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Mothers' facilitation of the occupational engagement of their children with FASD: A qualitative descriptive study in an under-resourced district in South Africa

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I salute all the children with FASD and their mothers who allowed me into their lives since 1995. You have taught me so much, and when I withdraw into the safety of my life you continue to overcome the challenges associated with FASD.

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Abstract

South Africa has the highest reported prevalence of Fetal Alcohol Spectrum Disorder (FASD) worldwide. The high prevalence is aggravated by limited remedial and rehabilitative services in the rural Northern Cape. Parents requested guidance to facilitate the development of their children with FASD. Understanding their needs and strengths will inform intervention programmes to create the stable environments children with FASD require for optimal life outcomes. The aim of the study is to explore the way that mothers facilitate the occupational engagement of their children with FASD as well as the challenges they face. Using a qualitative descriptive study design, the author purposively selected mothers to reveal three turning points in the lives of their children. Semi structured- and photo-elicitation interviews highlighted mothers' experiences. Interviews were transcribed verbatim and inductively analysed with content analysis. Two themes emerged, namely, "***Doing together"*** and "***Varying access to engagement"***. The findings of this study highlight the important role mothers play to facilitate the occupational engagement of children with FASD. Recognising mothers as agents of change and including them in intervention will enhance occupational therapy practice in the area of FASD.

Key words: FASD, caregivers, facilitation of occupational engagement

Word count: 184

Foreword

“Search the universe! You will find no two units alike. The scientists tell us there are no two cells, no two atoms, identical. Nature has bestowed upon each a peculiar individuality, an exclusive patent from the great giants of the forest to the tenderest blade. Catch in your hand, if you please, the gentle flakes of snow. Each is a perfect gem, a new creation; it shines in its own glory - a work of art different from all of its aerial companions. Man, the crowning achievement of nature, defies analysis. He is a mystery through all ages and for all time … In all races, genius is like a spark, which, concealed in the bosom of a flint, bursts forth at the summoning stroke. It may arise anywhere and in any race.” (Seme 1906)

Some mothers raising children with Fetal Alcohol Spectrum Disorders (FASD), in the Pixley Ka Seme District, demonstrate this spark of genius, as they nurture and guide their unique children living with the consequences of alcohol exposure before birth. This thesis aims to explore the stories of these mothers, as they facilitate the occupational engagement of their children with FASD.

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Definitions of Terms

Abstain: To refrain from the use of alcohol or other substances. (WHO 2014b).

Child: For the purpose of this study the term *child* refers to the offspring of a mother and includes the range of age groups from early primary school to young adults.

Child Support Grant: A grant to help raise a child. The grant of R420/month is paid to the primary care giver (e.g. parent, grandparent, or child over 16 years heading a family) with an income of less that R48 000 per year for a single person or when married less than R96 000 combined income per year (South African Government, 2018).

Co-occupation: is defined as "…a dance between the occupations of one individual and another that sequentially shapes the occupations of both persons" (Pierce 2009: 203).

District Based Support Team: The District Based Support Teams of the Department of Education assist with programme development, monitoring and evaluation. The team also support teaching, learning and management of learners with a variety of learning needs. These teams consist of staff from provincial and district offices as well as special schools (Sonday 2016).

Fetal Alcohol Syndrome (FAS): Fetal Alcohol Syndrome is the most severe form of the Fetal Alcohol Spectrum Disorders and includes typical facial features such as a long, smooth upper lip and short palpable fissure, as well as growth retardation and neurodevelopmental effects (Viljoen, Gossage, Brooke, Adnams & Jones 2005).

Fetal Alcohol Spectrum Disorders (FASD): is the umbrella term for a range of birth defects caused by the teratogenic effect of alcohol during prenatal alcohol exposure (Olivier, Curfs & Viljoen 2016).

Learning: In this dissertation, learning includes the acquiring of knowledge in academic learning as well as acquiring new skills required to participate in the occupations of leisure, selfcare and productivity.

Mother: For the purpose of this study, the term *mother* refers to a biological mother who gave birth to the child of interest (with FASD) as well as a non-biological, foster mother who is the primary care-giver of the child.

