • Easily distractible
Personal social skills	• 15 - 18 months level (DAS) • Verbose, friendly and active
Perceptuo-cognitive skills	• 12 - 15 months level (DAS) • Delay of 3 – 6 months
Play development	• 15 – 18 month level (RITLS) • Pre-symbolic level II: 13 – 17 months (Westby, 2000)
Self-help skills	• 9 - 12 month level (DAS) • Delay of 6 – 9 months
Motor skills	• Fine motor: 9 - 12 month level; delay of 6 – 9 months • Gross motor: 18 - 21 month level
Level 4 – Risk factors & resilience	
Risk factors	• Diagnosed with FASD • Multiple previous foster placements • Low level of biological parental education • Non-optimal developmental stimulation provided by biological parents for first year of life • Recurrent otitis media
Resilience factors	• Foster parents applied for adoption • Early diagnosis of FASD • Foster mother with higher educational attainment • Basic needs are met in foster family and optimal stimulation is provided
Areas of need	• Early communication intervention • Parent guidance and training • Occupational therapy • Audiological follow-up • Follow-up with an Ear-, Nose- and Throat specialist • Follow-up with Opthalmologist (re strabismus)

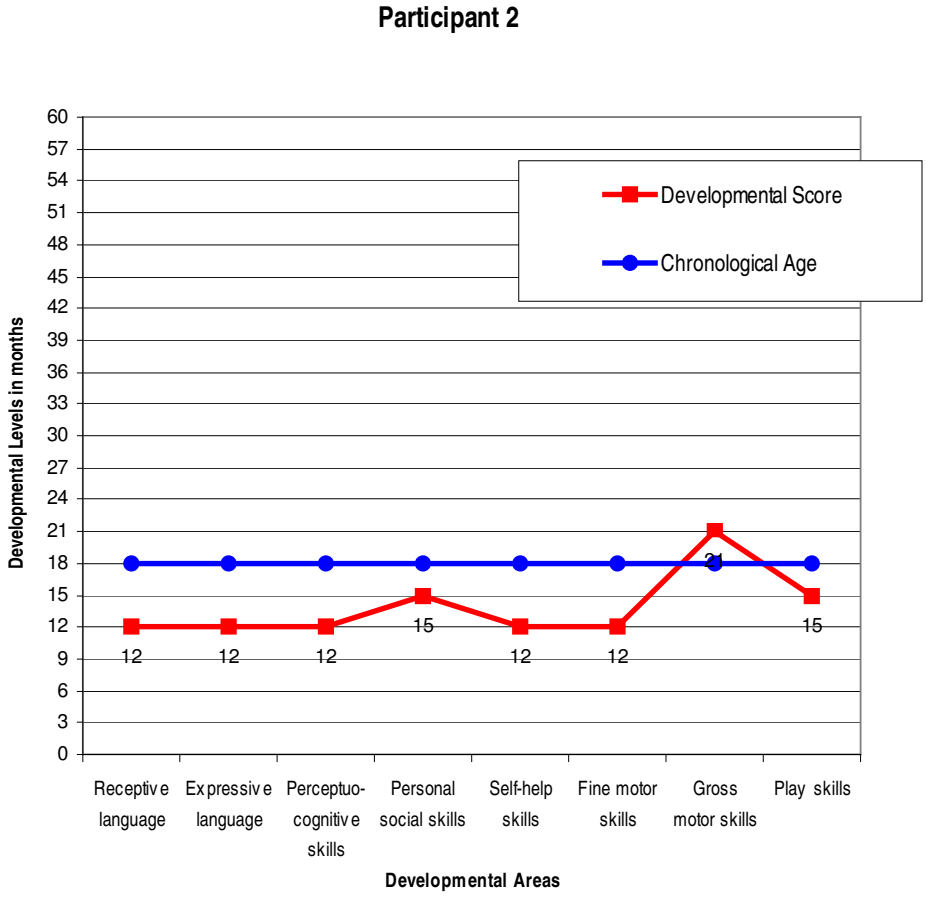


Figure 4.2 Participant 2: Comparison between chronological age and developmental level of functioning

According to Figure 4.2 Participant 2's developmental graph indicates that he is functioning below the expected level for his age in all areas. An exception is however present in the area of gross motor skills that appeared to be well developed above the level of 18 months.

Table 4.5: Summary of Participant 2's developmental functioning

Assessment area	Age appropriate	Mild delay (6 month delay)	Moderate delay (> 6 – 12 month delay)	Severe delay or anomaly (> 15 month delay)
Level 1 – Physical features and sensory integrity				
Genetic screening				**Typical features of FASD present**
Hearing and vision	Normal hearing in best ear			**Strabismus**
Level 2 – Communication and related skills				
Oral-motor abilities			**Lip and tongue functioning**	

Listening skills			**Inadequate responses**	**Poor reaction to whispered speech**
Receptive language			**6 – 9 month delay**	
Expressive language		**3 – 6 month delay**		
Pragmatic skills		**Delayed**		
Parent-child interaction	Optimal, but requires guidelines regarding book-reading			
Bookreading interaction/Emergent literacy skills		**Delayed**		
Level 3 – General developmental skills				
Behaviour				**Excessively active**
Personal social skills	Yes			
Cognitive skills		**3 – 6 month delay**		
Play development	Yes			
Self-help skills			**6 – 9 month delay**	
Motor skills	Gross motor skills		**6 – 9 month delay in fine motor skills**	

According to Table 4.5, Participant 2 presented with moderate developmental delay in the area of receptive language and in listening skills. Participant 2's history of chronic otitis media could possibly have contributed to his poor receptive language and listening skills (Olswang et al., 1998). Poor receptive language and listening skills may also be related to cognitive delay (Carmichael Olson et al., 2007). Mild delays were present in the areas of expressive language and pragmatic skills, as well as perceptuo-cognitive skills. Moderate delays were observed in the areas of self-help and fine motor skills. The stimulation provided during parent-child interaction was appropriate, but too directive during the book reading. The only area of development that displayed functioning above the expected age is the area of gross motor skills, which is similar to the results of Participant 1.

According to Greene et al. (1990), the effect of prenatal alcohol exposure on language development is likely to be hidden by unmeasurable factors, such as enhanced environmental stimulation as children grow older, i.e. attendance of nursery school and parental stimulation. Participant 2 stayed at home full day with his foster mother and may therefore have received much parental attention and stimulation throughout the day.

Participant 2 already displayed a severe delay in the area of receptive language development together with a moderate delay in the area of expressive development. Increased verbosity may have given the added impression that expressive language skills were better developed than receptive language skills. Participant 2 presented with the characteristic of increased verbosity of children with FASD (Clark, 2004), despite the evident language delay that were present. Participant 2's language delay was evident in his limited vocabulary of 20 single words, a limited phonetic repertoire and short mean length of utterance for his age (see Table 4.4). Verbosity could possibly be linked to poor pragmatic and social-cognitive communication skills. This phenomenon is also described as a social-butterfly personality type, characterized by a lack of depth in communication interaction, flitting from person to person and finding it difficult to engage in structured and meaningful conversations (Glasser, 2002).

Increased verbosity is characterized by ease at engaging in conversational interaction and talkativeness, but upon closer inspection of the child's utterances, many of the utterances are repetitive or circumlocutory in nature. Fillers or general words are used excessively and thus the content is not always meaningful (Abkarian, 1992).

Upon closer analysis of Participant 2, who is only 18 months old, verbosity consisted of many word repetitions and fillers during conversation such as "uh", "uhm" and "thingy", as well as topic shifting in an inappropriate manner. Furthermore, the responses of the child with FASD often have little relationship to the initial statements of the communication partner, representing poor topic maintenance. This phenomenon is described as peculiar to FASD. Streissguth, LaDue and Randels (1988:31, as cited in Clark, 2004:5), described verbosity as "talking too much and too fast, but having little to say". Streissguth et al. (1991) described that increased verbosity contributes to the discrepancy between young children with FASD's verbal and non-verbal output and appears to continue into adolescence.

According to Prizant and Wetherby (1993) a child's language development reflects his world knowledge. It can thus be inferred that at this stage Participant 2 possessed limited world knowledge, reflected by his functional vocabulary and delay in cognitive development. According to Greene et al. (1990) and Church et al. (1997), delayed language acquisition, as displayed by Participant 2, is a symptom of FASD

and has a profound effect on later language skills, academic performance and it reflects the decreased intellectual or cognitive integrity of the child. Problems with cognition thus co-exist with language problems in FASD and contribute to language deficits as observed in Participant 2.

Participant 2 had significant difficulty in the area of communication function and language use. Requesting and protesting with a gesture was characteristic of the participant's behaviour regulation. He inconsistently used pointing to request, had inappropriate eye contact, and did not always use words to protest and reverted to infantile crying behaviour. He also had difficulty in establishing joint-attention. Children learn the rules and conventions of language through experience and interaction with others (Clark, 2004). It is postulated that impaired social communication is a result of a combination of disruptive factors, i.e. linguistic behaviours, underlying social cognitive behaviours and higher order executive (planning) functions such as memory, attention and planning (Thorne et al., 2007). It appears that these social communication impairments were already emerging in Participant 2, at the age of 18 months.

Furthermore Participant 2 presented with inadequate listening skills that could be linked to a history of recurrent otitis media (see Table 1.2). The inadequacy of listening skills may also relate to difficulty with the suppression of competing auditory messages as evidenced in research by Church et al. (1997) regarding the listening skills of children with FASD. Church et al. (1997) also found that most young children with FASD would remain otitis prone throughout childhood requiring continuous medical management. The susceptibility to otitis media is ascribed in part to Eustachian tube tortuosity (twisting) or stenosis, as well as M.Tensor Veli Palatini deficiency in the area surrounding the proximal opening of the Eustachian tube (Church et al., 1997). Church et al. (1997) also indicated that delayed maturation of the peripheral and brainstem auditory pathways may present in children with FASD, contributing to language deficits, delayed development of language acquisition, and auditory processing deficits. As evident in Participant 2, difficulties in the area of listening skills combined with a medical history of chronic otitis media and possible

slow maturation of the auditory pathways may have contributed to the current delay in communication development.

Participant 2 also presented with a moderate delay in oral-motor skills development. According to Church et al. (1997) the presence of oral-motor impairment and tongue coordination difficulties can be expected in young children with FASD. Oral-motor deficits can contribute to early feeding difficulties and expressive language difficulties, such as the incomplete consonant repertoire in Participant 2.

Delayed development across different areas in Participant 2 was similar to literature findings (Rogers-Adkinson & Stuart, 2007; Sparks, 2000) and supported a comprehensive assessment approach for infants and young children with FASD in order to identify and describe all the different areas of impairment. The aim is to provide appropriate EI to alleviate the negative impact of impairment on the infant/young child with FASD's functioning, quality of life and later school readiness. According to Rogers-Adkinson and Stuart (2007), EI is a key factor to reduce the impact of FASD and is believed to prevent secondary disabilities or the need for long-term care (Loocke et al., 2005). Developmental plasticity can still play a role throughout early childhood (Louw et al., 1998) due to the active neuronal pathway configuration that takes place. EI with a focus on communication skills can therefore be effective in infants and young children with FASD (Rodgers-Adkinson & Stuart, 2007). ECI also provides support for the foster parents regarding their needs and the child's needs. The effectiveness of ECI can be measured in terms of the developmental gains being attained despite the established risk that is present. Participant 2's foster parents reported no needs at this stage and only expressed concerns regarding his hearing, visual status of the right eye, and general developmental functioning (see Table 4.1). Although the foster parents expressed no current concerns the researcher determined that they were not aware of the emerging difficulties displayed by the participant across different developmental domains. The established risk of FASD was already present accompanied by a concern for Participant 2's communication development and general development. The lack of knowledge regarding the implications of the diagnosis of FASD by the foster parents was of concern. Although results cannot be generalized to all families of children

with FASD, the lack of knowledge indicated the information needs of the foster parents regarding the impact of FASD on their child's development.

4.3.3. Participant 3: Presentation and discussion of results

Table 4.6 Developmental functioning of Participant 3, 35 months old

Assessment Area	Results
Level 1 – Sensory integrity and physical features	
Oro-facial structures & genetic screening	• Head size: appeared small for age • Face: mid-facial structures appear flattened • Jaw: appears symmetrical • Dentition: normal molar & incisor relationship, 2 front teeth demonstrated poor hygiene, misalignment of teeth • Lips: thin upper lip with an absent philtrum • Tongue and frenulum: surface colour and size were normal • Pharynx and tonsils: colour were normal • Hard and soft palate: colour, rugae and symmetry at rest were normal • Ears: low set and protruding • Eyes: wide-set, epicanthal folds present • Nose: anteverted nares
Hearing Assessment and vision	• Foster parent did not attend the scheduled hearing assessment session. • Vision appears normal
Level 2 – Communication and related skills	
Oral-motor abilities & feeding skills	• Jaw: normal range of motion • Lips: normal range of motion and strength • Tongue: normal range of motion and strength except for difficulty with tongue tip elevation • Soft palate: absent gag reflex, normal resonance during phonation.
Listening skills	• Reaction to environmental and toy sounds, whispered speech and speech: Good • Easily distractible
Receptive language	• Below 24 months (ARWT, DAS, RITLS) • The participant can respond to simple questions and follow 2 step instructions • Delay of more than 11 months
Expressive language	• Below 24 months (EOWPT, DAS, RITLS) • 1.25 – 2.0 mean length of utterance; vocabulary approximately 50 words • Articulation development: age appropriate • Speech production is 60 % intelligible to listeners outside the family • Delay of more than 11 months • Verbosity
Pragmatic skills	• During social interaction she uses denial, comments and requests on a verbal level. • She presents with poor eye contact, struggles to attend to speaker, poor turn taking and topic maintenance.
Parent-child interaction	• Optimal interaction (Klein & Briggs, 1987) • Mother was very actively and animatedly involved in the activity. • Mother used good scaffolding and verbal elicitation strategies • Mother used tactile cues and the child's name to keep her attention.
Book-reading/Emergent-literacy skills	• Mother chose an appropriate story & displayed appropriate scaffolding behaviours. • Mother created a physical environment that promoted successful interaction. • Participant displayed emergent storybook reading skills

Level 3 – General developmental skills	
Behaviour	• Easily confused when many events going on in surroundings • Easily distractible, very affectionate and loving behaviour, limited awareness of other person's personal space, impulsive
Personal social skills	• 33 - 36 month level (DAS) • Friendly talkative girl • Verbosity
Cognitive skills	• 27 month level (DAS) • Delay of 8 months
Play development	• Symbolic level III - IV 24 - 30 months • Not very successful at functional and cooperative play. Easily distracted • Planned symbolic play (24 – 30 months) moving towards Socio-dramatic play (3 – 5 years) (Westby, 2000) • Delay of 5 – 9 months
Self-help skills	• Age appropriate level, occasionally requires assistance
Motor skills	• Fine motor: 24 months functioning level; delay of 9 months • Gross motor: Age appropriate • Parents report that she appears very clumsy at times
Level 4 – Risk & resilience factors	
Risk factors	• Diagnosis of FASD • Significant developmental and communication delay present • Multiple foster placements
Resilience factors	• Early diagnosis of FASD • Optimal stimulation in foster home and basic needs are provided for
Areas of need	• Speech-language therapy • Occupational therapy • Hearing assessment • Dental/Orthodontic assessment

Participant 3

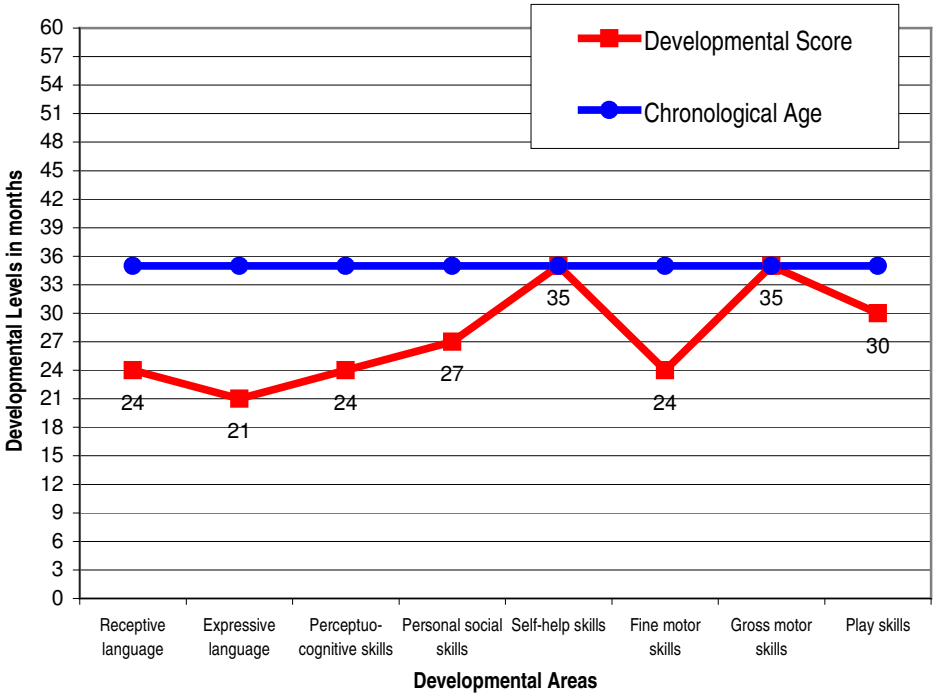


Figure 4.3 Participant 3: Comparison between chronological age and participant's level of developmental functioning

Figure 4.3 indicates developmental delays across all developmental areas in Participant 3, except in the areas of self-help and gross motor skills, which appear to be age appropriate. In comparison with Participant 1 and 2 (see Figure 4.1 and 4.2), it appeared that with increasing age an increase in developmental delay was evident across the three different children. Based on the results of the multiple case study design it appeared that the effect of prenatal alcohol exposure on the different developmental domains of the participants became more pronounced with increasing age, possibly due to increasing developmental demands (Ahola & Kovacik, 2007). This widening of the gap between chronological age and level of functioning (Rossetti, 2001) is also evident in children with Down Syndrome (Rossetti, 2001) and could therefore possibly be seen as a feature of children with established risks for developmental delay. This widening gap may be associated with secondary disabilities also appearing with an increase in age (Streissguth et al., 1997).

Table 4.7 Summary of Participant 3's developmental functioning

Assessment area	**Age appropriate**	**Mild delay (6 month delay)**	**Moderate delay (> 6 – 12 month delay)**	**Severe delay or anomaly (>15 month delay)**
Level 1 – Sensory integrity and physical features				
Hearing assessment	No data	----------	----------	----------
Genetic features				**Typical features of FASD present**
Level 2 – Communication and related skills				
Oral-motor abilities	Appropriate			
Listening skills	Good			
Receptive language			**> 11 month delay**	
Expressive language			**> 11 month delay**	
Pragmatics			**Inappropriate**	
Parent-child interaction	Appropriate			
Book reading/pre-literacy skills	Appropriate			
Level 3 – General developmental skills				
Behaviour			**Easily distractable**	
Personal social skills			**Yes**	
Perceptuo-cognitive skills			**8 month delay**	
Play development			**9 month delay**	
Self help	Age			

skills	appropriate			
Motor skills	Gross motor		**9 month delay – fine motor skills**	

According to Table 4.7, and concluding Participant 3's results, it was clearly indicated that moderate delays were present in the areas of receptive and expressive language, personal-social interaction, cognitive skills, fine motor skills and play development. Age appropriate functioning was observed in the areas of emergent literacy/book-reading skills, as well as in the area of listening skills, self-help skills, oral-motor abilities and gross motor skills. Research by Kalberg et al. (2006) indicated that fine motor skills are usually significantly more delayed than gross motor skills in children with FASD. Fine motor delays in children with FASD may be related to specific neurobehavioural deficits that affect these skills (Kalberg et al., 2006). The moderate delay in fine motor skills was, however, not observed in the developmental profiles of Participant 1 and 2. It is possible that delayed fine motor skills emerge later or may not be present in all children with FASD.

Optimal parent-child interaction can compensate for delays in expressive and receptive language (Greene et al., 1990). During interaction between Participant 3 and the foster mother it was observed that her interaction skills were appropriate for the participant's functioning level and she encouraged and supported a positive communication environment. The presence of the moderate delay in the areas of receptive and expressive language in Participant 3 was consistent with literature findings of Church et al. (1997) that the presence of FASD has a severe effect on language acquisition with concomitant cognitive difficulties. According to Church et al. (1997), it also appears that certain difficulties such as oral-motor impairments could improve with increase in age in children with FASD, but may still have a residual effect on speech intelligibility, as demonstrated by Participant 3. The same study also indicated the presence of decreased speech intelligibility in children with FASD, with slurred speech, dysfluencies and articulation problems. Participant 3 presented with difficulty with tongue movements especially with regard to tongue tip elevation that could negatively impact sound production for speech intelligibility. Tongue coordination difficulties in children with FASD may contribute to poor articulation skills. Incorrect or compensatory tongue placement during articulation of

speech sounds is also reported in the comprehensive research findings of Church et al. (1997).

In comparison with Participant 1 and 2, Participant 3 presented with an absent gag reflex. According to Hall (2001) the gag reflex is the only primitive reflex related to swallowing that continues through adulthood. The significance of the gag reflex may or may not be related to swallowing ability (Hall, 2001). Hyper- or hyporesponse of the gag may indicate neurological problems related to cranial nerve (CIX and CX) involvement or involvement of the cortex (Hall, 2001). Furthermore, Shipley and McAfee (2004) state that an absent gag reflex could also be related to muscular weakness in the velo-pharyngeal area or it can be indicative of a very high tolerance for gagging even if muscular integrity is normal. Due to cranio-facial anomalies and impaired function of other structures such as the tongue, Participant 3 may have presented with possible neurological or muscular involvement in the area of the soft palate.

Participant 3 also presented with a moderate delay in the area of personal-social skills. According to the literature young children with FASD may present with social-emotional delay, anti-social or disruptive behaviour, together with a slow-to-warm temperament as indicated in Table 1.2. Participant 3 presented with some characteristics of an apathetic personality type together with some characteristics of a social-butterfly type personality (Glasser, 2002). All these characteristics can contribute to inappropriate social interaction in the young child with FASD's repertoire of inappropriate personal-social skills. Participant 3 displayed multiple difficulties in this developmental domain. These difficulties can limit the participant's adaptive interaction functioning leading to dissatisfaction in personal relationships and not being able to communicate needs effectively (Aydlett, 1993). As observed in Participant 2 and confirmed by literature (Coggins et al., 2007) personal-social skills and social cognition are impaired in children with FASD. Personal-social skills and pragmatic skills are interwoven to result in successful communication interaction (Coggins et al., 2007).

According to Table 4.6, Participant 3 also presented with pragmatic difficulties such as poor turn taking, topic maintenance and attendance to the communication partner.

The participant's personal-social interaction was also characterized by verbosity, similar to that described in Participant 2. Research findings indicate that pragmatics in a social interaction setting are a reflection of internal adaptations when social cognition, language and executive functions come together to meet the demands of varying social interactions (Timler, Olswang & Coggins, 2005). Participant 3's verbosity was characterized by increased phrase repetitions, circumlocutory speech, increased use of fillers such as "uhm-uhm", with word finding difficulties using general words such as "ding" ("thing"), "dit" ("this") and "dat" ("that"), jumping from one topic to another without alerting the partner to a topic shift and immature sentence structure. Abkarian (1992), Clark (2004) as well as Rivers and Hedrick (1992; 1998) described these characteristics of word finding difficulties, inappropriate topic shifting together with immature sentence structure in their research.

Participant 3 displayed a moderate delay in the domain of play development, possibly relating to the observed cognitive delay (see Table 4.7). Play stages and the reflection of the inherent cognitive development stages of the infant or young child are closely linked (Fewell & Glick, 1993). According to Ahola and Kovacik (2007) the careful observer can pick up cues as to how the child is thinking by studying the child's behaviour during play. Furthermore, play is central to the development of cognition (Ahola & Kovacik, 2007). Another important link between language and play is that both reflect the development of underlying symbolic ability (Ahola & Kovacik, 2007; Fewell & Glick, 1993). Play is regarded as an "all-encompassing activity for young children and virtually all areas of development – cognition, motor, social, emotional, language – can be observed in a child's play" (Fewell & Glick, 1993:140). Participant 3's play skills reflected attempts at cooperative symbolic play (24 – 30 months), but she was easily distractible and reported to struggle with appropriate interaction during functional play with peers. Planned symbolic play was sometimes evident but not yet fully established. Her cognitive skills in relation to her play skills were at a 27 month level, indicating moderate delay in this area as well. Participant 3's play development was at a planned symbolic level and had not yet progressed to an age appropriate level where socio-dramatic play should be observed more often (Roth & Worthington, 2001). Delayed development in Participant 3 could be related to the fact that young children with FASD have difficulty to establish and maintain relationships with peers

(see Table 1.2) and have difficulty taking another person's perspective into account, i.e. displaying theory of mind deficits (Timler et al., 2005).

Other behavioural difficulties in children with FASD can also have a negative impact on play development. These difficulties can be autistic-like behaviours, off-task behaviour, limited goal directedness, impulsivity, low frustration threshold, poor self confidence, aggressive behaviour and a decreased capacity to initiate and organize play (Beirne-Smith et al., 2000; Carmichael Olson, 1995; Carmichael Olson & Burgess., 1997; Kim et al., 1999; Sparks, 1993). Participant 3 presented with off-task behaviour during play interaction and needed to be redirected to the play task at hand, displayed impulsive behaviour and had difficulty in organizing play with a partner.

According to Table 4.1, Participant 3's foster parent indicated a need for help in optimising her speech and language development and addressing the current deficits in these areas. This is a positive factor, as an expressed need for intervention is a first step in providing effective ECI services to families of young children with FASD. The provision of successful EI services to a family will also rest upon the parent's understanding that a child with FASD has a neurological impairment arising from prenatal alcohol exposure and may therefore alter a parent's perception of the child's behaviour (Carmichael Olson et al., 2007). In the South African context Popich, Louw and Eloff (2007), highly recommend caregiver education as a prevention strategy for communication disorders. In the case of children with FASD tertiary prevention can be provided. An example of tertiary prevention would be the continued provision of speech-language therapy after a period of ECI, with the aim of school readiness and reducing the effect of FASD on the child's communication development. In the multi-cultural environment of South Africa a family-centred approach to determine a family's needs are advocated (Popich et al., 2007). In the case of Participant 3 the main need expressed by the foster parents was a need for assistance with the participant's communication development.

4.3.4. Participant 4: Presentation and discussion of results

Table 4.8 Developmental functioning of Participant 4, 51 months old

Assessment Area	Results
Level 1 – Sensory integrity and physical features	
Oro-facial structures and genetic screening	• Face: mid-facial structures appear flattened • Jaw: appears symmetrical • Dentition: normal molar & incisor relationship, misalignment of teeth, very poor hygiene • Lips: thin upper lip, absent philtrum • Tongue and frenulum: surface colour and size were normal • Pharynx and tonsils: colour were normal • Hard and soft palate: normal colour, rugae and symmetry at rest, had a reconstructed cleft of the hard palate. Cleft classification Group 3: Cleft palate only, complete cleft including hard and soft palate (Bardach & Salyer, 1995). • Head shape: appears small for age, possible microcephaly • Ears: low set and protruding • Eyes: wide-set, epicanthal folds present • Nose: anteverted nares
Hearing abilities and vision	• Bilateral normal anatomy of the external meatus • Bilateral normal hearing thresholds • Bilateral normal retrocochlear conduction • Vision appears intact
Level 2 – Communication and related skills	
Oral-motor abilities	• Jaw: normal range of motion • Lips: struggles to pucker lips • Tongue: normal range of motion except for struggling with tongue tip elevation, rapid side-to-side movements slows down progressively • Hard and soft palate: absent gag reflex, normal velo-pharyngeal function during phonation
Listening skills	• Reaction to environmental and toy sounds: Good. • Reaction to whispered speech: Inadequate. • Reaction to speech: Good. • Parents report poor listening skills and inattention.
Receptive language	• 24 -30 month level (ARWT; RITLS; DAS) • Delay of 21 – 27 months
Expressive language	• 24- 30 month level (EOWT; RITLS; DAS) • Sentence length: 4 – 5 words (Bus story) & Information recounted indicates delay in expressive language • Developmental phonological disorder present: Substitutes fricative sound /f/ with a plosive sound /p/, final consonant deletion, fronting, initial syllable deletion, cluster reduction • Denasal speech resonance • Echolalic behaviour • Decreased speech intelligibility • Estimated current vocabulary: 20 – 50 words • Very talkative • Delay of 21 – 27 months
Pragmatic skills	• Uses denial, commenting and requesting on a verbal level. • Poor eye contact, difficulty to attend to speaker and difficulty with turn taking and topic maintenance. • Difficulty with communication repair. • Disregard for interpersonal space. • Increased reliance on gestures. • Increased verbosity.
Parent-child interaction	• Not always optimal (Klein & Briggs, 1987) • Appropriate storybook selection and involvement in activity by mother.

	• Mother named pictures and expanded on the participant's comments. She ensured that turns were taken and evidenced enjoyment of the activity. She gave instructions and asked appropriate questions. • Inappropriate scaffolding strategies were used at times. • The mother did not interact at an age appropriate play level.
Book reading/Emergent-literacy skills	• Mother chose an appropriate narrative story. • Mother used good scaffolding behaviours. • Mother read in a way that invited interest. • Mother asked too many direct questions on which the child responded negatively • Participant produced emergent storybook reading skills
Level 3 – General developmental skills	
Behaviour	• Easily distractible • Rapidly moves from one activity to another • Difficulty with sustained attention • Overtly affectionate
Personal social skills	• 33 - 36 month level (DAS) • Talkative girl • Delay of 13 – 16 months
Cognitive skills	• 36 month level (DAS) • Delay of 13 months
Play development	• Symbolic level IV - V 28 months – 36 months (Westby, 2000) • Not very successful at cooperative play with friends at her nursery school, will rather play on her own • Delay of 13 – 21 months
Self-help skills	• 30 month level (DAS) • Delay of 21 months
Motor skills	• Fine motor: 39 month level • Delay of 12 months • Gross motor: 36 – 39 month level • Delay of 12 – 15 months • Parents report that she appears very clumsy at times
Level 4 – Risk & resilience factors	
Risk factors	• Diagnosis of multiple disabilities (FASD, cleft palate, ADHD) • Developmental delay present in all areas of level 2 and 3 • Participant continued to be exposed to parental substance abuse behaviour in biological home environment.
Resilience factors	• Early diagnosis of FASD before 6 years of age • Basic needs being met in current foster placement and attempts at optimal stimulation
Areas of need	• Speech-language therapy • Occupational therapy • Nursery school placement • Parent education

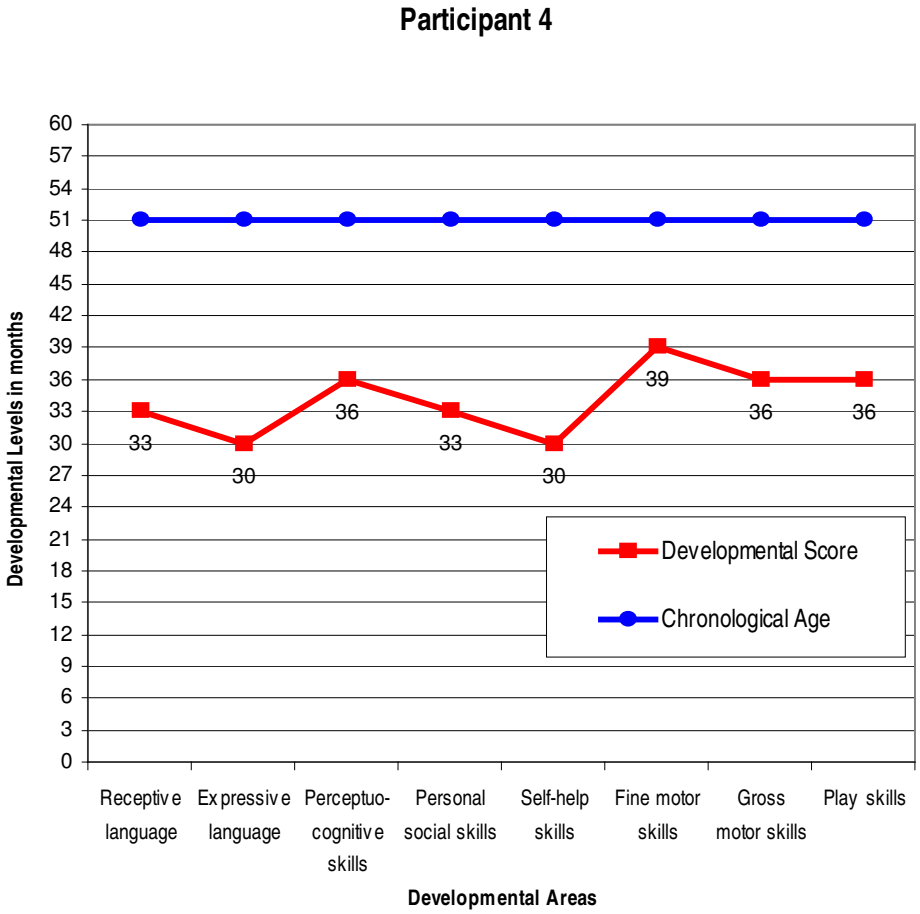


Figure 4.4 Participant 4: Comparison between chronological age and participant's level of developmental functioning

It is evident that Participant 4 was functioning at a much lower level than her chronological age across all developmental domains with some delays of up to 21 months (see Table 4.8). The large gap between the participant's chronological age and developmental age indicated severe overall developmental impairment. The results followed the trend already observed in Participant 1 to 3, that an increase in age demonstrated more pronounced developmental delays and impairments in the participants. Although this observation cannot be generalized to the whole clinical population of children affected by FASD, it was a significant finding in the current study. The downward developmental trend observed from Participant 1 to 3 was continued in Participant 4, but in addition, gross motor skills were now also delayed.

Table 4.9 Summary of Participant 4's developmental functioning

Assessment area	Age appropriate	Mild delay (6 month delay)	Moderate delay (> 6 – 12 month delay)	Severe delay or anomaly (> 15 month delay)
Level 1 – Sensory integrity and physical features				
Hearing abilities and vision	Normal hearing thresholds			
Genetic screening				**Typical features of FASD present. Complete cleft of the hard and soft palate**
Level 2 – Communication and related skills				
Oral-motor abilities	Age appropriate			
Listening skills	Environmental sounds, toy sounds and speech		**Inadequate for whispered speech**	
Receptive language				**Delay of 21 – 27 months**
Expressive language				**Delay of 21 – 27 months**
Pragmatic skills			**Not optimal**	
Parent-child interaction			**Not optimal**	
Book reading/Emergent-literacy skills			**Not optimal**	
Level 3 – General developmental skills				
Behaviour				**ADHD diagnosis**
Personal social skills				**Delay of 13 – 16 months**
Cognitive skills			**Delay of 13 months**	
Play development				**Delay of 13 – 21 months**
Self help skills				**Delay of 21 months**
Motor skills			**Fine motor skills; delay of 12 months**	**Gross motor skills; delay of 12 – 15 months**

According to Table 4.9 it was evident that the participant displayed severe delays in receptive language, expressive language, personal-social interaction, and play development, as well as gross motor skills. Greater delays were present on level 2, but most of the severe delays were apparent on level 3 of the EC assessment framework in Participant 4 (Kritzinger & Steenkamp, 2006), i.e. in the domain of general developmental skills. Apart from the severe delays, age appropriate developmental skills were present in the areas of hearing and listening. Furthermore, participant 4's verbal expression was unintelligible due to phonological developmental disorder and minimal oral-motor difficulty.

Participant 4 was able to respond to simple questions and follow very concrete one-step instructions. She had difficulty retelling a story or answering specific questions about a story. Participant 4's verbosity was characterized by circumlocutory speech, phrase repetitions, use of general words as fillers when apparent word finding difficulty was present, repetition of previously mentioned information, inappropriate topic shifting and increased speed of speech production. Coggins et al. (2007) found that children with FASD present with an impaired ability to recount pertinent information from a narrative. The generation of a satisfying narrative is a very complex task that demands the skilful integration of multiple linguistic, social cognitive and strategic planning (Coggins et al., 2007). Furthermore, the participant presented with a limited functional vocabulary and poor grammatical structure. Autistic-like echolalic behaviour was also noted during the assessment. To augment poor verbal expression Participant 4 tended to use more hand gestures to convey a message than a child of this age. Participant 4's deficits in language skills reflected functional deficits in social cognition, language and executive functions as also highlighted by (Coggins et al., 2007). Participant 4's personality type also played a role in social interaction and the effectiveness thereof. Participant 4 mainly displayed an apathetic personality type (Glasser, 2002), similar to Participant 3. According to Glasser (2002) children with FASD presenting with an apathetic personality type are usually more withdrawn, and display limited variation in facial expressions.

The area of parent-child interaction was non-optimal in Participant 4. During the free play session the foster parent experienced problems to respond appropriately to the participant's non-verbal and verbal cues. The mother did not adapt to an appropriate play level to accommodate the participant's delayed developmental functioning. Limited non-verbal encouragement, verbal praise or encouragement was provided when the participant completed a task successfully. The parent-child interaction-dyad was negatively affected as the mother overestimated the participant's developmental functioning. The parent therefore did not interact on a developmentally appropriate level with the participant. According to Rodgers-Adkinson and Stuart (2007), past experiences by the parent and child in book reading and play situations could contribute to the parent and child's current way of interaction. The social interaction skills of children with FASD are affected, which could contribute to difficulties in parent-child interaction (Rodgers-Adkinson & Stuart, 2007). Another contributing

factor to the limited parent-child interaction observed in Participant 4 could also be behavioural difficulties displayed by the child (Hyter, 2007).

Upon closer inspection of Participant 4's moderate delay in the area of book-reading or emergent literacy development, it could be inferred that a low level of parental literacy mediation may have been present in the child's biological or previous foster placement environments. The child was in the foster care system for 24 months, staying with two different foster families. Currently Participant 4 was living with her third foster family. According to Aram, Most and Mayafit (2006) parental literacy mediation which introduces the child to written language in their home environment, constitutes a central factor in the development of emergent literacy. Joint storybook reading is viewed as an important activity to promote literacy development. Regular storybook reading with accompanied interactions around the story can contribute to vocabulary development and improved language skills (Aram et al., 2006). Participant 4's moderate delay in emergent literacy skills may also be linked to a low exposure to storybook reading and other emergent literacy development activities in previous care-settings. Although general interaction skills were not adapted, the current foster mother's book-reading skills were mostly appropriate and she made use of good scaffolding techniques and created a positive social/emotional climate for the activity. The current foster mother's higher educational level, including a degree in early childhood education, may positively influence the further development of the participant's book-reading skills and emergent literacy development (Kritzinger & Louw, 1997) (See Table 3.1).

The area of personal-social skills was severely affected and the area of pragmatics was moderately affected in Participant 4. Pragmatic skills were characterized by poor eye contact, difficulty to attend to a communication partner, poor turn-taking, poor topic maintenance, and a disregard for personal space of the researcher who was a relative stranger to the participant. The participant was very affectionate and liked to be hugged, even by relative strangers as observed during the assessment session. The lack of age appropriate skills in these areas could possibly be ascribed to poor abstract communication skills, pragmatic deficits and decreased social cognition found in children with FASD (Rodgers-Adkinson & Stuart, 2007). Other contributing factors could be her history of multiple foster placements with a lack of adequate attachment

to her current foster parents. Her foster parents described her as an overtly friendly and talkative child. The talkativeness could be attributed to verbosity, similar to that observed in Participant 2 and 3. During social interaction and the play segments of the data collection assessment, the participant moved rapidly between objects, activities and conversational topics – a characteristic indicative of her concomitant ADHD diagnosis. The area of social interaction skills was not the only area where delays were indicated. Self-help skills were also severely delayed which can negatively influence Participant 4's future independence. Severe general developmental and communication delays were present in Participant 4, due to FASD and associated microcephaly indicative of possible cognitive impairment (Streissguth et al., 1997) (See Table 4.9).

It can thus be concluded that in the case of Participant 4 who was older than the previous three participants, she presented with more delays than the previous three participants on all four levels of the EC assessment framework (Kritzinger & Steenkamp, 2006). More areas of delay were present on level 3, but the greatest delay of 21 – 27 months was present on level 2, i.e. communication skills.

Participant 4 displayed a complex clinical profile due to the presence of multiple disorders. Three major diagnostic conditions were present, i.e. FASD, ADHD and cleft palate. Cranio-facial deformities such as a cleft palate and dento-facial defects are also common in this population (Church et al., 1997). It should be highlighted that all these conditions represent established risks for developmental disorders (Rossetti, 2001). Participant 4 presented with the most complex clinical profile of all the participants in this study.