Occupation: The purposeful activities an individual actively engages in on a daily basis that enables one to develop as an individual as well as a member of a community (Townsend 2007). Occupations add meaning to a person's life, are central to a person's identity, influencing the way one spends time and makes decisions (Pierce 2001). In this dissertation, mothering is explored as "one of women's most important occupations" which includes physical, emotional, social and nurturing activities (Poole, Willer & Mandelson 2009: 214).

Occupational engagement: In this study, *occupational engagement* refers to the mother's accounts of the ways in which she facilitates her child's performance and engagement, i.e. involvement and enjoyment linked to participating in learning, play and social occupations (Polatajko, Townsend & Craik 2007). Engagement in occupations is determined by the interplay between the person, their environment and their occupations (Townsend 2007).

Sensory Processing: Sensory processing is a neurological process. It includes receiving information from the environment through the senses as well as modulating, integrating and organising this sensory information for use (Schaaf & Miller 2005). Within a sensory integration framework, sensory processing is an important building block for complex learning, adaptive behaviour and socio-cognitive functioning.

Stigma: Stigma is the stereotypes, prejudice and discrimination that the general public associates with a labelled group, i.e. people with FASD. This has a harmful effect on people with behavioural health disorders (Corrigan et al. 2017).

Abbreviations

ARBD	Alcohol Related Birth Defects
ARND	Alcohol Related Neuro Developmental Delay
CCT	Cognitive Control Therapy
CMOP-E	Canadian Model of Occupational Performance and Engagement
DBST	District-based Support Team
FARR	Foundation for Alcohol Related Research
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorder
ICF	International Classification of Functioning, Disability, and Health
LLT	Literacy and Language Training
NFCS	National Food Consumption Survey
PAE	Prenatal alcohol exposure
PEI	Photo-elicited interview
pFAS	Partial Fetal Alcohol Syndrome
SES	Socio-economic status

Chapter 1: Orientation to the Study

This chapter introduces Fetal Alcohol Spectrum Disorder (FASD) as a common cause of learning and behavioural challenges in South Africa. It explores the history of alcohol and its use as a causal factor of FASD. Located within a particular geographical context, the chapter will describe some of the challenges people living with FASD and their families face. This will be followed by an overview of services for persons with FASD in the public sector in this geographical context. The chapter concludes by presenting a summary of the above information to affirm the rationale and problem statement for the study as well as the research question, aim and objectives of the study.

1.1. Fetal Alcohol Spectrum Disorders

Internationally, prenatal alcohol exposure is a leading cause of developmental disability (Mattson, Crocker & Nguyen 2011; Nash 2012), and may result in a congenital disorder (Urban 2017) with lifelong debilitating impact, namely Fetal Alcohol Spectrum Disorder (FASD). The teratogenic[1] effect of alcohol has been well described since the 1960's and 70's, but it was not common knowledge before the 60's. Although ancient manuscripts warn against alcohol use, these warnings do not specify abstinence from alcohol for all women of child bearing age (Calhoun & Warren 2007; Olivier 2017). The British Royal College of Physicians (1752) (cited in Olivier 2017) were first to record a warning against alcohol use in pregnancy during the 'gin epidemic'. This admonition stated that women who consume large amounts of gin may bear weak, irritable children (Olivier 2017).

It was only in 1968 that French scientist Lemoine described the birth defects in children prenatally exposed to alcohol (Calhoun & Warren 2007; Lemoine et al. 2003). Five years later, American scientists Smith and Jones coined the term Fetal Alcohol Syndrome (FAS) in their Lancet published article on the syndromic effect of prenatal alcohol exposure (Jones & Smith 1973).

The clinical diagnosis of FAS (Urban 2017) is based on three elements, namely: (a) typical facial features, (b) growth retardation, and (c) neurodevelopmental damage (Jones & Smith 1973; Sampson et al. 1997). The children of participants in this study were diagnosed with FASD using the criteria described by the US Institute of Medicine with modifications by Hoyme et al. (2005). A diagnosis of FAS required (1) at least two or more of the characteristic facial features (palpebral fissures; thin vermilion border, smooth philtrum); (2) pre- and /or postnatal growth retardation (height or weight ≤10%); (3) deficient brain growth (occipto-frontal head circumference/OFC ≤10%) and (4) confirmation of maternal alcohol consumption.

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[1] A teratogen is an agent that disturbs the development of the fetus *in utero*. (medicinenet.com, 2017).