4.3.5. Participant 5: Presentation and discussion of results

Table 4.10 Developmental functioning of Participant 5, 58 months

Assessment Area	Results
Level 1 – Sensory integrity & physical features	
Oro-facial structures & genetic screening	• Head size: appeared small for age, possible microcephaly • Hair: unusual lighter spots • Face: normal symmetry • Jaw: normal symmetry of mandible & maxilla • Dentition: 4 front teeth missing, misalignment of teeth, poor hygiene • Lips: poorly defined philtrum, thin upper lip • Tongue and frenulum: surface colour and size were normal • Pharynx: tonsils present • Hard and soft palate: normal colour and symmetry at rest, hard palate

	arch is high and narrow • Ears: low set, protruding • Eyes: normal • Nose: anteverted nares • Proportion of midfacial structures: normal • Hand crease pattern: simian crease in both hands
Hearing assessment and vision	• Participant's adoptive parents was not able to attend a second session for a hearing evaluation • Vision appears normal
Level 2 – Communication and related skills	
Oral-motor abilities and feeding skills	• Face: struggled to imitate facial movements • Jaw: normal range of motion and ungraded groping movements sometimes present during speech • Lips: normal range of motion and strength, oral apraxia present in movement on request • Tongue: normal range of motion and strength, oral apraxia present in movement on request • Soft palate: absent gag reflex, velo-pharyngeal closure appears normal • Normal independent feeding skills present
Listening skills	• The child's reaction to environmental sounds and toys sounds were good • Reaction to whispered speech and normal speech was inadequate • Parents do not feel that child has problems with hearing or listening skills
Receptive language	• 33 -35 month level (ARWT; DAS) • The participant can respond to simple questions and follow instructions • Wants to figure things out for himself before asking for help • Parents describe thinking skills as good • Delay of 23 – 25 months present
Expressive language	• 42 - 44 month level (EOWT; DAS) • Sentence length: 4 year level (Bus Story) • Information relayed: 3 year level (Bus Story) • Appropriate articulation and phonological skills • Talkative (verbosity) despite delayed acquisition of first words • Delay of 14 – 16 months present
Pragmatic skills	• Difficulty with turn-taking, joint attention and topic maintenance • Poor communication repair and clarification skills • Inappropriate comments, cussing (use of swear words) inappropriately in conversation, laughs inappropriately when swearing • Lack of theory of mind
Parent-child interaction	• Mother chose inappropriate book, did not display enjoyment and animation during task to facilitate the participant's verbal responses. • Mother let child take lead and did not provide enough scaffolding or structure.
Book reading/Emergent-literacy skills	• Mother chose appealing theme and pictures, but too difficult plot • Mother used minimal scaffolding behaviours • Mother did not create optimal physical environment to promote successful interaction, did not read the story. • The participant displayed emergent storybook reading skills, but immature for age

Level 3 – General developmental skills	
Behaviour	• Throws tantrums when not getting his own way • Rather plays on his own than with others, usually starts fighting with his peers after a short while of playing • When he is admonished he will sometimes use foul language (swear words) • He expects to be rewarded for doing simple tasks, such as picking up his toys after play • Difficulty with sharing and taking turns • Friendly and interacts with strangers with ease • Very busy and fleeting attention span when attending to play activities
Personal social skills	• 42 month level (DAS) • Delay of 16 months present • Very friendly and talkative
Perceptuo-cognitive skills	• 48 month level (DAS) • Delay of 10 months present • Parents describe thinking skills as good
Play development	• Symbolic level VII: 3 years 6 months – 4 years: Level of play development (Westby, 2000) • Not very successful at cooperative play • Observed planned symbolic play (24 – 30 months) moving towards socio-dramatic play (3 – 5 years)
Self help skills	• 48 month level (DAS) • Delay of 10 months present • Not yet completely toilet trained, and needs help with bathing and getting ready for bed
Motor skills	• Fine motor: 51 months (DAS) • Delay of 7 months present • Gross motor: Age appropriate (DAS) • Parents have no concern in these areas
Level 4 – Risk factors & resilience	
Risk factors	Pre- and postnatal: • Intra-uterine growth retardation • Diagnosis of FASD • Poor caregiving environment • Perinatal condition: • Early withdrawal symptoms from alcohol after birth (vomiting, poor self-regulation and jitteriness) • Developmental delay in all areas of level 2 and 3 • Foster parents not aware of delays
Protective factors	• Foster care placement at birth • Early diagnosis of FASD • Foster mother with higher educational attainment • Basic needs are met in foster family and an attempt at optimal stimulation is provided
Areas of need	• Speech-language therapy • Occupational therapy • Family counselling to address behavioural difficulties and provide support and information to parents • Supportive nursery school

Participant 5 presented with severe delays in the developmental domains of receptive and expressive language, personal-social skills and play skills. Perceptuo-cognitive skills were moderately delayed. These findings relate to the symptoms described by Coggins et al. (2007), i.e. difficulties in language, social cognition and executive

functioning of children with FASD. According to Participant 5's developmental profile (see Table 4.10), feeding skills together with gross motor skills were the only age appropriate domains.

A hearing assessment could not be conducted, as the participant's foster parents were not able to attend a session to complete the assessment. Therefore the possibility of otitis media, even though not indicated in the case history, but reported in the literature as a characteristic of children with FASD, could not be examined.

The typical cranio-facial characteristics of FASD (i.e. poorly defined philtrum) and the physical characteristics of FASD (i.e. head size appeared small for age) were observed in Participant 5. Typical cranio-facial characteristics of FASD were observed in all five participants, e.g. low-set ears, poorly defined philtrum, anteverted nares and a small head. According to the literature and diagnostic criteria of FASD, the presence of pre- and postnatal growth retardation, as well as FASD specific cranio-facial dysmorphology are typically present in young children with FASD (Clarren & Astley, 1997; Steinhaussen et al., 2003).

Unique characteristics not ascribed to FASD in the literature - see Table 4.10 - were that Participant 5 had presented with an absent gag reflex (also observed in Participant 3 and 4), and unusual lighter spots in the hair. According to Hall (2001) an absent gag-reflex could be related to cranial nerve involvement (Hall, 2001). However, no information relating to an absent or a high-tolerance gag-reflex associated with FASD was found in the literature to substantiate these research findings present in Participants 3, 4 and 5. The case history indicated possible early drug withdrawal symptoms, difficulties with self-regulatory behaviour, and a possible compromised immune system in Participant 5.

On level 2 of the assessment framework, in the area of oral-motor functioning the participant demonstrated groping tongue movements indicative of oral apraxia (Abkarian, 1993; Clarren et al., 2000; Sparks, 2000). Participant 5 demonstrated a receptive-expressive language gap (Abkarian, 1993; Sparks, 2000), where expressive skills were mostly affected. The greater expressive language delay was unlike that observed in Participant 2. The participant displayed short mean length of utterance as

well as a limited functional vocabulary during the narrative task. Language impairment was also apparent in instructional tasks. The receptive language impairment in Participant 5 could also be related to cognitive impairment. In the interview with the adoptive parents, it was reported that the participant was a very quiet baby and that he is currently very talkative, presenting with verbosity. Participant 5's talkativeness occurred spontaneously, displaying another dimension of verbosity than Participant 4. According to Glasser (2002) children with FASD are described as having two distinct personalities, either a 'social butterfly' – very active and talkative with no depth to interaction – or apathetic and withdrawn. It appeared that Participant 5 had a 'social butterfly' personality (see Table 1.3). Participant 5's increased talkativeness was characterized by the use of many social fillers, non-descriptive words such as "die een" ("this one"), "daai dingetjie" ("that thingy"), "dit" ("this") and "dat" ("that") and circumlocutory speech. The verbosity displayed by Participant 5 was very similar in character to Participant 3's talkativeness. Increased verbosity in children with FASD confirms poor social cognition in this population (Coggins et al., 2007).

The poor social interaction skills and behavioural difficulties observed in Participant 5 are extensively described in older children with FASD (Batshaw & Conlon, 1997; Carmichael Olson, 1995; Carmichael Olson & Burgess, 1997; Colangelo & Jones, 1982; Jacobson et al., 1993; Schoenbrodt & Smith, 1995; Steinhausen et al., 2003). Participant 5's behaviour was characterized by tantrums, foul language, poor ability to share, over friendly towards strangers, excessively active, a fleeting attention span and a preference to play alone. Timler et al. (2005) recommend that therapy for children with FASD focus on enhancing skills such as problem solving, social communication skills and coping skills. These skills are interrelated with communication development and could also affect change and improvement in the areas of social-cognition, language and executive function (Coggins et al., 2007).

Regarding the area of play development (see Table 4.10), Participant 5 had difficulty with cooperative play and displayed delayed play development. It was reported that he preferred to play alone, and did not like sharing toys with other children during play. He was inclined to throw tantrums when not getting his way. Poor turn taking skills could have contributed to poor interaction during play. The participant did not

take responsibility in picking up toys and putting them away after play if he was not rewarded for the task. The literature indicates that children with FASD have a decreased capacity to initiate and organize play and display difficulty with peer interaction (Carmichael Olsen & Burgess, 1997; Clarren et al., 2000; O'Malley & Nanson, 2002; Sparks, 2000). Difficulty in the area of play and particularly cooperative play could possibly be associated with children with FASD's impairments in theory of mind and social cognition. Children with FASD struggle to take another person's perspective into account during conversational and narrative tasks (Timler et al., 2005). Other aspects that could also contribute to impairment in this area are sensory modulation disorder present in young children with FASD (Atchison, 2007).

The participant presented with a 10-month cognitive delay as measured on the DAS (Fewell & Vadasy, 1984). Mild to moderate cognitive impairments together with complex learning impairments are characteristic of children with FASD' profile (Colangelo & Jones, 1992; Jacobson et al., 1997; O'Malley & Nanson, 2002; Shprintzen, 2001). According to the research of Henry et al. (2007) the cognitive delay in children with FASD is further compounded by cognitive inflexibility, poor executive functioning and poor processing capabilities.

An overview of the general developmental progression of Participant 5 was also obtained with the use of results of the DAS (Fewell & Vadasy, 1984) and the RITLS (Rossetti, 1990), and is depicted in Figure 4.5.

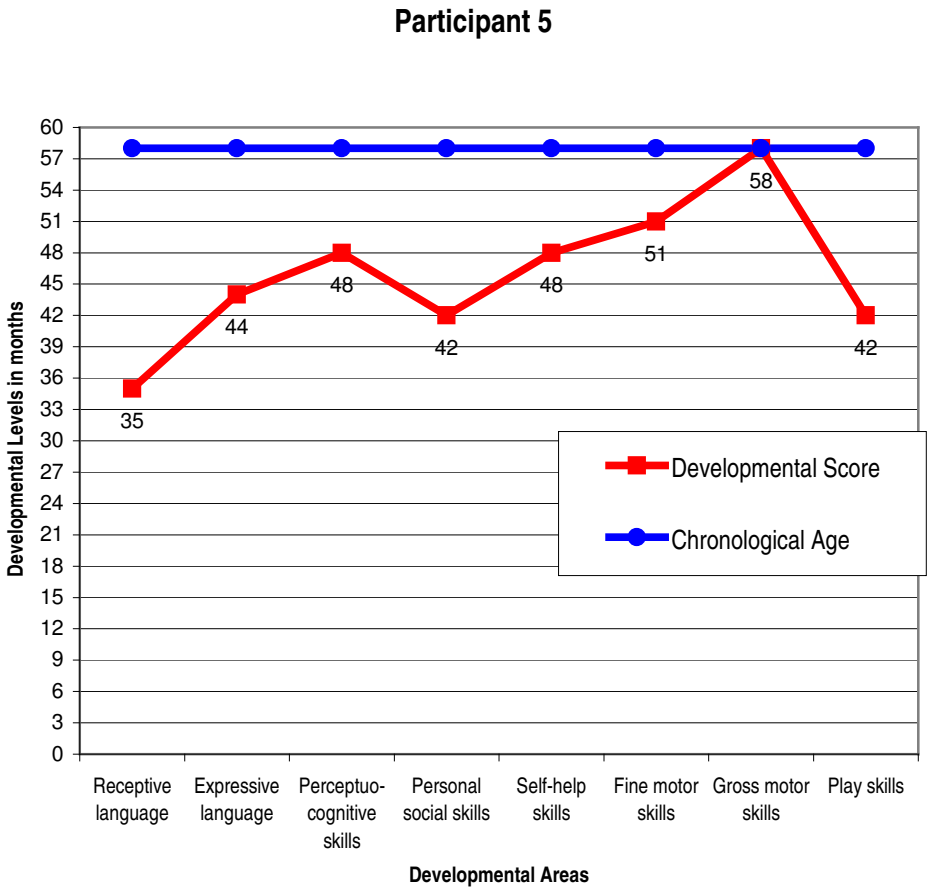


Figure 4.5 Participant 5: Comparison between chronological age and participant's level of developmental functioning

As depicted in Figure 4.5 it was evident that all developmental areas are delayed, except gross motor skills. Thus a general developmental delay is present in Participant 5. A conclusive summary of the participant's developmental functioning is presented in Table 4.11.

Table 4.11 Summary of Participant 5's developmental functioning

Assessment area	Age appropriate	Mild delay (6 month delay)	Moderate delay (> 6 month – 12 month delay)	Severe delay or anomaly (> 15 month delay)
Level 1 –Physical features & sensory integrity				
Oro-facial structure and genetic screening				**Typical features of FASD**
Hearing skills	No data obtained			
Level 2 – Communication and related skills				
Oral-motor abilities and feeding skills	Feeding skills are normal		**Oral apraxia; limited range of motion**	
Listening skills	Environmental		**Not adequate for**	

	sounds and toy sounds		**whispered speech or speech**	
Receptive language				**23 – 25 month delay**
Expressive language				**14 – 16 month delay**
Pragmatic skills			**Not optimal**	
Parent-child interaction			**Not optimal**	
Book reading/emergent-literacy skills			**Not optimal**	
Level 3 – General developmental skills				
Behaviour			**Not optimal**	
Personal social skills				**16 month delay**
Perceptuo-cognitive skills			**10 month delay**	
Play development				**Yes**
Self help skills			**10 month delay**	
Fine motor skills			**Delay of 7 months**	
Gross motor skills	Yes			

According to Table 4.11, Participant 5 presented with moderate delays in the areas of oral-motor abilities, pragmatics, book-reading skills, parent-child interaction, listening skills, cognition, self-help and fine motor skills. Moderate delays were present in most areas of general developmental skills on level 3. The most severe delays were however present in receptive and expressive language skills on level 2.

Participant 5 appeared inattentive towards speech sounds and was more interested in environmental sounds. In the literature abnormalities in orientation to auditory stimuli, speech discrimination and involuntary responses to environmental noises due to a lack of habituation are indicated in FASD (Abkarian, 1993; Carmichael Olson, 1995; Carmichael Olson & Burgess, 1997; Clarren et al., 2000; Crites et al., 1992; Gerber, 1998; Kim et al., 1999; Sparks, 2000). Participant 5 could be presenting with a possible central auditory processing disorder, but this could not be investigated due to the missed appointment (see Table 4.10). The lack of data regarding the participant's hearing status is recognised as a limitation in the study. Hearing assessment should form part of a comprehensive EC developmental assessment of any young child (Kritzinger & Steenkamp, 2006).

Delayed attainment of self-help skills were observed and reported in Participant 5. Children with FASD feel insecure and at times easily frustrated that could contribute

to difficulties in the development of independent self-help skills (Streissguth, et al., 1997).

The participant also presented with a 7-month delay regarding his fine motor development, which is also described in the literature as characteristic of developmental impairments present in children with FASD. Difficulties with fine motor skills can also contribute to delayed independency (Batshaw & Conlon, 1997; Kim et al., 1999; Schoenbrodt & Smith, 1995; Sparks, 1993; Steinhausen et al., 2003).

The results of the collective case studies indicated that the five participants presented with impairments on all four levels of the Four-level Early Communication Assessment Framework (Kritzinger & Steenkamp, 2006). However, the most severe impairments were present on level 2, namely communication skills. The Four-level Early Communication Assessment Framework was successfully used to describe the results of the individualized assessment protocol and structured interview. A developmental profile of each of the five participants' histories and in-depth descriptions of their communication profiles were obtained. Furthermore, it appears that the three aspects highlighted by Coggins et al. (2007), namely impairment regarding social cognition, language and executive functioning were emerging at an age as young as 18 months in Participant 2, and were fully present in Participant 3, 4 and 5. Social cognition impairments were especially characterized by poor language use in social contexts, verbosity and a lack of theory of mind. Verbosity was also observed at the young age of 18 months in Participant 2. Language impairment was characterized by limited vocabularies and poor grammatical sentence structure, whereas executive functioning impairments were observed as limited planning abilities, lack of creative and practical problem solving skills as well as difficulty in reasoning.

4.4 CONCLUSION

In conclusion, the major areas of delay of each participant are presented in Table 4.12, in order to highlight the distinctive impairments that they presented with.

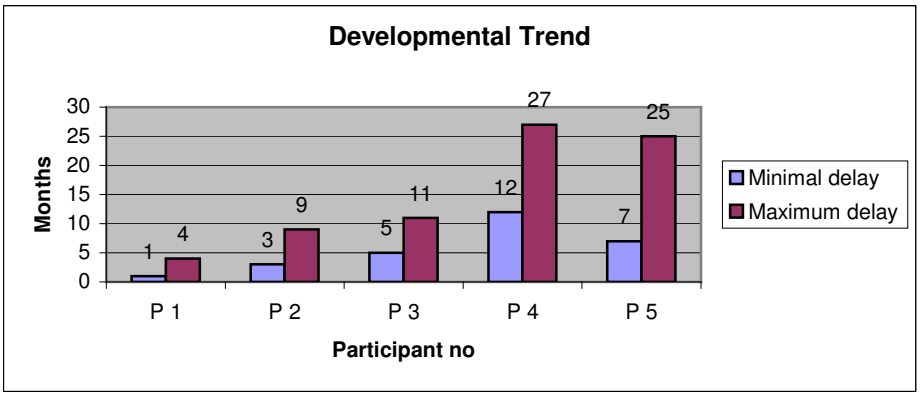
Table 4.12 Individual participants' developmental domains presenting with greatest impairment (n=5)

Participant and chronological age	*Key areas of impairment*	*Associated conditions*
Participant 1 **4 months**	• Oral-motor skills & feeding • Personal-social skills • Self-help skills	Small-for-gestational age Low birth weight GERD
Participant 2 **18 months**	• Communication skills & verbosity • Cognition • Fine motor skills	Recurrent otitis media
Participant 3 **35 months**	• Communication & verbosity • Cognition • Fine motor skills	Recurrent colds and flu Absent gag reflex
Participant 4 **51 months**	• Communication & verbosity • Personal-social skills • Cognitive skills • Play development • Self-help skills • Motor skills	Cleft palate ADHD Recurrent otitis media Frequent illnesses Absent gag reflex
Participant 5 **58 months**	• Communication & verbosity • Personal-social skills • Play development	Recurrent colds and flu Absent gag reflex Oral apraxia

The results of this study indicated that the group of participants was not homogenous although similarities were found in their profiles (see Table 4.12). Due to the similarities that were found speech-language therapists should keep in mind that children with FASD present with complex histories, cultural perspectives and clinical profiles (Rogers-Adkinson & Stuart, 2007). Dynamic, interactive assessment in an interdisciplinary team is thus crucial (Coggins et al., 2007; Guralnick, 2000). Participant 4 presented with the greatest delay with multiple impairments.

The three similar impairments observed in the participants were impairment regarding social cognition, language and executive functioning. These three impairments become apparent during assessment of level 2 and 3's developmental domains according to the Four-level Early Communication Assessment Framework of Kritzinger and Steenkamp (2006). Knowledge regarding the triad of impairments described by Coggins et al. (2007) could serve as a guideline for the speech-language therapist when assessing a young child with FASD.

The developmental profiles of the individual participants were combined to present a collective case study of the results of the five participants. The developmental trend that emerged from the results of the collective case study is depicted in Figure 4.6.



Key: **Minimal delay = 1-6 months in comparison with chronological age**
Maximum delay = more than 6 months in comparison with chronological age

Figure 4.6 Collective developmental trend emerging from the five participants

According to Figure 4.6, it was evident in the results of the collective case study that the delays and impairments present in the participants became more pronounced with an increase in age. This trend corresponds with the findings of Henry et al. (2007), indicating that secondary disabilities associated with FASD often became more impaired as the individual ages. There was an increase in the greatest delays and a decrease in the minimal delays, indicating that the severity of delays was increasing. The trend was only visible with the combined profiles of the five participants and does not necessarily indicate greater delays with age for all infants and young children with FASD. None of the participants received any form of ECI and therefore the trend could differ for infants and young children with FASD who received timely ECI. A definitive trend can, however, only be determined with a longitudinal study (Leedy & Ormrod, 2005). To minimize the severe impact of FASD on infants and young children with FASD and their families, timely ECI is strongly indicated (Carmichael Olson & Burgess, 1997; Rogers-Adkinson & Stuart, 2007). Timely ECI is important, because developmental plasticity is still present to facilitate developmental gains and to minimize the effect of the communication and general developmental impairments that are present (Batshaw & Conlon, 1997).

It is also clear from the results of the collective case studies that prenatal alcohol exposure has an impact on core developmental processes such as the neuro-physiological growth of the brain and nervous system, psychological development regarding personality formation and social cognition and communication (Henry et al., 2007). Due to the effect of FASD on the core developmental processes a wide

array of developmental domains are affected in infants and young children affected with FASD. The detailed profile of the communication development of a small group of infants and young children with FASD demonstrated the wide array of developmental domains that was affected.

According to Church et al. (1997) ECI for hearing, speech, language and cranio-facial disorders can assist to ameliorate the intellectual, behavioural and emotional problems exhibited by children with FASD. Language impairment, communication delay, verbosity and possible processing disorders were present in all the participants. The results correspond with those of Kodituwakku et al. (2006), who identified language impairments as a primary distinguishing characteristic in a group of children with FASD in an epidemiological study in South Africa. Research by Coggins et al. (2007) indicated a key deficit that children with FASD share is their difficulty in using language in sophisticated social contexts (see Tables 4.,2 4.4, 4.6, 4.8 and 4.10). The results of the study also confirmed severe communication impairments as the area of key deficit. The participants in the study also presented with impairment in responding and interacting appropriately in different social contexts such as parent-child interaction, emergent literacy activities and free play.

Furthermore, to confirm the evidence of language impairments in infants and young children with FASD, voxel-based morphometry data showed anomalies in the temporo-parietal cortices in the left hemisphere, which are the areas critical for language processing (Kodituwakku et al., 2006). Speech-language therapy is therefore most important for children with FASD, as language functioning is a predictor of school success (Rossetti, 2001). Individual therapy will provide the speech-language therapist with a unique opportunity to provide safety in a therapeutic relationship and to model effective communication skills that can enhance a young child with FASD's skill building regarding communication and related skills (Henry et al., 2007). According to Henry et al. (2007) language impairments in particular, are also likely to contribute to the children's poor coping strategies that often lead to negative and undesirable behaviours. Thus language impairments will impact on the areas of academic, behavioural and social interactive competence in young children with FASD.

It is thus evident that the participants in this study presented with complex multiple neuro-developmental needs and key deficits in the domain of communication and related skills, with far reaching impact on their daily functioning, every day family life and future academic success.

4.5. SUMMARY

In this chapter, the results of the individual descriptive profiles and the collective case studies were described and discussed according to the sub-aims set out for this study. The results were firstly presented according to the description of the characteristics of the participants and their environment and secondly regarding their communication abilities.

The participants presented with incomplete case histories. All the participants presented with affected communication and related skills and the prerequisite skills thereof. Furthermore, a decrease in developmental functioning with an increase in age was detected in the developmental profiles of five participants in collective case studies. Delays in development became more severe with an increase in age in the collective group of participants.

The distinctive characteristics of the five participants were early difficulties with self-regulation and feeding as well as irritable behaviour. Communication impairments, such as poor social cognition, poor language use, verbosity, a receptive-expressive language gap and limited functional vocabularies were observed in the participants from 18 months and older. Decreased executive functioning regarding problem solving and reasoning were also observed. Furthermore, the general developmental areas that appeared to be mostly affected by FASD were play skills, fine motor skills and the development of self-help skills to attain independence.

The nature of the impairments present in multiple domains across all five participants also emphasizes the multiple, interdependent environmental systems in which young children with FASD develop (Rogers-Adkinson & Stuart, 2007). Environmental risk was present in four of the participants who remain in the foster care system. Rogers-Adkinson and Stuart (2007:152) assert that, “family is the most fundamental factor influencing the lives and outcomes of children”.

CHAPTER 5

Conclusion and Recommendations

Aim: To present the general conclusions of this study and to discuss the clinical and theoretical implications of the results. The study is also critically evaluated and recommendations for future research are indicated.

5.1. INTRODUCTION

The individual communication profiles and the collective developmental trend of five young children, aged four months to 58 months, diagnosed with the specific category of FAS, were presented successfully within their adoptive and foster family contexts. The participants in the study are part of a worldwide increasing clinical population of infants and young children who require early communication intervention (Coggins et al., 2007; Hyter, 2007; Rossetti, 2001).

Despite an increase in this clinical population, improved services to address the impairments and the social impact related to FASD in the South African context are not readily available (Brits, 2005; Viljoen, 1999). Efforts to diagnose young children with FASD are not yet successful in South Africa. The lack of early diagnosis could possibly be ascribed to the social stigma associated with the diagnosis of FASD (Brits, 2005; Viljoen, 1999). The use of mass media such as television, radio and newspapers, to increase awareness of FASD in South Africa, is giving greater exposure to this neuro-developmental spectrum disorder (Brits, 2005). Research on alcohol related birth defects made much progress under leadership of Prof Viljoen at the Division of Human Genetics at the University of the Witwatersrand (www.wits.ac.za). The research served to increase awareness among medical and allied health professionals, as well as the public in South Africa (Adnams et al., 2001; Viljoen & Krause, 2001; Viljoen et al., 2001b; Viljoen, 1999). South African research has covered a wide range of topics relating to FASD: Statistics relating to FASD in the different provinces (Viljoen et al., 2001a), identification of at-risk communities (Viljoen et al., 2001a), community-based programmes geared towards combating FASD (Viljoen et al., 2001a), FAS endemic community studies (Viljoen, 1999), epidemiology studies of FASD in the Western Cape (Adnams et al., 2001), identification of genetic factors contributing to FASD in South Africa (Viljoen &

Krause, 2001), patterns of cognitive-motor development of school age children with FASD (Adnams et al., 2001), characteristics of mothers of children with FASD in the Western Cape province (Viljoen et al., 2001b), and the main diagnostic features of FASD (Viljoen, 1999). A limited number of FASD related undergraduate research studies in the field of Communication Pathology could be found to date (Chetty, 2007; Clarke, 2004) in the literature. The current study should be seen as an attempt to contribute to the Early Communication Intervention knowledge pool of FASD in South Africa.

FASD is considered as one of the foremost spectrum disorders that are currently affecting children in South Africa and worldwide (Viljoen et al., 2001a). The results of the current study also attempted to highlight the importance of comprehensive ECI services provided by knowledgeable speech-language therapists within an interdisciplinary team.

Due to the risk for communication delay from as young as four months of age in the first participant, and the presence of severe communication disorders in the other four participants, the importance of ECI is emphasized. The description of five individual communication profiles of infants and young children with FAS and their care-giving environments revealed a rich knowledge base. The knowledge may be used by speech-language therapists to aid them in providing more effective ECI services to young children with FASD and their families.

The speech-language therapist working in the field of EI in South Africa should therefore have the necessary skills and knowledge to work with young children with FASD and their families. The complexity of the required knowledge and skills is portrayed within a systemic perspective (Garbarino & Ganzel, 2000) in Figure 5.1.

Figure 5.1 highlights the fact that the speech-language therapist working with infants and young children with FASD and their families should have a comprehensive integrated knowledge base regarding the systems theory and how it can be applied to FASD (Garbarino & Ganzel, 2000). The South African context as macrosystem and the family context as microsystem play an important role in aiding the speech-language therapist's understanding of FASD in South Africa. This may assist the speech-language therapist to provide contextually relevant ECI services to this unique clinical population in South Africa.

A knowledgeable speech-language therapist in South Africa also has a diverse role to fulfill within the interdisciplinary team when working with these young children with FASD and their families. In Figure 5.2 the diverse roles of the speech-language therapist is illustrated.

5.2. CONCLUSION OF RESULTS

Issues of importance emerged from the results and will be discussed in terms of their theoretical and clinical implications.

5.2.1. Conclusion to sub-aim 1: Developmental histories of the participants

The developmental histories of infants and young children with FASD were described from the perspective of the Four-level Early Communication Assessment Framework (Kritzinger & Steenkamp, 2006). The implementation of this assessment framework assisted the researcher to obtain a comprehensive and in-depth view of the participants' developmental histories. The results of the study highlight the issue of lost histories of infants and young children with FASD before their placement in foster care. In this study fragmented information was obtained for Participants 1 – 4. In the case of Participant 5, the adoptive parents had adequate information because he was placed in their care directly after birth where after he was adopted. It can thus be concluded that speech-language therapists may work with clinical cases with incomplete case histories. The implications for the assessment process are thus that associated risk factors such as low birth weight, prematurity and a deprived early environment may not be known. This implies that the full impact of the transactional nature of all factors influencing the infant or young child with FASD's development may be unknown.

The incomplete histories can be ascribed to either misplaced information or truly lost histories. Further research regarding why foster parents are not comprehensively informed about the early histories of infants or young children with FASD is required. Effective teamwork should enable social workers and speech-language therapists to communicate more effectively within the team. However, based on the available information obtained from the foster/adoptive parents of the five participants in this study the following conclusions can be drawn:

- *Prenatal and birth history*: Participant 1 presented with low birth weight (2,4 kg). In the literature low birth weight is commonly found among infants with FASD due to the mother's poor nutritional status and the child's intrauterine growth retardation (Hall, 2001). Research on nutrition in rats suggests that prenatal alcohol exposure may affect the functioning of some internal organs such as the intestines, which may affect absorption of the nutritional value contained in some foods (Murillo-Fuentes, Murillo & Carreras, 2003). The speech-language therapist can therefore expect that the infant with FASD may present with low birth weight, a known risk to affect communication development (Rossetti, 2001).

- *Early behavioural characteristics:* Characteristics such as increased activity, irritability and inconsolability were reported in some of the participants. Irritability and inconsolability co-occurred in two of the participants. These symptoms can be linked to a specific FASD phenotype widely described in the literature (Atchison, 2007; Carmichael Olson et al., 2007; Coggins et al., 2007; Henry et al., 2007). Alcohol withdrawal symptoms may have resulted in difficulties with self-regulation that persisted in some of the participants. These difficulties manifested in one participant and resulted in a diagnosis of ADHD.

  These early behavioural characteristics can serve as possible early indicators of the presence of FASD for professionals working with

neonates and infants suspected of FASD. Timely referral to enhance early diagnosis of FASD can thus be increased. Earlier diagnosis could then contribute to timely referral to appropriate early intervention services.

It can thus be concluded that the description of early child behavioural characteristics in the interview with caregivers/parents is important to assist professionals with early referral to a paediatric neurologist. Early referrals can aid earlier diagnosis of FASD and associated conditions.

It can also be concluded that these early behavioural difficulties in young children can assist the therapist in planning appropriate intervention to train parents to manage the symptoms effectively.

- *Medical history:* It is possible that all five participants presented with compromised immune systems in early childhood. Their medical histories and illnesses include tonsillitis, chronic otitis media, regular colds and episodes of influenza. Research by Giberson and Weinberg (1992), Johnson et al. (1981) as well as Zhang et al. (2005), indicate a clear link between immune system abnormalities and prenatal exposure to alcohol. The participants in the multiple case study presented with possible increased susceptibility for infection. Therefore the appropriate management of the health problems of young children with FASD requires consistent medical care. The early effective management of otitis media can possibly contribute to decrease developmental speech and language delays (Olswang et al., 1998).

- *Early feeding behaviour:* Feeding difficulties are a symptom of most developmental disabilities and a risk factor for the development of communication delay (Rossetti, 2001). Two participants displayed early feeding difficulties, with one of them presenting with complex difficulties. The complex early feeding difficulties were associated

with inadequate oral-motor skills required for bottle-feeding, cleft palate, in-coordination of the suck-swallow-breathe synchrony, endurance deficits and possible food intolerances or allergies. Arvedson and Brodsky (2002) also reported that significant feeding problems are common in some young children with FASD. Additional factors associated with problematic bottle-feeding in infants with FASD can include limited sucking patterns, easy fatigue, irritability and distractibility (Arvedson & Brodsky, 2002).

Carmichael Olson et al. (2007) reported that infants with FASD present with feeding difficulties during the early developmental stages that tend to decrease with age. The same was found in the current study. The participants' feeding difficulties appeared to resolve with age.

Due to the fact that early feeding difficulties is a common occurrence among children with FASD (Arvedson & Brodsky, 2002) appropriate assessment and management is essential. The specific assessment of feeding difficulties in children with FASD, as well as the appropriate intervention and management options require further research.

The speech-language therapist should play an instrumental role in addressing feeding problems in infants with FASD as feeding intervention comprise an essential component of ECI (ASHA, 2008). This implies that the speech-language therapist should be a team member from very early on in the life of the infant with FASD and the family.

- *General development*: A need for improved dissemination of information between care centres, social workers and foster parents is indicated in the results. Delays regarding communication skills, self-help skills and motor skills were present in most of the participants. Infants and young children with FASD present with developmental

delays in multiple domains (Henry et al., 2007), which requires effective inter-disciplinary management.

- *Parental concerns and needs:* The foster parents in the study had insufficient knowledge regarding the sequelae of FASD. None of the foster parents were aware that children with FASD would present with special developmental needs requiring EI. The foster parents did not view speech-language therapy as necessary, as could be seen in the poor compliance with services offered as part of the research, i.e. hearing assessment and ECI. Inadequate parental concern about communication development could be present, due to a lack of information on FASD.

  The responsibility of providing adequate information regarding the diagnosis of FASD and the sequelae thereof to foster parents is the responsibility of the interdisciplinary team (Guralnick, 2000). Each team member is responsible for providing the necessary information regarding FASD in different developmental domains. The speech-language therapist should provide information regarding the feeding, oral-motor skills, communication development and hearing impairment associated with FASD.

5.2.2. Conclusion to sub-aim 2: Description of child participants' family/care-giving contexts

The results corresponded with other studies (Thorne et al., 2007; Vig et al., 2005), indicating that none of the participants were residing with their biological families anymore. Only one of the participants was fully adopted at the time of the study. The other four participants are still exposed to possible unstable environments in foster placement (Vig et al., 2005) Where prenatal alcohol exposure was present in biological care-giving systems, these systems were not optimal for positive child rearing (Carmichael Olson et al., 2007). Carmichael Olson et al. (2007) further suggested that most young children with FASD placed in foster care have experienced some degree of cumulative environmental risk earlier in their lives prior to foster placement. Recent

statistics in the USA indicate that 70 % of children with FASD are in foster/adoptive homes (Carmichael Olson et al., 2007).

The care-giving environment within the foster and adoptive families of all the participants were characterized by smaller family units, higher educated parents, higher income per family and more emotional stability than with the biological families. These care-giving characteristics promote a positive environment for interaction where attachment can be fostered. These positive care-giving contexts may ameliorate the impact and sequelae of FASD and other risk factors in the lives of the participants (Osofsky & Thompson, 2000; Thorne et al., 2007).

Although the family/care-giving contexts of only five participants were described, they represented a wide variety of early histories and contexts. The participants in this study did not originate from homogenous care-giving contexts. A detailed description of the care-giving context of the infant or young child with FASD is therefore essential to understand the diverse nature of child rearing contexts and the role and impact thereof on the lives of infants and young children with FASD (Carmichael Olson et al., 2007).

In conclusion the speech-language therapist should have knowledge regarding the foster care system, procedures and the effect of foster care placement and child-rearing practices in respect of FASD in order to provide effective ECI services.

5.2.3. Conclusion to sub-aim 3: Communication profiles of the child participants

Although an area of intense research interest (Carmichael Olson et al., 2007; Church et al., 1997; Thorne et al., 2007) there are limited clinical or longitudinal studies of the language and communication development in infants and young children with prenatal alcohol exposure. The current study attempted to contribute to the knowledge base of the communication features of children with FASD by describing a collective case study of five young children within their foster care families.

An in-depth description of each participant's communication functioning was obtained through application of the assessment protocol in an individualized approach. It appeared that the area of greatest delay in each participant was the area of communication and related skills. This finding is important as impairment in communication and related skills can be viewed as a common thread linking the infants and young children with FASD (Carmichael Olson et al., 2007; Coggins et al., 2007).

The results indicated that the following communication impairments were present: Oral-motor impairments contributing to early feeding difficulties as well as poor speech intelligibility, developmental phonological impairment, receptive-expressive language disorder, an increase in communication delay with increased chronological age, increased talkativeness/verbosity, poor personal-social interaction skills, inappropriate use of language, poor listening skills contributing to inattentiveness, inadequate emergent literacy skills due to lack of environmental exposure, and simple discourse structure. Thus the participants presented with a multiple, complex and unique set of impairments.

Recent research suggests that young children with FASD can often acquire basic linguistic skills in a typical manner, but then proceed to experience difficulty to be socially competent communicators as they grow older (Coggins et al., 2007). However, the results of the current study indicated that communication and linguistic deficits were present in each of the five children i.e., at 4m, 18m, 35m, 51m and 58 m. The youngest participant presented with the slightest delay, whereas the oldest participant presented with severe delay and impairment in all areas of communication and related skills. It can thus be concluded that the participants required ECI from infancy.

According to Carmichael Olson et al. (2007) different views regarding the developmental disorders and impairments associated with FASD are present. One such a view is that a young child prenatally exposed to alcohol will outgrow mild early developmental delay, and therefore developmental monitoring and ECI services should not be provided. The results of the collective case study indicated that the participants did not outgrow their early

developmental delays. The degree of impairment appeared to increase in the older participants. The communication characteristics in school-aged children with FASD are described in a substantial body of research as a discrepancy between verbal abilities (vocabulary and syntax) and a diminished capacity to use these skills effectively in communication (Sparks, 2000; Thorne et al., 2007). School-aged children with FASD are therefore learners with special needs, and can present with associated conditions such as ADHD.

Based on the results of the study the early identification and assessment of infants suspected of being prenatally exposed to alcohol, is of utmost importance to result in a diagnosis. It appeared that early placement in foster care facilitated the diagnosis of FASD in the participants (see Table 3.2). Precursors to communication impairment, such as feeding difficulties were identified in an attempt to improve the infant or young child with FASD's developmental outcome. Guralnick's (2001) useful developmental systems model for early intervention with children who have special needs - as depicted in Figure 1.1 (Chapter 1) - could be implemented in ECI services to infants and young children with FASD and their families. The aim is to reduce the impact of disabling child characteristics and cumulative environmental risk, while at the same time enhancing protective factors found in the child and the family. The developmental systems model can aid the speech-language therapist to compile a comprehensive intervention programme to provide resource, social and information supports to the family. Direct intervention to the infant or young child with FASD can be provided to enhance their communication functioning. A further aim of ECI is to enhance family interaction adapted to the family's unique needs related to FASD (Carmichael Olson et al., 2007; Guralnick, 2000).

Inter-disciplinary assessment and treatment is required for infants and young children with FASD and their families (Guralnick, 2000). Due to the complex needs of the population with FASD, the family requires interdisciplinary support by team members such as the social worker, educational psychologist, speech-language therapist, occupational therapist, audiologist, dietician, nurses and different medical specialists.

The communication profiles obtained of the five participants in this study contributed to identify specific developmental characteristics of infants and young children with FASD. The information gained by a detailed communication profile can then be used to identify areas of strength, deficit and needs of the particular infant or young child with FASD and the family. Research on the effectiveness of specific ECI programmes is necessary (Carmichael Olson et al., 2007; Thorne et al., 2007) to lead to more positive outcomes for the infant and young child with FASD and their families.

Due to the permanent nature of FASD continued services will be required after the ECI period through pre-school, primary school, adolescence and adulthood (Streissguth et al., 1997). Research about the school-aged population of children with FASD is more widely published (Church et al., 1997; Sparks, 2000; Thorne et al., 2007), than research regarding the early years of infancy and toddlerhood. Further ECI research is thus necessary to enhance appropriate ECI service delivery and to contribute to the description of the complex communication profile of infants and young children with FASD.

The results furthermore indicated, that for the speech-language therapist to provide effective ECI services to this unique population of young children, a systemic perspective is required (Garbarino & Ganzel, 2000). The broad South African context forms the exosystem and the family context forms the microsystem – see Figure 5.1. The latter system consists of families and mothers with alcohol abuse problems and has been associated with maltreatment, traumatic stress and prenatal alcohol exposure (Henry et al., 2007; Hyter, 2007). The broad South African exosystem is currently characterized by poverty, a decrease in skilled workers, the HIV and AIDS pandemic, violence, crime, xenophobia, a lack of service provision and at times a lack of access to services, as well as a decrease in functional resource availability such as electricity (Swanepoel, 2004).

The speech-language therapist working with infants and young children with FASD should therefore have the necessary knowledge and a comprehensive perspective regarding their diverse role within the interdisciplinary team (see

Figure 5.2), the impact of prenatal alcohol exposure, maltreatment and postnatal trauma on the infant or young child with FASD's development.