However, not all alcohol exposed pregnancies result in the full syndrome with all three elements. In some individuals, the impact of alcohol exposure *in utero* is limited to neurological or neuro-behavioural signs without any phenotypical facial features or growth deficiency. Various factors such as maternal health and nutrition, genetic and environmental factors, timing, amount and pattern of drinking determine the developmental outcome of prenatal alcohol exposure (Kalberg & Buckley 2007; Olson et al. 2007). Since the late 1990's, this phenomenon gave rise to the umbrella term Fetal Alcohol Spectrum Disorder (FASD) (Calhoun & Warren 2007; Hoyme et al. 2005). The term FASD embraces the full spectrum of the disorder, namely: Alcohol Related Neuro Developmental Delay (ARND), Alcohol Related Birth Defects (ARBD), Partial Fetal Alcohol Syndrome (pFAS), as well as the most severe effect, FAS (Viljoen, Gossage, Brooke, Adnams & Jones 2005).

Children with FASD live with cognitive, emotional, developmental, behavioural, sensory and physical challenges (Abele-Webster, Magill-Evans & Pei 2012; Culshaw 2015; Nash 2012; Mattson et al. 2011; Murthy, Kudlur, George & Mathew 2009). These challenges impact negatively on their adaptive functioning and engagement in their daily occupations (Culshaw 2015; Whaley, O'Connor & Gunderson 2001). FASDs are the result of alcohol consumption during pregnancy. The next section will give an overview of alcohol use in general, followed by an account of alcohol consumption amongst woman.

1.2. A brief History of Alcohol Use

Historical evidence shows traces of alcohol from as early as 7000 – 6600 BC in ancient China, and 6000 BC in Egypt and Mesopotamia (Urban 2017). At the time, artisans brewed alcohol on a small scale when excess fruit or grain was available. Ancient tribes and villages consumed alcohol periodically, and communally, usually to celebrate special festivals (WHO 2014a). As alcohol was consumed, moral values arose to dictate either regular, moderate drinking in some cultures or occasional excessive (binge) drinking in other cultures (Urban 2017). However, some societies such as American first nations, Oceania, indigenous Australians and the Khoisan of south western Africa, had no history of alcohol use. These cultures did not grow accustomed to alcohol use over generations and the abrupt introduction of alcohol had calamitous results (WHO 2014a; Urban 2017).

Industrialisation introduced new varieties of alcohol brews and mass production. Combined with transport, distribution and marketing, people had access to greater amounts of alcohol which changed patterns of alcohol consumption (WHO 2014a). Increased access to alcohol led to social and other forms of harm, with examples including crime, social unrest, and poor health, as demonstrated in the gin epidemic of 1720 – 1751 (Urban 2017; Olivier 2017).

Although low levels of alcohol consumption may be considered to have some health benefits, excessive consumption is associated with alcohol-related harm. Thus, harmful or hazardous drinking became distinct from low-risk drinking (WHO 2014a).

Alcohol use has many negative impacts. It has a toxic effect on organs, the psychoactive effect of alcohol can lead to intoxication (impaired consciousness, coordination and discretion) and some people may become alcohol dependent (WHO 2014a). A family history of alcohol abuse increases one's risk to the harmful effects of alcohol as a result of both genetic and environmental factors. Various genes impact initiation, metabolism and susceptibility to the toxic and dependency effect of alcohol amongst vulnerable people (WHO 2014a). Environmentally, parents' drinking patterns influence family functioning, parenting practice, as well as the parent-child relationship. The domestic misuse of alcohol may lead to child abuse and neglect, which in turn may lead to psychological problems in childhood and misuse of alcohol later in life (WHO 2014a).

Societies with higher socio-economic status (SES) tend to drink more, on more frequent occasions and have less people abstaining from alcohol. However, according to the Global Status Report on Alcohol and Health, (WHO 2014a) people with low SES are more vulnerable to the harmful effect of alcohol use. Manual workers are more susceptible to the adverse outcomes associated with high alcohol consumption than non-manual workers and seem to carry the harm over to the following generations. The WHO (2014a) explains this vulnerability of people living in low socio-economic conditions as follows: in higher socio-economic contexts there are often safer drinking environments and people are more likely able to purchase protective barriers such as better health care, or using transport services, as opposed to driving or walking under the influence. The final factor contributing to the harmful effect is controversial according to the WHO, and is based on a principle of 'all or nothing'. The WHO found people of lower SES drink on fewer occasions but consume more alcohol on those occasions. This pattern of binge drinking is especially harmful (WHO 2014a). Another factor at play may be the nutritional status of the alcohol consumer, as better nutrition (usually associated with higher SES) provides more protection against the harmful effects of alcohol (May et al. 2016). The research for this thesis is set in a low SES community with high levels of unemployment as will be explained in section 1.4.