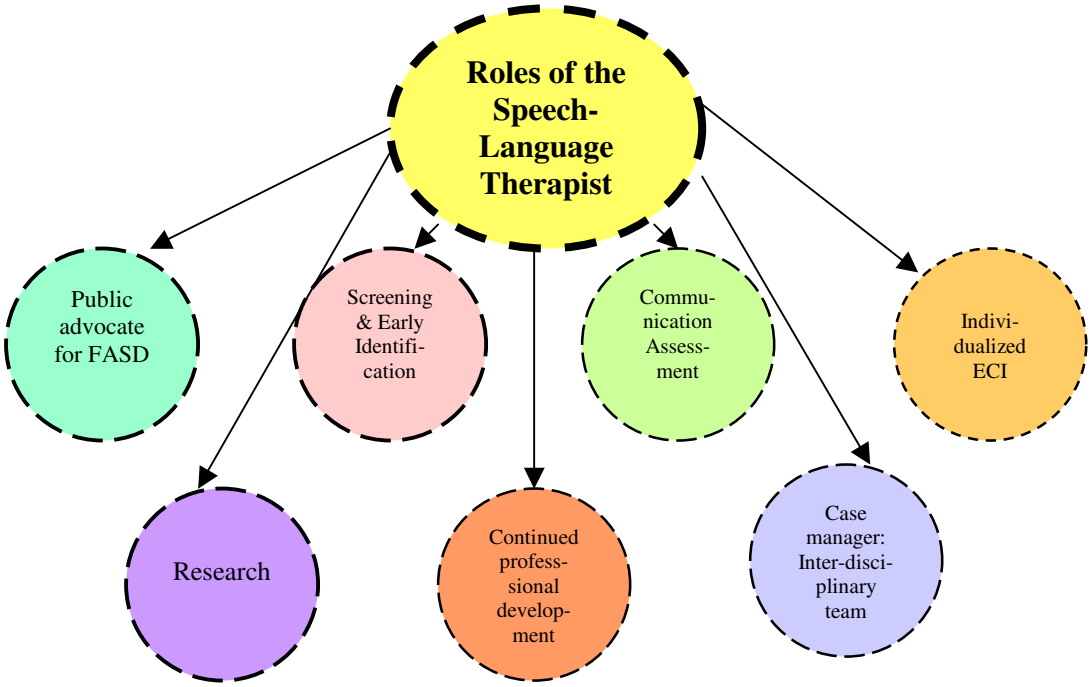


Figure 5.2 Roles of the Speech-language therapist working with children with FASD and their families

The diverse roles of the speech-language therapist emphasize the multi-dimensional problem of FASD within the systems perspective and highlights the need for their presence in an interdisciplinary team in managing this challenging clinical population.

Thus, due to the challenging nature of providing ECI to this population, services should be provided in an integrated interdisciplinary team. Services should be able to address all the participants and their foster parents' and/or biological parents' current needs.

5.3. CRITICAL EVALUATION OF THE STUDY

A critical evaluation of the study was conducted in order to reflect on the value and limitations of the results and to guide the planning and execution of further research.

A collective case study design following a qualitative approach was chosen since only a small group of infants and young children with FASD could be located to participate in the study. The limited sample implies that the results cannot be generalized (Leedy & Ormrod, 2005). Possible bias, due to the limited sample size and the descriptive approach of the study, was controlled in part by conducting a pilot study (Leedy & Ormrod, 2005). The carefully selected interview questions and items in the Communication Assessment Protocol, based on an in-depth literature study ensured the consistent application of the interview schedule and protocol across all participants. A second rater for the assessment of the mother-child communication interaction was utilized to enhance the reliability of the results (Thorne et al., 2007). Triangulation (De Vos, 2002a) of multiple sources of data, i.e. the interview schedule and the assessment protocol that included informal and formal assessment instruments, was utilized to enhance the reliability of the results.

The researcher expected to find more participants for the study due to high prevalence of FASD in South Africa (Pienaar 2003; Viljoen et al., 2001). The incidence of FASD in Gauteng in four identified at-risk communities ranges from 1.2 % - 3.7 % (www.doh.gove.za, 2004-12-04). These incidence figures are fourfold higher than most at-risk communities in developed countries. There appears to be a discrepancy between availability of young research participants and incidence rates of FASD. Possible reasons could be that the diagnosis of FASD among the pre-school population is low. Children with FASD are often not diagnosed early in infancy in South Africa and therefore the diagnosis is more likely to be made at a school-age level in South Africa (Viljoen et al., 2001a). Other possible reasons for a lack of research participants could be a lack of comprehensive interdisciplinary services, inadequately developed ECI services in some communities in South Africa, biological parents/foster parents that are not health-seeking resulting in children being identified by social workers in communities rather than in the health system, lack of knowledge regarding FASD among medical and allied health professionals, unwillingness to diagnose children with such a stigmatised disorder and the multiple placement of children with FASD in the foster care system.

Despite limited participants the study was successful in fulfilling its aims by presenting a description of the developmental histories, family/care-giving contexts and detailed communication profiles of the participants.

This study may be one of the first exploratory studies to describe the developmental history, family/care-giving context and the communication functioning of young children with FASD in South Africa. The structured interview schedule and Communication Assessment Protocol proved to be sensitive and useful tools, but must be tested on a larger sample of infants and young children with FASD in South Africa. A well-designed validation study is recommended to confirm the results and utility (Thorne et al., 2007) of the suggested assessment protocol used in this study.

The instruments used in the study, within the Four-level Early Communication Assessment Framework (Krizinger & Steenkamp, 2006), were useful in rendering multiple sources of data regarding the infant or young child with FASD's early communication and related skills.

However, one serious limitation of the study was that the hearing assessments of all the participants in the study could not be completed, due to poor parent compliance to attend the scheduled hearing assessments. Valuable information regarding their basic hearing status could thus not be collected. Further testing for central auditory processing disorders (CAPD) may also be required.

5.4. RECOMMENDATIONS

It is concluded that the design of the structured interview schedule and the adaptation of the communication assessment protocol (Kritzinger & Steenkamp, 2006) led to useful instruments for obtaining information regarding the infant or young child with FASD's development and family/care-giving context. These instruments were also useful to describe the communication functioning of the participants within a four-level early communication assessment framework that includes the child's physical characteristics and sensory integrity, communication and related skills, general development and risk/resilient factors. However, further research is needed to address the limitations of the study. Based on the results recommendations for clinical practice and further research are now presented.

5.4.1. Recommendations for clinical practice

The speech-language therapist's role within an EI team for infants and young children with FASD is multi-dimensional. The team should start with creating awareness of FASD and the maternal risk factors associated with this condition on a level of primary prevention. The team should act as an advocate, with a responsibility towards communities (McConkey, 1995; Rossetti, 2001). Part of advocacy will include social development, education of at-risk communities as well as screening programmes. The speech-language therapist has a further role on the team, i.e. to conduct EC assessment, provide information regarding the impact of FASD on oral-motor, hearing and communication abilities and render family-centred intervention services.

Governmental institutions and NGO's involved in the adoption of infants suspected of FASD should involve interdisciplinary team members where information about the child is supplied to the foster parent candidates.

A further role of the speech-language therapist is to plan discharge (ASHA, 2008). Appropriate bridging between ECI and pre-school services should be optimally facilitated. Considering the multi-dimensional role of the speech-language therapist on the FASD team, a flow diagram for the early assessment and management of infants and young children with FASD and their families in the South African context, is presented in Figure 5.3.

According to Figure 5.3, appropriate and adequate service delivery begins at community level by creating awareness of FASD through community campaigns targeting at-risk communities in all the provinces of South Africa, at health forums, media discussions, day-care and nursery school facilities, primary health care clinics, well-baby clinics and care centres. Increased awareness can create parent/caregiver/health professional concern resulting in earlier identification of infants and young children with possible FASD. The parent/caregiver will then visit a general medical practitioner or a health clinic in the community where screening can be implemented.

Referral to a medical specialist such as a paediatric neurologist or geneticist will then be the next step to formally diagnose the infant or young child with FASD. Upon diagnosis it is the responsibility of the specialist to provide information to the parent/caregiver regarding the general sequelae of FASD and to refer to a specialized interdisciplinary health team for comprehensive assessment. According to Guralnick (2000; 2001) an interdisciplinary team approach facilitates family-centred, integrated services that can be based within a developmental framework and attempts to achieve inclusion. The speech-language therapist forms part of this team. After the completion of all assessments an interdisciplinary team meeting, where the social worker can serve as case manager, will be held. During the team meeting an in-depth discussion of all assessment results will be carried out. A family meeting is scheduled by the team manager and includes all the relevant parties. At the initial family meeting detailed feedback regarding the assessment results are provided to the parent/caregiver and different team members, parental/caregiver needs are addressed, intervention services are prioritised and goals for the individualized EI plan is determined. Depending on the needs of the family, training and support are provided throughout the EI period (Rossetti, 2001). If the biological family is present in the EI process then the alcohol abuse problem within the family context will also need to be addressed by the appropriate team members (Sparks, 2000). The speech-language therapist and other team members will provide EI services focussing on family involvement and education, cost effectiveness and a comprehensive home programme. Serial assessment is done on a continual basis as needed by

each team member (Rossetti, 2001). The speech-language therapist will thus adjust ECI goals as the infant or young child attain goals and add new developmentally appropriate goals to the ECI plan. When the young child with FASD reaches the age to be discharged from ECI, all team members together with the family contribute to discharge planning to provide bridging from EI service providers to inclusive/special needs services in the pre-school or nursery school context (Briggs, 1997; Carmichael Olson et al., 2007; Sparks, 1993).

Appropriate EI service delivery will form the foundation to facilitate optimal long-term developmental outcomes for the young child with FASD. The flow diagram of service provision within an interdisciplinary team context should assist the speech-language therapist to participate in appropriate service delivery for this population.

5.4.2. Recommendations for future research

- To test the Four-level Early Communication Assessment Protocol (Kritzinger & Steenkamp, 2006) on a larger sample of subjects from different geographical areas across South Africa within different age groups within 0 – 5 years. The results of such a study may provide clinicians with guidelines regarding more appropriate ECI service delivery.
- Research to provide information to speech-language therapists to develop more appropriate individualized ECI programmes for this unique clinical population.
- Research to adapt the Communication Assessment Protocol to each age level within the ECI population, i.e. with more focus on feeding and regulatory behaviours in infancy and the focus shifting to more specific assessment regarding social-communication interaction and language as the child grows older.
- Follow-up studies to investigate the effectiveness of ECI programmes for this specific population.

- A long-term study to investigate the effectiveness of interdisciplinary EI service delivery to infants and young children with FASD and their families.
- Research to develop a culturally, linguistically appropriate information booklet that can be distributed to parents and foster parents after diagnosis to empower them with knowledge regarding FASD and the developmental sequelae, within the South African context.

A wide scope for research studies in the field of ECI is thus still required regarding FASD in South Africa. Viljoen and colleagues (Adnams et al., 2001; Viljoen, 1999; Viljoen et al., 2001a, 2001b) recommended a broader scope of research in other fields relating to FASD to further enhance the knowledge and skills of medical and allied health professionals working with young children with FASD and their families.

5.5. FINAL CONCLUSION

The Department of Health (Ntsabula, 2001) identified FASD as a priority condition to receive services, but limited public and professional awareness of the condition hampers the provision of appropriate EI services and contributes to the lack of EI services dedicated to this population. Services are required to educate prospective parents regarding the use of alcohol during pregnancy, to inform parents and foster parents regarding expected communication development outcomes of children with FASD, to provide early diagnosis and appropriate ECI.

According to Kathard, Naude, Pillay and Ross (2007:7) speech-language therapists working in the context of South Africa today should *"develop ways of guiding relevant research for relevant practice"*. The researcher trusts that this study is relevant for the South African society of today. However, it is not only relevant for speech-language therapists, because FASD implies that there are other social, cultural and moral problems at work in different communities in our country that needs to be taken into consideration when implementing the relevant research results. The research results should contribute towards best practice in ECI services that will be provided to young children with FASD and their families in South Africa. The high incidence of FASD in South Africa may appear insurmountable, but therapists have the responsibility to be clinicians and researchers, because this inextricably mutual

relationship should continue to stimulate the growth and development of ECI services to infants and young children and their families affected by FASD (Walley, Khan, Shah, Witter & We, 2007).

5.6. SUMMARY

This final chapter provided the conclusions deducted from the results on the communication abilities of five young children with FASD. Important theoretical and clinical implications with regard to service delivery to this population are discussed. A critical evaluation of the study was conducted to identify the contributions and limitations. Finally, recommendations for further research and clinical practice were made.

This study concludes by emphasizing the importance of professional knowledge of the specific characteristics of infants and young children with FASD in South Africa. As a result of the high prevalence of FASD in South Africa, speech-language therapists should encounter infants and young children with FASD in their caseloads. An interview schedule and early communication assessment protocol is now available to assist speech-language therapists in this endeavour. Speech-language therapists are urged to provide optimal services to the special population of infants and young children with FASD and their families in South Africa.

References:

Abate, P., Varlinskaya, E.I., Cheslock, S.J., Spear, N.P. & Molina, J.C. 2002. Neonatal Activation of Alcohol-related Prenatal Memories: Impact on the First Suckling Response. *Alcoholism: Clinical and Experimental Research,* Vol. 26, No. 10, p. 1512-1522.

Abkarian, G.G. 1992. Communication Effects of Prenatal Alcohol Exposure. *Journal of Communication Disorders.* Vol. 25, p. 221 – 240.

Adnams, C.M., Kodituwakku, P.W., Hay, A., Molteno, C.D., Viljoen, D. & May, P.A. 2001. Patterns of Cognitive-Motor Development in Children with Fetal Alcohol Syndrome From a Community in South Africa. *Alcoholism: Clinical and Experimental Research,* Vol. 25, p. 557 – 562.

Ahola, D. & Kovacik, A.2007. *Observing and Understanding Child Development: A Child Study Manual.* United States: Thomson Delmar Learning.

American Speech-Language-Hearing Association. 1989. *Communication-Based Services for Infants, Toddlers and their Families.* ASHA, p. 32-34, 94.

American Speech-Language-Hearing Association. 2008. *Roles and Responsibilities of Speech-Language Pathologists in Early Intervention: Technical Report.* [Technical Report] www.asha.org/policy, accessed on 2008-09-20.

Ammerman, A. & Parks, C. 1998. Preparing Students for More Effective Community Interventions: Assets Assessment. *Family and Community Health,* Vol. 21, No 1, p. 32 – 45.

Anderson, D., Nelson, J. & Fowler, S. 1978. In Northcott, W.H. (ed.) Developmental Assessment Schema. *Curriculum Guide: Hearing Impaired Children (0 – 3 years) and their Parents.* Washington D.C.: The Alexander Bell Association for the Deaf, Inc.

Anderson-Yockel, J & Haynes, W.O. 1994. Joint Book-Reading Strategies in Working-Class African American and White Mother-Toddler Dyads. *Journal of Speech and Hearing Research,* Vol. 37, p. 583 – 593.

Andersson, L.L. 2004. Appropriate and Inappropriate Interpretation and Use of Test Scores in Early Intervention. *Journal of Early Intervention,* Vol. 27, No. 1, p. 55 – 68.

Antoniadis, A. & Daulton, D. 1992. Meeting the Needs of Children in Pennsylvania Who are Exposed to Alcohol and Other Drugs. *Infant-Toddler Intervention. The Transdisciplinary Journal,* Vol. 2, No. 1, p. 53 – 62.

Aram, D., Most, T. & Mayafit, H. 2006. Contributions of Mother-Child Storybook Telling and Joint Writing to Literacy Development in Kindergartners with Hearing Loss. *Language, Speech and Hearing Services in Schools,* Vol 37, p. 209-223.

Arizona Revised Statutes (ARS) 15 – 761. p. 1 – 38.

Armstrong, M.B. 1998. Storybooks to Literacy: A Collaborative Shared Reading Project. *Infant-Toddler Intervention: The Transdisciplinary Journal,* Vol. 8, No. 4, p. 365 – 375.

Aronson, M. 1997. Children of Alcoholic Mothers: Results from Goteborg, Sweden. In A. Streissguth & J. Kanter (eds.), *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities.* Seattle: University of Washington Press.

Arvedson, J.C. & Brodsky, L. 2002. Pediatric Swallowing and Feeding: Assessment and Management. *Early Childhood Intervention Series.* 2nd ed. Unites States: Thomson Delmar Learning.

Atchison, B.J. 2007. Sensory Modulation Disorders Among Children with a History of Trauma: A Frame of Reference for Speech-Language Pathologists. *Language, Speech and Hearing Services in Schools.* Vol. 38, No. 2, p. 109 –116.

Aydlett, L.A. 1993. Assessing Infant Interaction Skills in Interaction-Focused Intervention, *Infants and Young Children,* Vol. 5, No. 4, p. 169 – 177.

Bagnato, S., Neisworth, J. & Munson, S. 1997. *LINKing: Assessment and Early Intervention.* Baltimore: Brooks.

Bailey, K.D. 1994. *Methods of Social Research*. 4th ed. New York: The Free Press.

Bailey, B.D. & Simeonson, R.J. 1988. *Family Assessment in Early Intervention.* Ohio: Merrill Publishing Company.

Bam, I. 2000. *'n Ondersoek na die Vroëe Kommunikasie Ontwikkeling van 6 – 12 Maande Oue Babas met MIV in Sorgsentrums in Gauteng.* Unpublished B.Communication Pathology Dissertation, University of Pretoria.

Batshaw, M.L. & Conlon, C.J. 1997. Substance Abuse: A Preventable Threat to Development. In M.L. Batshaw, *Children with Disabilities*. 4th ed. Baltimore: Paul H. Brookes Publishing Co.

Becker, M., Warr-Leeper, G.A. & Leeper, H.A. 1990. Fetal Alcohol Syndrome: A Description of Oral Motor, Articulatory, Short-Term Memory, Grammatical, and Semantic Abilities, *Journal of Communication Disorders,* Vol. 23, p.97 – 124.

Beirne-Smith, M., Ittenbach, R.F. & Patton, J.R. 2002. *Mental Retardation.* 6th ed. New Jersey: Merril Prentice Hall.

Belcher, H.M.E., Butz, A.M., Wallace, P., Hoon, A.H., Reinhardt, E., Reeves, S.A. & Pulsifer M.B. 2005. Spectrum of Early Intervention Services for Children With Intrauterine Drug Exposure. *Infants and Young Children,* Vol.18, No. 1, p.2-15.

Billeaud, F.P. 2003. *Communication Disorders in Infants and Toddlers: Assessment and Intervention.* (3rd ed.). Missouri: Butterworth Heinemann.

Briggs, M.H. 1997. *Building Early Intervention Teams: Working Together for Children and Families.* Gaithersburg, Maryland: Aspen Publishers, Inc.

Brits, E. 2005. Nuwe navorsing oor alcohol laat rooi ligte flikker: Selfs min dop kan baba knou, *Beeld,* p. 15. Woensdag 23 Februarie 2005

Buitendag, M. 1994. *Afrikaanse Reseptiewe Woordeskat Toets.* Pretoria: Raad vir Geesteswetenskaplike Navorsing.

Butterfield, J. (ed) 2002. *Collins Paperback Dictionary and Thesaurus*. Glasgow: HarperCollins Publishers.

Carmichael Olson, H. 1995. The Effects of Prenatal Alcohol Exposure on Child Development. In J.A. Blackman (ed.), *Medical Aspects of Early Intervention. Infants and Young Children Series.* Maryland: Aspen Publishers, Inc.

Carmichael Olson, H. & Burgess, D.M. 1997. Early Intervention for Children Prenatally Exposed to Alcohol and Other Drugs. In M.J. Guralnick (ed.), *The Effectiveness of Early Intervention.* Baltimore: Paul H. Brookes Publishing Co.

Carmichael Olson, H., Jirikowic, T., Katin, D., & Astley, S. 2007. Responding to the Challenge of Early Intervention for Fetal Alcohol Spectrum Disorders. *Infants & Young Children,* Vol. 20, No. 2, p. 172-189.

Chapman, J.K. 2000. Developmental Outcomes in Two Groups of Infants and Toddlers: Prenatally Cocaine Exposed and Non-Cocaine Exposed. Part 1. *Infant-Toddler Intervention. The Transdisciplinary Journal,* Vol. 10, No. 1, p. 19 – 36.

Chapman Bahr, D. 2001. *Oral Motor Assessment and Treatment: Ages and Stages.* Boston: Allyn & Bacon.

Chetty, L. 2007. *The Nature of Early Intervention services for infants (0-2 years) suspected of Fetal Alcohol Spectrum Disorder at Public Hospitals in Gauteng,* Unpublished B. Communication Pathology Dissertation, University of Pretoria.

Church, M.W. Eidis, F., Blakley, B.W. & Bawie, E.V. 1997. Hearing, Language, Speech, Vestibular and Dentofacial Disorders in Fetal Alcohol Syndrome. *Alcoholism: Clinical and Experimental Research.* Vol. 21, No. 2, p. 227-237.

Clarren, S. & Astley, S. 1997. Development of the FAS Diagnostic and Prevention Network in Washington State. In A. Streissguth & J. Kanter (eds.), *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities.* Seattle: University of Washington Press.

Clark, J.F. 2004. *An Investigation into the Nature and Frequency of Language Play in Children with Fetal Alcohol Syndrome.* Unpublished B.A. Speech and Hearing Therapy Thesis. University of Witwatersrand.

Clarren, S.K., Carmichael Olson, H., Clarren, S.G.B. & Astley, S.J. 2000. A Child with Fetal Alcohol Syndrome. In M.J. Guralnick (ed.), *Interdisciplinary Clinical Assessment of Young Children with Developmental Disabilities*. Baltimore: Paul H. Brookes Publishing Co.

Coggins, T.E., Olswang, L.B., Carmichael Olson, H. & Timler, G.R. 2003. On Becoming Socially Competent Communicators: The Challenge for Children with Fetal Alcohol Exposure. *International Review of Research in Mental Retardation,* Vol. 27, p. 121 – 150.

Coggins, T.E. & Timler, G. 2000. Assessing Language and Communicative Development: The Role of the Speech-Language Pathologist. In M.J. Guralnick (ed.), *Interdisciplinary Clinical Assessment of Young Children with Developmental Disabilities.* Baltimore: Paul H. Brookes Publishing Co.

Coggins, T.E., Timler, G.R. & Olswang, L.B. 2007. A State of Double Jeopardy: Impact of Prenatal Alcohol Exposure and Adverse Environments on the Social Communicative Abilities of School-Age Children with Fetal Alcohol Spectrum Disorder. *Language, Speech and Hearing Services in Schools.* Vol. 38, No. 2, p. 117 – 127.

Colangelo, W. & Jones, D.G. 1982. The Fetal Alcohol Syndrome: A Review and Assessment of the Syndrome and its Neurological Sequelae. *Progress in Neurobiology,* Vol. 19, p. 271 – 314.

Cole, E.B. & St. Claire-Stokes, J. 1984. Caregiver-Child Interactive Behaviours: A Videotape Analysis Procedure. *Volta Review,* Vol. May 1984, p. 200 – 213.

Coles, C.D., Platzman, K.A., Raskind-Hood, C.L., Brown, R.T., Falek A. & Smith, I.E. 1997. A Comparison of Children Affected by Prenatal Alcohol Exposure and Attention Deficit, Hyperactivity Disorder. *Alcoholism: Clinical and Experimental Research,* Vol. 21, No. 1.

Cone-Wesson, B. 2005. Prenatal Alcohol and Cocaine Exposure: Influences on Cognition, Speech, Language and Hearing. *Journal of Communication Disorders,* Vol 38, p. 279 – 302.

Crites, L.S., Fischer, K.L., McNeish-Stengel, M. & Siegel, C.J. 1992. Working with Families of Drug-Exposed Children: Three Model Programs. *Infant-Toddler Intervention. The Transdisciplinary Journal,* Vol. 2, No. 1, p. 13 – 23.

Department of Health, 2001. *Fetal Alcohol Syndrome Among World's Highest in SA, First International Conference in the Developing World on Birth Defects and Disabilities.* Sandton, Johannesburg, South Africa. http://www.doh.gov.za/docs/pr/2001/pr0906c.html., accessed on 2004-12-04.

De Vaus, D.A. 2001. *Research Design in Social Research*. London: SAGE Publications Ltd.

De Vos, A.S. 2002a. Qualitative data analysis and interpretation. In A.S. de Vos (ed.), *Research at Grass Roots: For the Social Sciences and Human Service Professions.* 2nd ed. Pretoria: Van Schaik Publishers.

De Vos, A.S. 2002b. Combined Quantitative and Qualitative Approach. In A.S. de Vos (ed.), *Research at Grass Roots: For the Social Sciences and Human Service Professions.* 2nd ed. Pretoria: Van Schaik Publishers.

Dittmer, C.D. & Lentz, S. 2004. *Fetal Alcohol Syndrome.* http://www.emedicine.com/PED/topic767.html, accessed on 2005-01-28.

Doehring, D.G. 2002. *Research Strategies in Human Communication Disorders.* (3rd ed). Texas: Pro-ed.

Dollaghan, C.A., Campbell, T.F., Paradise, J.L., Feldman, H.M. Janosky, J.E., Pitcairn, D.N. & Kurs-Lasky, M. 1999. Maternal Education and Measures of Early Speech and Language. *Journal of Speech, Language and Hearing Research.* Vol. 42, p. 1432 – 1443.

Evens, F.J. 2002. The Perceptions of Speech-Language Therapists Regarding Nutritional Issues in Early Intervention. Unpublished Masters in Communication Pathology Dissertation, University of Pretoria.

Evens, F.J., Louw, B. & Kritzinger, A. 2004. Theoretical Perspectives on Nutritional Issues in Early Communication Intervention. *Clinica: Applications in Clinical Practice of Communication Pathology,* Monograph 7. University of Pretoria.

Fair, L. & Louw, B. 1999. Early Communication Intervention within a Community-Based Intervention Model in South Africa. *The South African Journal of Communication Disorders,* Vol.46, p. 13 – 23.

Fewell R.R. & Glick, M.P. 1993. Observing Play: An Appropriate Process for Learning and Assessment. *Infants & Young Children,* Vol. 5, No. 4, p. 35 – 43.

Fewell, R.R. & Vadasy, P.F. 1983. *Learning Through Play.* New York: Teaching Resources, Inc.

Fouche, C.B. 2002. Research Strategies. In A.S. de Vos (ed.), *Research at Grass Roots: For the Social Sciences and Human Service Profession.* 2nd ed. Pretoria: Van Schaik Publishers.

Fouche, C.B. & Delport, C.S.L. 2002. The Place of Theory and the Literature Review in the Qualitative Approach to Research. In A.S. de Vos (ed.), *Research at Grass Roots: For the Social Sciences and Human Service Professions.* 2nd ed. Pretoria: Van Schaik Publishers.

Fouche, C.B. & De Vos, A.S. 2002. Quantitative research designs. In A.S. de Vos (ed.), *Research at Grass Roots: For the Social Sciences and Human Service Professions.* 2nd ed. Pretoria: Van Schaik Publishers.

Garbarino, J. & Ganzel, B. 2000. The Human Ecology of Early Risk. In J.P. Shonkoff & S.J. Meisels (eds.) *Handbook of Early Childhood Intervention*. 2nd ed. Cambridge: Cambridge University Press.

Gardner, M. 1990. *Expressive One-Word Picture Test.Revised.* Pro-ed Inc.

Gardner, M. 1985. *Receptive One-Word Picture Test. Revised.* Pro-ed Inc.

Gentry, B., Griffith, L. & Dancer, J. 1998. Prenatal Alcohol Exposure and Communication, Behavior, and Nonverbal Intelligence of three School-Age Children. *Perceptual and Motor Skills,* Vol. 86, p. 1089 – 1090.

Gerber, S. E. 1998. *Etiology and Prevention of Communicative Disorders*. 2nd ed. San Diego: Singular Publishing Group, Inc.

Giberson, P.K. & Weinberg, J. 1992. Fetal Alcohol Syndrome and Functioning of the Immune System. *Alcohol Health & Research World.*

Glasser, J. 2002. Cycle of Shame. *U.S. News and World Report.* http://www.keepmedia.com/jsp/article_detail_print.jsp, accessed on 2004-12-07

Greene, T., Ernhart, C.B., Martier, S., Sokol, R. & Ager, J. 1990. Prenatal Alcohol Exposure and Language Development. *Alcoholism: Clinical and Experimental Research.* Vol. 14, No. 6, p. 937-948.

Guralnick, M.J. 1997. Second-Generation Research in the Field of Early Intervention. In M.J. Guralnick (ed.), *The Effectiveness of Early Intervention*. Baltimore: Paul H. Brookes Publishing Co.

Guralnick, M.J. 2000. Interdisciplinary Team Assessment for Young Children: Purposes and Processes. In M.J. Guralnick (ed.), *Interdisciplinary Clinical Assessment of Young Children with Developmental Disabilities.* Baltimore: Paul H. Brookes Publishing Co.

Guralnick, M.J. 2001. A Developmental Systems Model for Early Intervention. *Infants and Young Children.* Vol. 14, No. 2, p. 1-18.

Hall, K. D. 2001. *Pediatric Dysphagia Resource Guide.* San Diego: Singular Thomson Learning.

Harty, M. 2004. The Association Between Maternal Self-Efficacy and Maternal Perception of Child Language Competence. Unpublished MastersThesis. University of Pretoria.

Henry, J., Sloane, M. & Black-Pond, C. 2007. Neurobiology and Neurodevelopmental Impact of Childhood Traumatic Stress and Prenatal Alcohol Exposure. *Language, Speech and Hearing Services in Schools.* Vol. 38, No. 2, p. 99 – 108.

Höne, U. 1999. *Enkelgevalstudie: 'n Beskrywing van 'n Terapieprogram vir 'n Moeilik Diagnoseerbare Kind in Vroëe Kommunikasie Intervensie.* Unpublished B.Communcation Pathology Dissertation, University of Pretoria.

Hughes, S. 1992. Serving Culturally Diverse Families of Infants and Toddlers with Disabilities. *Infant-Toddler Intervention: The Transdisciplinary Journal,* Vol. 2, No. 3, p. 169-177.

Hugo, R. & Pottas, L. 1997. Paediatric Audiology: Holistic Evaluation of the Baby and Toddler. *Clinica: Applications in Clinical Practice of Communication Pathology.* University of Pretoria.

Hugo, R., Louw, B., Kritzinger, A. & Smit, G.J. 2000. CHRIB Listening Scale. *Infant-Toddler Intervention. The Transdisciplinary Journal,* Vol. 10, No. 1, p. 47 – 53.

Hyter, Y.D. 2007. Prologue: Understanding Children Who Have Been Affected by Maltreatment and Prenatal Alcohol Exposure. *Language, Speech and Hearing Services in Schools,* Vol. 38, No. 2, p. 93 – 98.

Hyter, Y.D. & Way, I. 2007. Epilogue: Understanding Children Who Have Been Affected by Maltreatment and Prenatal Alcohol Exposure: Future Directions. *Language, Speech and Hearing Services in Schools,* Vol. 38, No. 2, p. 157- 159.

Jacobson, S.W., Jacobson, J.L., Sokol, R.J., Martier, S.S. & Ager, J.W. 1993. Prenatal Alcohol Exposure and Infant Information Processing Ability. *Child Development,* Vol. 64, p. 1706 – 1721.

Janzen, L.A., Nanson, J.L. & Block, G.W. 1995. Neuropsychological Evaluation of Preschoolers with Fetal Alcohol Syndrome. *Neurotoxicology and Teratology,* Vol. 17, p. 273 – 279.

Jelm, J.M. 1990. *Oral-Motor/Feeding Rating Scale.*Tucson: Therapy Skill Builders.

Jessop, M.A. 2005. *Clients of the Pretoria Cochlear Implant Programme: Characteristics and Perceived Outcomes of Children and Their Families.* Unpublished Masters Dissertation, University of Pretoria.

Johnson, S., Knight, R, Marmer, D.J. & Steele, R.W. 1981. Immune Deficiency in Fetal Alcohol Syndrome. *Pediatric Research,* Vol. 15, No. 6, p. 908 – 911.

Joint Committee on Infant Hearing, 2000. Position Statement, *Audiology Today,* Special Issue 12, p. 7 – 27.

Kadevarek, J.N. & Sulzby, E. 1998. Parent-Child Joint Bookreading: An Observational Protocol for Young Children. *American Journal of Speech-Language Pathology.,* Vol. 7, No. 1, p. 33 – 47.

Kaemingk, K. & Paquette, A. 1999. Effects of Prenatal Alcohol Exposure on Neuropsychological Functioning. *Developmental Neuropsychology.* Vol. 15, No. 1, p. 111 – 141.

Kalberg, W.O., Provost, B., Tollison, S.J., Tabachnick, B.G., Robinson, L.K., Hoyme, H.E., Trujilo, P.M., Buckley, D., Aragon, A.S. & May, P.A. 2006. Comparison of Motor Delays in Young Children with Fetal Alcohol Syndrome to Those with Prenatal Alcohol Exposure and with No Prenatal Alcohol Exposure. *Alcoholism: Clinical and Experimental Research,* Vol. 30, No. 12, p. 2037 – 2045.

Kathard, H., Naude, E., Pillay, M. & Ross, E. 2007. Improving the relevance of Speech-Language Pathology and Audiology Research and Practice, *The South African Journal of Communication Disorders,* Vol. 54, p. 5 – 7.

Kedesdy, J.H. & Budd, K.S. 1998. *Childhood Feeding Disorders: Biobehavioural Assessment and Intervention.* Baltimore: Paul H. Brookes Publishing Company.

Kim, Y.M., Sugai, G.M. & Kim, G. 1999. Early Intervention Needs of Children at Risk due to Prenatal Drug Exposure: A Survey of Early Childhood Educators. *Journal of Research in Childhood Education,* Vol. 15, No. 2, p. 207 – 215.

Klein, M.D. & Briggs, M.H. 1987. Observation of Communicative Interaction. *Journal of Childhood Communication Disorders,* Vol. 10, No. 2, p. 95 – 106.

Kodituwakku, P., Coriale, G., Fiorentino, D., Aragon, A.S., Kalberg, W.O., Buckley, D., Gossage, J.P., Ceccanti, M. & May, P.A. 2006. Neurobehavioural Characteristics of Children with Fetal Alcohol Spectrum Disorders in Communities from Italy: Preliminary Results. *Alcoholism: Clinical and Experimental Research,* Vol. 30, No. 9, p.1551-1561.

Kritzinger, A. 2005. *Assessment of Parent-Child Communication Interaction.* KMP 482 Study guide, Department of Communication Pathology, University of Pretoria.

Kritzinger, A. & Louw, B. 1997. A Description of Joint Book-Reading Practices of Mothers and Their Young Children, 0 – 2 years. *Clinica: Applications in Clinical Practice of Communication Pathology,* Monograph 2. University of Pretoria.

Kritzinger, A. & Louw, B. 2000. A Comprehensive Assessment Protocol for Infants and Toddlers At Risk for Communication Disorders. Part 1: Case History. *CLINICA: Applications in Clinical Practice of Communication Pathology.* Monograph 5, p. 1 – 18.

Kritzinger, A. & Louw, B. 2002. A Comprehensive Assessment Protocol for Infants and Toddlers at Risk for Communication Disorders, Part II: Assessment Protocol. *CLINICA: Applications in Clinical Practice of Communication Pathology,* Monograph 7, p. 3 – 17.

Kritzinger, A., Louw, B. & Hugo, R. 1996. Early Communication Functioning of Infants with Cleft Lip and Palate. *The South African Journal of Communication Disorders,* Vol. 43, p. 77 – 84.

Kritzinger, A. & Steenkamp, L. 2006. Communication Development of a Young Child with Fetal Retinoid Syndrome: A Seven Year Follow-up Study. *The South African Journal of Communication Disorders,* Vol. 53, p. 39 – 48.

Leedy, P.D. & Ormrod, J.E. 2005. *Practical Research: Planning and Design*. 8th ed. New Jersey: Prentice Hall.

Lesar, S. 1992. Prenatal Cocaine Exposure: The Challenge to Education. *Infant-Toddler Intervention: The Transdisciplinary Journal,* Vol. 2, No. 1, p. 37 – 52.

LoBaido, A.C. 2005. 'Rainbow Family' Cares for AIDS Babies: Christian 'Little Angels' Home Takes in South African Children of All Races. *WorldNetDaily,*Morning Edition. http://www.worldnetdaily.com/news/article.asp?ARTICLE_ID=47479, accessed on 2007-03-13.

London, L., Sanders, D. & Te Water Naude, J. 1998. Farm Workers and the Legacy of the 'DOP'-system. *South African Medical Journal,* Vol. 88, No. 9, p. 1092 – 1095.

Loocke, C., Conry, J., Cook, J.L., Chudley, A.E., & Rosales, T. 2005. Identifying Fetal Alcohol Spectrum Disorder in Primary Care. *Canadian Medical Association Journal,* Vol. 172, p. 628-630.

Louw, B. 1997. *Guidelines for Speech-Language Therapists and Audiologists: Early Communication Intervention.* SASHLA: Ethics and Standards Committee.

Louw, B. & Avenant, C. 2002. Culture as Context for Intervention: Developing a Culturally Congruent Early Intervention Program. *International Pediatrics,* Vol. 17, No. 3, p. 145 – 150.

Louw, B. & Kritzinger, A. 1998. Genetically based communication disorders: Technological advances relevant to the speech-language therapist and audiologist. *CLINICA: Applications in Clinical Practice of Communication Pathology,* Monograph 3. University of Pretoria, p.

Louw, B. & Kritzinger, A. 2002. CHRIB Evaluation Protocol *CLINICA: Applications in Clinical Practice of Communication Pathology*, University of Pretoria.

Louw, D.A., Van Ede, D.M. & Louw A.E. 1999. *Menslike Ontwikkeling*. 3de Uitgawe. Kaapstad: Kagiso Tersier.

Madell, J.R. 1999. *Behavioural Evaluation of Hearing in Infants and Young Children.* New York: Thieme Medical Publishers.

Markel, H. 2005. Parents and Substance Abuse. *Medscape Pediatrics,* Vol. 7, No. 1. http://www.medscape.com/viewarticle/503855_print. 2005-05-12.

Mattson, S.N. & Riley, E.P. 1997. Neurobehavioural and Neuroanatomical Effects of Heavy Prenatal Exposure to Alcohol. In A. Streissguth & J. Kanter (eds.), *The Challenge*

of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. Seattle: University of Washington Press.

May, P.A. Brooke, L., Gossage, P., Croxford, J., Adnams, C., Jones, K.L., Robinson, L. & Viljoen, D. 2000. Epidemiology of Fetal Alcohol Syndrome in a South African Community in the Western Cape Province. *American Journal of Public Health.* Vol. 90, No. 12, p. 1905 – 1912.

McCauley, R.J. 2001. *Assessment of Language Disorders in Children.* New Jersey: Lawrence Erlbaum, Inc. Publishers.

McConkey, R. 1995. Early Intervention in Developing Countries. In P. Zinkin (ed.), *Disabled Children and Developing Countries, Clinics in Developmental Medicine.* London: Cambridge University Press.

McGrath, J.M., Kenner, C. & Amspacher, K.A. 2004. Factors That Can Influence Fetal Development. In C. Kenner and J.M. McGrath (eds.), *Developmental Care of Newborns and Infants: A Guide for Health Professionals*. St. Louis: Mosby.

McLean, M.E., Wolery, M. & Bailey, D.B. 2004. *Assessing Infants and Preschoolers with Special Needs.* Upper Saddle River, New Jersey: Pearson.

Morrison, D. & Villareal, S. 1993. Cognitive performance of Prenatally Drug Exposed Infants. *Infant-Toddler Intervention. The Transdisciplinary Journal,* Vol. 3, No. 3, p. 211 – 220.

Murillo-Fuentes, M.L., Murillo, M.L. & Carreras, O. 2003. Effects of Maternal Ethanol Consumption During Pregnancy or Lactation on Intestinal Absorbtion of Folic Acid in Suckling Rats. *Life Sciences,* Vol. 73, p. 2199 – 2209.

Neuman, W.L. 2000. *Social Research Methods: Qualitative and Quantitative Approaches.* (4th ed.). Boston: Allyn & Bacon.

Ntsabula, A. 2001. *Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders*, *Birth Defects and Disabilities*. Department of Health. Pretoria, South Africa.

O'Connor, M.J., Kogan, N. & Findlay, R. 2002. Prenatal Alcohol Exposure and Attachment Behaviour in Children. *Alcoholism: Clinical and Experimental Research,* Vol. 26, No. 10, p. 1592-1602.

O'Malley, K.D. & Nanson, J. 2002. Clinical Implications of a Link Between Fetal Alcohol Spectrum Disorder and Attention-Deficit Hyperactivity Disorder. *Canadian Journal of Psychiatry,* Vol. 47, No. 4, p. 349 – 354.

O'Leary, C.M. 2004. Fetal Alcohol Syndrome: Diagnosis, Epidemiology and Developmental Outcomes. *Journal of Paediatrics and Child Health,* Vol. 40, p. 1 – 7.

Olswang, L.B., Rodriguez, B. & Timler, G. 1998. Recommending Intervention for Toddlers with Specific Language Learning Difficulties: We May Not Have All the Answers, But We Know A Lot. *American Journal of Speech-Language Pathology,* Vol. 7, No. 1, p. 23 – 32.

Osofsky, J.D. & Thompson, M.D. 2000. Adaptive and Maladaptive Parenting: Perspectives on Risk and Protective Factors, In J.P. Shonkoff & S.J. Meisels (eds.), *Handbook of Early Childhood Intervention*. 2nd ed. Cambridge: Cambridge University Press.

Owens, R.E. 1999b. *Language Development: An Introduction.* 4th ed. Boston: Allyn & Bacon.

Owens, R.E. 1999a. *Language Disorders: A Functional Approach to Assessment.* 3rd ed. Boston: Allyn & Bacon.

Paul, R. 2001. *Language Disorders from Infancy through Adolescence: Assessment and Intervention.* 2nd ed. Missouri: Mosby.

Pickering, M., McAllister, L., Hagler, P., Whitehill, T.L., Penn, C., Robertson, S.J. & McCready, V. 1998. External Factors Influencing the Profession in Six Societies. *American Journal of Speech-Language Pathology,* Vol. 7, p. 5 – 17.

Pienaar, A. 2003, Woensdag, 22 Oktober. 'n Dop wat Skop. *BEELD*. p. 9.

Plante, E. & Beeson, P.M. 1999. *Communication and Communication Disorders: A Clinical Introduction.* Boston: Allyn & Bacon.

Popich, E., Louw, B. & Eloff, I. 2007. Caregiver Education as a Prevention Strategy for Communication Disorders in South Africa. *Infants and Young Children,* Vol. 20, No. 1, p. 64-81.

Prizant, B.M. & Wetherby, A.M. 1993. Communication and Language Assessment for Young Children, *Infants & Young Children,* Vol. 5, No. 4, p. 149 – 168.

Renfrew, C.E. 1972. The Bus Story – A Test of Continuous Speech. Oxford: The Abbey Press.

Rivers, K.O. 2000. Working With Caregivers of Infants and Toddlers With Special Needs From Culturally and Linguistically Diverse Backgrounds. *Infant-Toddler Intervention: The Transdisciplinary Journal,* Vol. 10, No. 2, p. 61 – 72.

Rivers, K.O. & Hedrick, D.L. 1992. Language and Behavioral Concerns for Drug-Exposed Infants and Toddlers. *Infant-Toddler Intervention. The Transdisciplinary Journal,* Vol. 2, No. 1, p. 63 – 73.

Rivers, K.O. & Hedrick, D.L. 1998. A Follow-up Study of Language and Behavioral Concerns of Children Prenatally Exposed to Drugs. *Infant-Toddler Intervention. The Transdisciplinary Journal,* Vol. 8, No. 1, p. 29 – 51.

Robson, C. 2000. *Real World Research: A Resource for Social Scientists and Practitioner-Researchers*. 2nd ed. London: Blackwell Publishing.

Rogers-Adkinson, D.L. & Stuart, S.K. 2007. Collaborative Services: Children Experiencing Neglect and the Side Effects of Prenatal Alcohol Exposure. *Language, Speech and Hearing Services in Schools.* Vol. 38, No. 2, p. 149 – 156.

Rossetti, L.M. 1990. *The Rossetti Infant-Toddler Language Scale.* Illinois: LinguiSystems, Inc.

Rossetti, L.M. 1998. Early Communication Intervention: New Developments in Assessment and Treatment, Seminar held at the University of Pretoria, 14 August, 1998.

Rossetti, L.M. 2001. *Communication Intervention. Birth to Three*. 2nd ed. Australia: Singular Thomson Learning, Inc.

Rossetti, L.M. 2006. *The Rossetti Infant-Toddler Language Scale Manual*. USA: LinguiSystems.

Roth, F.P. & Worthington, C.K. 2001. *Treatment Resource Manual for Speech-Language Pathology.* 2nd ed. Canada: Singular Thomson Learning.

Sandall, S.R. 1997. Developmental Assessment in Early Intervention. In A.H. Widerstrom, B.A. Mowder & Sandall S.R. (eds.), *Infant Development and Risk: An Introduction.* 2nd ed. Baltimore: Paul H. Brookes Publishing Co.

Schoenbrodt, L. & Smith, R.A. 1995. *Communication Disorders and Interventions in Low Incidence Pediatric Populations*. San Diego: Singular Publishing Group, Inc.

Shipley, K.G. & McAfee, J.G. 2004. *Assessment in Speech-Language Pathology. A Resource Manual*. 3rd ed. San Diego: Singular Publishing Group, Inc.

Shonkoff, J.P. & Meisels, S.J. 2000. *Handbook of Early Childhood Intervention*. 2nd ed. Cambridge: Cambridge University Press.

Shprintzen, R.J. 2001. *Syndrome Indentification for Audiology. An Illustrated Pocket Guide*. San Diego: Singular Thomson Learning, Inc.

Sparks, S.N. 1993. *Children of Prenatal Substance Abuse. School-Age Children Series*. San Diego: Singular Publishing Group, Inc.

Sparks, S.N. 2000. Prenatal Substance Use and its Impact on Young Children. In T.L. Layton, E.R. Crais & L.R. Watson (eds.), *Handbook of Early Language Impairment in Children: Nature.* New York: Delmar Thomson Learning Co.

Sparks, S.N. & Gushurst, C. 1997. Interactions of Neonates and Infants with Prenatal Cocaine Exposure. In L.M. Rossetti & J.E. Kile (eds.), *Early Intervention for Special Populations of Infants and Toddlers.* San Diego: Singular Publishing Group, Inc.

Stackhouse, J. 2000. Barriers to Literacy Development in Children with Speech and Language Difficulties. In D.V.M. Bishop & L.B. Leonard (eds.), *Speech and Language Impairments in Children: Causes, Characteristics, Intervention and Outcome.* East Sussex: Psychology Press Ltd.

Steinhaussen, H., Willms, J., Winkler Metzke, C. & Spohr, H. 2003. Behavioural Phenotype in Foetal Alcohol Syndrome & Foetal Alcohol Effects. *Developmental Medicine & Child Neurology,*Vol. 45, No. 3, p. 179 – 182.

Stock Kranowitz, C. 1998. *The Out-of-Sync Child: Recognizing and Coping with Sensory Integration Dysfunction.* New York: The Berkley Publishing Group, Penguin Group Inc.

Streissguth, A.P., Aase, J.M., Clarren, S.K., Randels, S.P., LaDue, R.A. & Smith, D.F. 1991. Fetal Alcohol Syndrome in Adolescents and Adults. *Journal of the American Medical Association,* Vol. 265, p. 1961 – 1967.

Streissguth, A.P., Barr, H., Kagan, J. & Bookstein, F. 1997. Primary and Secondary Disabilities in Fetal Alcohol Syndrome. In A. Streissguth & J. Kanter (eds.), *The Challenge of Fetal Alcohol syndrome: Overcoming Secondary Disabilities.* Seattle: University of Washington Press.

Streissguth, A.P., Bookstein, F., Barr, H., Sampson, P.D., O'Malley, K. & Young, J.K. 2004. Risk Factors for Adverse Life Outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects. *Journal of Developmental and Behavioral Pediatrics.* Vol. 24, No. 4, p. 228 – 238.

Strydom, H. 2002a. The Pilot Study. In A.S. De Vos (ed), *Research at Grass Roots. For the Social Sciences and Human Service Professions.* 2nd ed. Pretoria: Van Schaik Publishers.

Strydom, H. 2002b. Ethical Aspects of Research in the Caring Professions. In A.S. De Vos (ed), *Research at Grass Roots. For the Social Sciences and Human Service Professions.* 2nd ed. Pretoria: Van Schaik Publishers.

Strydom, H. 2002c. Information Collection: Participant Observation. In A.S. De Vos (ed.), *Research at Grass Roots. For the Social Sciences and Human Service Professions.* 2nd ed. Pretoria: Van Schaik Publishers.

Strydom, H. & Delport C.S.L. 2002. Sampling and Pilot Study in Qualitative Research. In A.S. De Vos (ed.), *Research at Grass Roots. For the Social Sciences and Human Service Professions.* 2nd ed. Pretoria: Van Schaik Publishers.

Swanepoel, De Wet. 2004. A Review of the South African Context: Information for Community-based Speech-language and Hearing Services. *Clinica: Applications in Clinical Practice of Communication Pathology,* Monograph 7, p. 11 – 16.

Swigert, N.B. 1998. *The Source of Pediatric Dysphagia.* East Moline, Illinois: Linguisystems, Inc.

Te Water Naude, J., London, L., Pitt, B. & Mahomed, C. 1998. The DOP-system around Stellenbosch – Results of a Survey. *South African Medical Journal,* Vol. 88, No. 9, p. 1102-1105.

Thorne, J.C., Coggins, T.E., Carmichael Olson, H. & Astley, S.J. 2007. Exploring the Utility of Narrative Analysis in Diagnostic Decision Making: Picture-Bound Reference, Elaboration, and Fetal Alcohol Spectrum Disorders. *Journal of Speech, Language and Hearing Disorders,* Vol. 50, p. 459-474.

Tiegerman-Farber, E. 1995. *Language and Communication Intervention in Preschool Children.* Boston: Allyn & Bacon.

Timler, G.R., Olswang, L.B. & Coggins, T.E. 2005. "Do I Know What I Need to Do?" A Social Communication Intervention for Children with Complex Clinical Profiles. *Language, Speech and Hearing Services in Schools,* Vol. 36, p. 73-85.

Uys, K.J. 2000. *Oral Feeding Skills of Premature Infants.* Unpublished Masters in Communication Pathology Dissertation, University of Pretoria.

Van der Leeden, M., Van Dongen, K., Kleinhout, M., Phaff, J., De Groot, C.J., De Groot, L. & Hesseling, P.B. 2001. Infants Exposed to Alcohol Prenatally: Outcome at Three and Seven Months of Age. *Annals of Tropical Paediatrics,* Vol. 21, p. 127 – 134.

Van Dyke, D.C., Mackay, L. & Ziaylek, E.N. 1982. Management of Severe Feeding Dysfunction in Children with Fetal Alcohol Syndrome. *Clinical Pediatrics,* Vol. 21, No. 6, p. 336 – 339.

Vig, S., Chinitz, S. & Shulman, L. 2005. Young Children in Foster Care: Multiple Vulnerabilities and Complex Service Needs. *Infants & Young Children.* Vol. 18, No. 2.

Viljoen, D. 1999. Fetal Alcohol Syndrome. (Editorial), *South African Medical Journal,* Vol. 89, No. 9, p. 959 – 960.

Viljoen, D., Craig, P., Hymbaugh, M.P.H., Boyle, C. & Blount, S. 2001.a Fetal Alcohol Syndrome --- South Africa, 2001. *MMWR.* Vol. 52, No. 28, p. 660 – 662. http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5228a2.htm, accessed on 2003-11-27.

Viljoen, D., Croxford, J., Gossage, J.P., Kodituwakku, P.W. & May, P. 2001.b Characteristics of Mothers of Children with FAS in the Western Cape Province of South Africa: A Case Control Study. *Journal of Studies on Alcohol,* Vol. 62, p. 962 – 965.

Viljoen, D. & Krause, A. 2001. Genetic Protection Against Fetal Alcohol Syndrome? *Alcoholism: Clinical & Experimental Research.* December. http://www.eurekalert.org/pub_releases/2001-12/ace-gpa121101.php, accessed on 2004-08-21.

Walley, J., Khan, M.A., Shah, S.K., Witter, S. & We, X. 2007. How to get Research into Practice: First get Practice into Research. *Bulletin of the World Health Organization,* Vol. 85. No. 6, p. 424 – 425.

Werner, E.E. 2000. Protective Factors and Individual Resilience. In J.P. Shonkoff & S.J. Meisels (eds.), *Handbook of Early Childhood Intervention.* 2nd ed. Cambridge: Cambridge University Press.

Wetherby, A.M. & Prizant, B.M. 1989. The Expression of Communicative Intent: Assessment Guidelines. *Seminars in Speech and Language,* Vol 10, No. 1, p. 77-91.

Westby, C.E. 2007. Child Maltreatment: A Global Issue. *Language, Speech and Hearing Services in Schools,* Vol. 38, No. 2, p. 140 – 148.

Westby, C.E. 1988. Symbolic Play Scale Check List. *Seminars in Speech and Language,* Vol. 9, No. 1, p. 1 – 10.

Weitzman, E. 1992. *Learning Language and Loving It.* Toronto: The Hanen Centre.

Weitzner-Lin, B. 2004. *Communication Assessment and Intervention with Infants and Toddlers.* Missouri: Butterworth Heineman.

Williams, L. 2001. In Touch: FAS/FAE – Fetal Alcohol Syndrome/Effects. *National Indian & Innuit Community Health Representative Organization.* Vol 21. No. 1, p. 1-9.

Young, J.M. & Hauser-Cram, P. 2006. Mother-Child Interaction as a Predictor of Mastery Motivation in Children with Disabilities Born Preterm. *Journal of Early Intervention,* Vol. 28, No. 24, p. 252-263.

Zhang, C. & Bennett, T. 2001. Multicultural Views of Disability: Implications for Early Intervention Professionals. *Infant-Toddler Intervention: The Transdisciplinary Journal,* Vol. 11, No. 2, p. 143 – 154.

Zhang, X., Sliwowska, J.H. & Weinberg, J. 2005. Prenatal Alcohol Exposure and Fetal Programming: Effects on Neuroendocrine and Immune Function. *Experimental Biology and Medicine,* Vol. 230, p. 376 – 388.

Appendix A:
Copies of ethical clearance letters

Ethical Clearance Letter A:

Obtained from: Faculty of Humanities

Date obtained: December 2004

Original copy: Available in supervisor's dissertation copy

Ethical Clearance Letter B:

Obtained from: Medical Ethics Research Commitee

Date obtained: April 2005

Original copy: Available in supervisor's dissertation copy

Appendix B:
Parent/Caregiver Information Leaflet and Informed Consent

Parent/Caregiver Information Leaflet and Informed Consent

Study Title: A communication profile of young children (0 – 5 years) prenatally exposed to alcohol and other drugs.

Investigator: Miss Mari de Beer

(Each parent/caregiver will receive, read and understand this document before the start of the study)

NATURE OF THE RESEARCH STUDY

A descriptive cross-sectional research design in the form of a structured interview with the caregivers and an assessment session to investigate the communication skills of young children prenatally exposed to alcohol and/or other drugs and their caregiving environments.

INTRODUCTION

You are invited to volunteer for a research study. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about all the procedures involved.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to describe the communication skills of young children who were prenatally exposed to alcohol and/or other drugs, in order to provide clinical guidelines to speech-language therapists and audiologists to aid them in the assessment and therapy of the children and their caregivers.

WHAT IS THE DURATION OF THIS STUDY?

You will be interviewed by the investigator for 45 minutes regarding your child's developmental and medical history as well as the caregiving situation. The information required about your child is of such a nature that you will be able to answer the questions. Your child will be assessed by the investigator for approximately 60 minutes during which you will participate in some play and book-reading activities. The investigator will play with your child during the assessment and your child will not be forced to do something. The investigator is trained to work with young children and their parents. You and your child will not be separated at any time during the assessment. The interview will be taped on a recorder and certain parts of the assessment session will be video recorded for later analysis by the investigator. A digital photograph of your child will be taken to aid the investigator in description of your child's facial features. The interview and assessment will be scheduled at your convenience.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

Yes, the study has been approved by the Research Proposal and Ethics Committee of the Faculty of Humanities at the University of Pretoria.

WHAT ARE MY RIGHTS AS A PARTICIPANT IN THIS STUDY?

Your participation in this study is entirely voluntary (you decide if you want to take part in the study or not) and you can refuse to participate or stop at any time without giving any reason. The investigator retains the right to withdraw you from the study if it is considered to be in your best interest.

MAY ANY OF THESE STUDY PROCEDURES RESULT IN DISCOMFORT OR INCONVENIENCE?

Participating in the study will not result in any discomfort to you or your child. The interview and assessment time will be arranged with you.

During the assessment of the child, you will be present and your child will not be separated form you. During the assessment the investigator will play with your child and she/he will not be forced to do any tasks.

WHAT ARE THE RISKS INVOLVED IN THIS STUDY?

There will be no harm to you and your child if you decide to participate in this study. The assessment results will be discussed with you if you want the information. You will be referred to appropriate therapy services for your child if you want to. The information gained from this research will help speech-language therapists and audiologists in the future to provide better services to children, who were prenatally exposed to alcohol and/or other substances and their mothers/primary caregivers.

ARE THERE ANY WARNINGS OR RESTRICTIONS CONCERNING MY PARTICIPATION IN THIS STUDY?

There are no warnings or restrictions concerning your participation in this study.

FINANCIAL ARRANGEMENTS

You will not be paid to participate in this trial.

CONFIDENTIALITY

All information obtained during the course of this study is strictly confidential. Data that may be reported in scientific journals will not include any information that identifies you or your child as participants in this study.

A video recording will be made of your child and you playing together. The video will only be used for the purposes of the study.

Miss Mari de Beer
Investigator
Department of Communication Pathology
University of Pretoria

Prof. Alta Kritzinger
Supervisor
Department of Communication Pathology
University of Pretoria

Mrs. Ursula Zsilavecz
Co-Supervisor
Department of Communication Pathology
University of Pretoria

Prof. Brenda Louw
Department Head
Department of Communication Pathology
University of Pretoria

Department of Communication Pathology
University of Pretoria

VERBAL PATIENT INFORMED CONSENT

(applicable when parent/caregiver cannot read or write)

I, the undersigned, Miss Mari de Beer, or the interpreter, have read and have explained fully to the parent/caregiver, named _____ , the parent/caregiver information leaflet, which has indicated the nature and purpose of the study in which I have asked the research participant to participate.

The parent/caregiver indicated that he/she understands that he/she will be free to withdraw from the study at any time for any reason.

I hereby certify that the parent/caregiver has agreed to participate and let her child participate in this study.

Parent/Caregiver's Name: _____ (please print)

Investigator's Name: Miss Mari de Beer

Investigator's Signature: _____
Date: _____

Witness's Name: _____

Witness's Signature: _____
Date: _____

Department of Communication Pathology
University of Pretoria

WRITTEN INFORMED CONSENT

I hereby confirm that I have been informed by the investigator, Miss Mari de Beer, or the interpreter about the nature and purpose of this study. I have also received, read and understood the written information (Parent/Caregiver Information Leaflet and Informed Consent) regarding the study.

I hereby give consent that my child may participate in the study and that video recordings can be made of my self and the child, as well as a tape recording of the interview, for the purpose of the study.

I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a research report.

I may, at any stage, withdraw my consent and participation in the study. I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

Parent/Caregiver's Name: _____ (please print)

Parent/Caregiver's Signature: _____
Date: _____

Investigator's Name: Miss Mari de Beer

Investigator's Signature: _____
Date: _____

I, Miss Mari de Beer or the interpreter herewith confirm that the above mentioned parent/caregiver has been informed fully about the nature and conduct of the above study.

Witness's Name: _____ (please print)

Witness's Signature: _____
Date: _____

Interview Guide with Parent/Caregiver

Interview conducted with: Parent/Foster parent

Section A: Biographical Information

1. What is your/the child's name? _____
2. What is your/the child's date of birth? _____
3. What is the biological mother's date of birth? _____
4. What is the biological mother's highest level of education?
Grade _____
Matric _____
Diploma _____
Degree _____
Post-graduate level _____
5. What is the biological mother's occupation? _____
6. What is the biological father's date of birth? _____
7. What is the biological father's highest level of education?
Grade _____
Matric _____
Diploma _____
Degree _____
Post-graduate level _____
8. What is the biological father's occupation?_____
9.Does the child live with both parents? Yes _____ No _____
If no, provide reason: _____
10. If the child is in foster care:
How long: _____
11.Does the child have any brothers and/or sisters? Yes _____ No _____
How many?_____ What are their different ages? _____
12. How many people live in the house?
Number of adults: _____
Number of children: ____
13. Is your/the child experiencing any problems?
Tick if appropriate: Cleft palate
Heart problems
Hearing problems
Speech problems
Voice problems
Attention problems
Behavioural problems
Other _____
14. If your/the child has been diagnosed with a problem, when was the problem first noticed?
And by whom?_____

15. Does the child have a speech-language or hearing problem?
Yes_____No_____
16. Can you describe the problem please? _____
17. Have any other speech-language therapist or audiologist seen your child?
Yes _____ No _____
Who and when? _____
What did she tell you?_____
18.Have any other specialists seen the child?
Yes_____ No _____
What type of doctor? _____
What did the doctor tell you?_____
19. Are there any other speech, language, or hearing problems in your family? If yes, please describe. Yes _____ No _____
20. What languages are spoken in the home? What is the language spoken most?
Languages: _____
Language spoken most: _____
21. What languages does the child speak? What is the language spoken most by the child?
Primary language: _____ Other:_____
22. With whom does the child spend most of his or her time? _____
23. Is the child in day care? Yes _____ No _____

- Creche _____
- Nursery school _____
- At home _____

Section B: Prenatal and Birth History

1. How was your health during the pregnancy? _____
2. Did you have any problems/illnesses during the pregnancy? Can you please describe them to me. _____
3. Have you had any spontaneous abortions or still births previously?
   Yes _____ No_____
4. Did you receive any medical treatment during the pregnancy?
   Yes_____ No _____
5. Was the baby born full term? (if not full term ask the reason for prematurity)
   _____
6. Why was your baby born early?_____
7. Did you smoke during the pregnancy?_____
8. How many cigarettes did you smoke during the pregnancy? _____
9. Did you drink during the pregnancy? _____
10. How often did you drink during the pregnancy?_____
11. How many drinks did you take at one time?_____
12. Did you stop drinking at any time during the pregnancy?_____
13. Did you use any other substances, for example weed, during your pregnancy?
    _____
14. Did you have a normal birth or a caesarean section? _____
15. What did your baby weigh at birth? _____
16. What were your baby's Apgar scores?

1 min: _____ 5 min: _____

17. How long was the baby in hospital after the birth? Days: _____Weeks:____
18. Were you concerned about the baby after the birth? (if yes, what were your concerns?
_____
19. Did your baby vomit during the first few days after birth? _____
20. How long was it before your baby could breast/bottlefeed successfully? ___
21. How would you describe your baby's early behaviour,

- Quiet _____
- Irritable_____
- Friendly_____
- Over active _____
- Inconsolable ____

Section C: Medical History

1. Please name all the illnesses that your/the child has had.
   How old was he/she when he/she had the illnesses? (Tick and indicate in appropriate blocks)

Allergies		Bronchitis		Tonsillitis	
Colds & Flu		Mumps		Encephalitis	
Asthma		Chicken pox		High fever	
Fits		Croup		Colic	
Meningitis		Draining ear		Tuberculosis	
German measles		Headaches		Sores in the mouth	
Measles		Gastro-enteritis		Ear infections	
Sinusitis		Other?			

2. Has your child had any surgeries? If yes, what type and when? Yes _____ No _____
   Type: _____
   When: _____
3. Have your/the child been in any accidents? _____
4. Has the child had any injuries for which he/she was admitted to hospital?____
5. What kind of injury/ies? _____
6. Is the child taking any medications? Yes____ No _____Type : _____
5. Have there been any negative reactions to medications? _____

Section D: Developmental History

General Development

1.Please tell me at what age your/the child began to do the following activities.

Activity	Age mastered
Crawl	
Sit	
Stand	
Walk	
Feed self	
Dress self	
Use toilet	

2.Does the child have difficulty:

- Walking_____
- Running _____
- Participating in other activities that require big and small movements?

Feeding History

1. Are there or have there been any feeding problems? _____ If yes, describe.

_____

Feeding problem	Description
Sucking	
Swallowing	
Drooling	
Chewing	
Choking	
Other	

2. How does your child eat now? _____
3.Does he/she eat different kinds of foods? _____
4.What food does your child like most?_____
5.What food does your child like least?_____

Hearing Abilities

1. Does your/the child have problems with hearing or with listening?
   Yes _____ No _____
   (If yes, ask the following questions)
   - Does your child listen to loud sounds only?_____
   - Does your child listen differently to sounds at different times? ___

Comprehension and Understanding

1. Is your child easily confused when there are many things taking place around him/her?
   If yes, please describe. _____
2. How does your child respond when you give him/her directions?_____
3. How does your child respond to simple questions?_____
4. How would you describe your child's intelligence and thinking skills? _____

Speech and Language Development

1. Describe the sounds your child made before using words or the sounds that your child produces now _____
2. Does your child keep on learning new sounds/ words/ sentences?_____
3. When did your child say his/her first real word?_____
4. Did your child have his own words for objects, people? _____
5. How many different words is your child saying now?_____
6. Does your child use sentences?_____
   Two words _____Three words_____ More _____
7. Did your child's speech or language development seem to stop for a time? Yes ___No___ If yes, why do you think it stopped? _____
8. Do you think your child is talkative or quiet?_____
9. How does your child usually let you know what he/she wants?_____
10. Do you think your child's speech is normal for his/her age? Yes __ No __
    If no, please also respond to the following questions.
    - How well do you understand your child's speech?_____
    - How well do people outside the family understand your child's speech?_____
    - How does your child react if she/he is not understood by others? __
11. How will you describe your child's behaviour?_____
12. What does your child like doing most?_____
13. What does your child like doing least?_____

Section E: Parental concerns and needs

1. What concerns you most about your child's speech, language or hearing skills now?
   _____
2. What do you think is the reason for your child's speech and language difficulties now?
   _____
3. What have you done to help your child to learn to talk?_____
4. Has anything about your child's speech and language development bothered you?
   Yes__No __ If yes, please describe. _____

We have reached the end of the interview.
Thank you for your participation it is highly appreciated.

Compiled by Mari de Beer 2004
Sources: Kritzinger & Louw,2000; Rossetti, 1996; Shprintzen, 2001; Shipley & McAfee, 2004; Sparks, 1993.

Appendix D:
Communication Assessment Protocol

Communication Assessment Protocol: Infants and Young Children with FASD (0-60 months)

Identifying information:

- Participant number : _____
- Participant date of birth : _____
- Participant's chronological age : _____

Assessment levels and areas:

Level 1 – Physical features and sensory integrity

1. Genetic screening checklist (Kritzinger & Louw, 1998):
   Description of main results:
   _____
   _____
   _____

   More than 3 minor or 1 major anomaly present: Yes/No
   If yes, refer.

2. Otoscopic examination (Shipley & McAfee, 2004):

	Intact tympanic membrane with light reflex viewed	**Abnormalities noted in the external meatus:**
Left ear		
Right ear		

   Refer:

3. Hearing assessment:

Method of assessment	**Indicate with √**
Visual response audiometry (VRA)	
Immittance measurements	
Oto-acoustic emissions (OAE)	
Play audiometry	

   Summary of results:
   - Right ear: _____
   - Left ear: _____

4. Visual screening:
   Description of anomalies noted regarding:
   Function: _____
   Structure: _____

Level 2 – Communication and related skills

1. **Oral-peripheral examination (Shipley & McAfee, 2004):**
   Summary of findings regarding structure and function:

Structure	Description
Jaw	
Lips	
Tongue	
Soft palate:	

2. **Oral-Motor/Feeding Rating Scale (Jelm, 1990):**
   Summary of findings regarding different aspects of feeding:

Oral-motor/Feeding patterns	Description according to key
Breast:	
Bottle:	
Spoon feeding:	
Cup drinking:	
Biting/soft cookie	
Biting/hard cookie	
Chewing	
Straw drinking	

3. **The Rossetti Infant-Toddler Language Scale (Rossetti, 1990):**

Language/Communication Skill area	Criterion-referenced outcome: Age performance profile
Interaction attachment	
Pragmatics	
Gesture	
Play	
Language comprehension	
Language expression	

4. **Expressive One-Word Picture Vocabulary Test (Gardner, 1990):**
   Raw score: _____
   Age equivalent: _____

5. **Phonetic repertoire – CHRIB Assessment Protocol (Kritzinger & Louw, 2002):**
   Vowel repertoire: _____
   Consonant repertoire:
   Plosives: _____
   Fricatives: _____
   Glides: _____
   Nasals: _____
   Diphtongs: _____

-

6. Receptive One-Word Picture Vocabulary Test (Gardner, 1985):
Raw score: _____
Age equivalent: _____

7. **Afrikaanse Reseptiewe Woordeskat Toets (Buitendag, 1994):**
Raw score: _____
Age equivalent: _____

8. **The Bus Story (Renfrew, 1972):**

Aspect	**Age related score**
Information	
Sentence length	

9. CHRIB Assessment Protocol: Subsection Communication skills (Louw & Kritzinger, 2002;Wetherby & Prizant, 1989):

Pragmatic Skill	**Description**
Behaviour regulation	
Social interaction	
Shared attention	
Turn-taking abilities/Discourse structure	
Communication method	
Non-verbal communication	
Communicative gestures	

10. Observation of Communicative Interaction (Klein & Briggs, 1987):

11. Assessment of Parent-Child Communication Interaction (Kritzinger, 2005):

Parent/caregiver's actions	**Promote/inhibits interaction**

12. Kaderavek-Sulzby Bookreading Observational Protocol (Kaderavek & Sulzby, 1998):
***Successful interaction: Yes/No**

	Descriptions
Positive/Negative aspects of storybook selection	
Indicate to what extent the parent made use of scaffolding behaviours	
Positive/Negative aspects of social/emotional climate	

Positive/Negative aspects of child's verbal responsiveness	

13. CHRIB Listening Scale (Hugo, Louw, Kritzinger & Smit, 2000):

1.Situation 1: During communication evaluation: Reaction to…

	Good (1) Inadequate (2) Poor (3)
Environmental sounds	
Whispered speech	
Non-speech sounds (toys)	
Speech	

2.Situation 2: During hearing evaluation or test:
Describe reactions that were evaluated:

_____
_____
_____

Level 3 – General developmental skills

1. Developmental Assessment Schema (Anderson, Nelson & Fowler, 1978):

Developmental domain	**Developmental performance level**
Behaviour	
Personal social skills	
Perceptuo-cognitive skills	
Play development	
Self-help skills	
Motor skills	

2. Symbolic Play Scale Checklist (Westby, 2000):

Play level corresponding with language developmental stage	**Indicate with √**
Presymbolic level I: 8 – 12 m	
Presymbolic level II: 13 – 17 m	
Symbolic level I: 17 – 19 m	
Symbolic level II: 19 – 22 m	
Symbolic level III: 2 y	
Symbolic level IV: 2 y 6 m	
Symbolic level V: 3 y	
Symbolic level VI: 3 y – 3 y 6 m	
Symbolic level VII: 3 y 6 m – 4 y	
Symbolic level VIII: 5 y	

3. Stages of Play Development (Roth & Worthington, 2001):

Stage of play development	**Indicate with √**
Non-meaningful manipulation of objects: 6 – 8 m	
Purposeful exploration of objects: 8 – 12 m	
Self-related symbolic play:	

12 – 18 m	
Other-related play: *18 – 24 m*	
Planned symbolic play: *24 – 30 m*	
Socio-dramatic play: *3 – 5 y*	

Level 4 – Risk & Resilience factors

Please list all risk factors indicated:

_____
_____
_____

Please list all aspects of resilience indicated:

_____
_____
_____

Compiled by: Mari de Beer (2004)

Appendix E:
Example of assessment report

Report provided to the Parent/Caregiver upon Completion of the Evaluation - Participant 3's report is provided as example

Mari de Beer

δ Speech-language Therapist δ

B.Communication Pathology

STA no. 0024988

SPEECH-LANGUAGE EVALUATION REPORT

Name	**:**	**----------**
Date of Birth	**:**	**----------**
Chronological age	**:**	2 years 11 months
Date of evaluation	**:**	7 January 2006
Copies of report to	**:**	**----------**

Dear Mr and Mrs X (foster parents of Participant 3)

Behaviour during evaluation:
She is a friendly girl and co-operated well during an approximately 90-minute evaluation. She has a short attention span and her concentration in a one-to-one situation was not satisfactory, she is furthermore easily distractible.

BACKGROUND HISTORY:
Background history was obtained through a comprehensive interview with you as the foster mother.

General:
- She is one of four children.
- She is currently in foster care, since April 2005.
- Afrikaans is the primary language spoken in your foster home.
- She attends nursery school on a half-day basis.

Medical History:
- Unknown birth and prenatal history.
- She has suffered from tonsillitis as well as colds and flu.

DEVELOPMENT:
Feeding:
She has never experienced sucking or swallowing problems, since being placed with you in foster care. Previous problems are thus not known. Currently she has a good appetite and loves to eat a variety of food, especially fruit.

Motor development:
She presented with delayed attainment of motor developmental milestones. You describe her as a clumsy child who currently struggles with fluent gross motor movements for running.

Speech & Language development:
It is not known if the onset of her first words were at a developmentally appropriate age. She takes a long time to learn new words. She currently probably has a vocabulary of 50 words. She uses two word sentences most of the time, this is not age appropriate any more and sentence length should be improving. Her speech and language development appeared to stop for a while when placed in foster care in April 2005. She was very quiet for the first four months. She gets easily confused when there are many things going on and then she shuts off. She can follow simple two-step instructions. You currently describe her as a very talkative child, a little "chatterbox".

Emotional development:
She is a friendly and outgoing little girl. She displays some behavioural problems towards her foster siblings as well as towards children at her nursery school in that she is very bullying towards them.

Previous consultation:
No previous consultations were reported.

SPEECH EVALUATION:

1. **Oro-facial examination (Louw & Kritzinger, 1998; Shipley & McAfee, 2004):**
   The mid-facial structures appear flattened. Regarding her dentition two front teeth are misshapen and there is poor alignment of the teeth. She furthermore presents with an absent gag reflex. Her head shape appeared small for her age. Her ears are low set and her eyes appear wide set. She presents with epicanthal folds and anteverted nares of the nose.

2. **Articulation:**
   Her articulation development is currently age appropriate. Her speech production is however, only about 60 % intelligible to listeners outside the family according to her foster mother.

LANGUAGE EVALUATION:
RECEPTIVE LANGUAGE:

1. **Afrikaanse Reseptiewe Woordeskat Toets (Buitendag, 1994):**
   This is a receptive language test and assesses the child's comprehension. It is required of the child to point at pictures when asked. She obtained the following age equivalent scores for the test that was performed:

   Chronological age : ***2 years 11 months***

   Language comprehension : < 2 years

2. **Developmental Assessment Schema (DAS)(Anderson et al., 1978):**
   This informal assessment scale indicates the age level of her understanding of language. Your subjective view was used to obtain most of the information. According to this scale she understands language at a **24 - 27 month** level, again confirming the delay in her comprehension of language.

From the above results, it is evident that she will benefit greatly from language enrichment that can be provided through early communication intervention.

3. **The Rossetti Infant-Toddler Language Scale (Rossetti, 1990):**
This criterion-referenced scale was again used informally in a play situation to observe her ability to understand English.

Chronological age: 2 years 11 months

Language comprehension: 21 – 24 month level

The results again confirm the delay in the development of her language comprehension.

EXPRESSIVE LANGUAGE:

1. **The Rossetti Infant-Toddler Language Scale:**
This evaluation takes place informally where speech is elicited and observed during a play situation with the therapist.

Chronological age: 2 years 11 months

Language expression: 21 – 24 month level

She thus also demonstrates a delay in her expressive language skills. Therapy will again be of great benefit.

1. **Expressive One-Word Picture Vocabulary Test – Revised (EOWPT-R):**
This test requires the child to name pictures that are shown to her. She obtained an age equivalent score of **< 2 years** which indicates that she would benefit from language enrichment to extend her functional vocabulary.

2. **Bus story (A subtest of the Reynell Language Scale):**
During this item a story is told to the child using sequencing pictures. The child then has to retell the story. The child's story is evaluated according to the information remembered as well as the sentence length used. This is then compared to age equivalent norms.

Information : *Below 3 years*
Sentence length : *Below 3 years*

The above score, once again reflects the delay in her receptive, as well as expressive language. During the attempted retelling of the story her speech was somewhat unintelligible. She had a mean length of utterance of 1.25 to 2.0.

PRAGMATIC EVALUATION (Wetherby & Prizant, 1998):

Pragmatics refers to a person's use of language and communication intent. She demonstrated poor eye contact and struggles to attend to the speaker. She also struggles to maintain a topic and to take turns in an appropriate fashion.

Communicative intentions that are present are: she uses denial, commenting and requesting appropriately.

PLAY EVALUATION:

Language is learnt through play. Currently her play development is at a ***2 year to 2 year 6 month age level***, according to the Westby Symbolic Play Scale (Westby, 2000). She is at a symbolic level in her play. This stage can also be referred to as the planned symbolic stage according to Roth and Worthington's stages of play development (Roth & Worthington, 2001). She is not yet very successful at functional and cooperative play according to her your reports. She gets easily distracted.

PRE-LITERACY EXPOSURE:

During book reading she is able to hold the book facing right-side up and she is able to turn pages on her own. She produces emergent storybook reading skills and she initiated comments about the book's pictures and she was engaged and evidenced enjoyment of the storybook interaction. This displays good pre-literacy exposure which can contribute to promotion of her language development

GENERAL DEVELOPMENTAL AREAS:
Developmental Assessment Schema (DAS) (Anderson et al., 1978):

Chronological age	***:***	***35 months***	
Personal-social skills	:	27 – 30 months	- delayed
Perceptuo-cognitive skills	:	24 – 27 months	- delayed
Self help skills	:	Age appropriate	
Fine motor skills	:	24 – 27 months	- delayed
Gross motor skills	:	Age appropriate	-although clumsy at times

CONCLUSIONS AND RECOMMENDATIONS:

1. She presents with a significant receptive and expressive language delay. These areas of her development should be addressed in therapy in order to improve her ability to follow instructions and express herself adequately.
2. A hearing test by an audiologist is also recommended to establish if she has normal hearing abilities. This will be performed by the researcher or a final year student at the Department of Communication Pathology at the University of Pretoria under the expert guidance of a qualified audiologist.
3. Weekly speech-language therapy is recommended. The family was referred to CHRIB at the Department of Communication Pathology at the University of Pretoria, where they will be entitled to receive free therapy. This together with the diligent completion of a weekly home programme will contribute to the improvement of her language abilities.

It was a pleasure to evaluate her and to meet her foster parent. If you require any further information please do not hesitate to contact me.

Yours sincerely
Mari de Beer
Researcher

Appendix F:
Transcriptions of the "Bus story"-test (Renfrew, 1972)

Transcription:
"The Bus Story" – Renfrew Language scales:

Participant 4 = P4
Researcher = R

R: Dis nou jou beurt om die storie vir my en die diere maatjies te vertel oor wat met die stoute bus gebeur het? Gebruik die prente kaartjies van die storie om jou te help.

P4: Die stoute bus, hy het weg gegaan. Toe wou hy hom regmaak….uh…..regmaak ja en toe weg.

R: En wat gebeur toe volgende?

P4: Sien jy die trein?

R: Ja ek sien dis 'n stoom trein.

P4: Die trein…uh…die trein met die bus maak gesigte…..jy weet mos…..uh…..toe doen hulle dit. Toe …uh…ja toe gaan die ding in daai ding en toe kom die man…ja….uhm…dis daai man en hy se stop.

R: Wat gebeur dan nou nog verder in die storie?

P4: En toe ry hy nog en nog….uhm….ja toe…..uhm….gaan hy by die draad….uh…uh….toe's hy moeg oor die ding….Koei se moo-moo…. (maak weer moo soos nou-nou toe)….

R: Ons is nou klaar met die koei in die storie. Hah kyk net daar! Wat het nou gebeur?

P4:….en hy het oe. Uhm….daar gaan hy…uh… toe sit hy vas in ….uh….in daardie ding….uh….jy weet mos die modder daai ding. En toe ry hy weer…en toe en toe ry hy nog. Nou's ek klaar ne.

R: Sjoe maar jy het 'n fantastiese storie vertel. Ek en al die dieremaatjies het dit sommer baie geniet.

Transcription:
"The Bus Story" – Renfrew Language scales:

Participant 5 = P5
Researcher = R

R: Dis nou jou beurt om die storie vir my en die diere maatjies te vertel oor wat met die stoute bus gebeur het? Gebruik die prente kaartjies van die storie om jou te help.

P5: Jislaaik! Dis 'n nice bus…..(ek het net so een…uh…ek dink so een by die huis). Toe kom die man en die bus is stout en hy het ge….uh…gestout…en toe daai ding en hy weg ry….uh….en hardloop weg.

R: Wat het toe gebeur nadat hy weg gehardloop het?

P5: Check nou die trein en die bus….brrrm-brrrrm en choo-choo….uh dis mos hoe hulle praat…en hy jaag met hom en toe….en toe…ja, en toe gaan die trein by daai ding in….(sien jy by daai ding in, net so, laat'k wys)…Hy ry en ry en ry. En toe se die police stop! En hy het sulke ding geblaas….daai ding die ….om te se stop.

R: En wat gaan nou met die bus gebeur?

P5: En toe ry hy en die bus ry en toe's hy moeg. Hy spring….uhm….hy spring in die muur ne…..ja net so oor. Sommer so (sien jy?) net so hoog en toe maak die koei sulke groot oe….en ….en jislaaik toe se hy moo.

R: Sjoe, daai koei moo baie hard, maar wat het nou nog verder in die storie gebeur?

P5: En toe is daar trouble…uh daar is trouble wat die ding het nie (hah-hah-hah) ….uh-uh hy het nie daai goeters, man jy weet mos die goeters, o ja nie brieke nie. Boem! Hy ry in die water en toe…..en toe… kom die man…en toe…uh….hy het met die hyskraan kom bel…en toe is die ding daar en doen sy ding daar en…uh….en toe hy ry weer

R: Sjoe maar jy het 'n fantastiese storie vertel. Ek en al die dieremaatjies het dit sommer baie geniet.

Appendix G:
Declaration of independent work

University of Pretoria
Faculty of Humanities

Declaration signed by candidate:

I declare that this dissertation that I am handing in for the degree M.Communication Pathology at the University of Pretoria, is my own work and has not been submitted previously for another degree at another university. Where secondary material is used, it is acknowledged and referenced in accordance with the university requirements. I am aware of the university's policy regarding plagiarism.

Signature: _____ Date: _____

Stamp of the Commissioner of Oaths:

Declaration signed by study leader/co-leader:

I herewith declare that I acknowledge the handing in of Maria Magdalena De Beer's dissertation for examination. The co-leader has also consented to this handing in.

Signature (Co-leader): _____ Date: _____
Signature (Study leader: _____ Date: _____