Although societies today frown upon the use of alcohol as payment or partial payment for workers, the phenomenon was not uncommon in ancient societies. Slaves building pyramids in Egypt and Roman soldiers all received daily rations of alcohol (Urban 2017). In South Africa, slaves and workers received partial payment in alcohol in what was known as the 'Dop System' since early colonisation (Cloete 2005 and 2012; Urban 2017). Although none of the participants in this study have received payment or partial payment in the form of alcohol, historically, the 'Dop System' may have played a role in the way participants view alcohol and the use thereof (Cloete 2005).

Men tend to drink more than women and harmful alcohol use is a leading risk factor for death amongst men. However, women seem to be more vulnerable to alcohol related harm when they drink similar amounts of alcohol in similar drinking patterns when compared to those of men. The vulnerability of women is related to their smaller body weight, smaller liver capacity and higher proportion of body fat (WHO, 2014a). In addition, alcohol consumption during pregnancy may cause FASD.

The drinking patterns amongst women vary considerably worldwide (Urban 2017). With economic development and changing gender roles, drinking among women seems to be on the increase (WHO 2014a). Urban (2017) used the Global Report (WHO, 2014b) to compare the drinking patterns of South African women to that of women in Belgium and the USA. More women in South Africa abstain from alcohol, but the women who do drink consume double the amount of alcohol compared to women in Belgium and the USA as illustrated in table 1. Amongst pregnant woman, this pattern of binge drinking is most dangerous to the unborn baby (Urban et al. 2016).

Table 1. Selected drinking data amongst women from three countries

(adapted from Urban 2017; WHO 2014b)

	South Africa	**USA**	**Belgium**
Lifetime abstainers (15 years and older)	55%	17%	9%
Current drinkers (during past 12 months)	26%	63%	80%
Alcohol per capita – drinkers only (litres pure alcohol/ year)	16.0 litres	7.8 litres	7.8 litres

Cloete (2005; 2012; 2015) described alcohol consumption as an occupation amongst the women of childbearing age in the Western Cape. In the Northern Cape, drinking amongst women of childbearing age is equally as prevalent and normalised as the next section on FASD prevalence will demonstrate.

1.3. FASD Prevalence Rates

The Foundation for Alcohol Related Research (FARR) measured the highest reported rates of FASD worldwide in South Africa with 12.2% in De Aar (Urban et al. 2008) and 13% in Bethelsdorp, Port Elizabeth (www.farrsa.org.za 2016). The more recent prevalence rate in the Renosterberg Local Municipality, Pixley Ka Seme District, in the Northern Cape revealed an alarming high rate of 28% (Olivier 2017). The table below compares FASD prevalence rates in South Africa to international rates and the map (Figure 1) depicts the South African study sites (FARR SA 2018). The next section will describe the Pixley Ka Seme District where the highest rates were measured and where the research study is situated.

Table 2. FASD Prevalence rates in South Africa compared internationally (FARR SA 2018).

International FASD rates per country	FASD rate per 1 000	%
USA	10 – 30	1 – 3
Canada	10	1
Croatia	12	1,2
France	18	1,8
Poland	20	2
Italy	25	3,5

FASD rates in South Africa	FASD rate per 1 000	%
Johannesburg	26	2,6
Wellington (1998 – 2002) with USA research team	89,2	8,9
De Aar (2002)	122	12,2
De Aar (2010) 30% decrease due to FARR's interventions	86	8,6
Upington (2003)	74,7	7,4
Aurora (2011)	80 – 130	10
Witzenberg (2013)	25 – 180	9,6
Kimberley (2014)	20 – 110	6,4
Vredenburg/Saldanha (2016)	68,2	6,8
Bethelsdorp, Port Elizabeth (2017)	20 – 270	13
Renosterberg (2017)	282	28

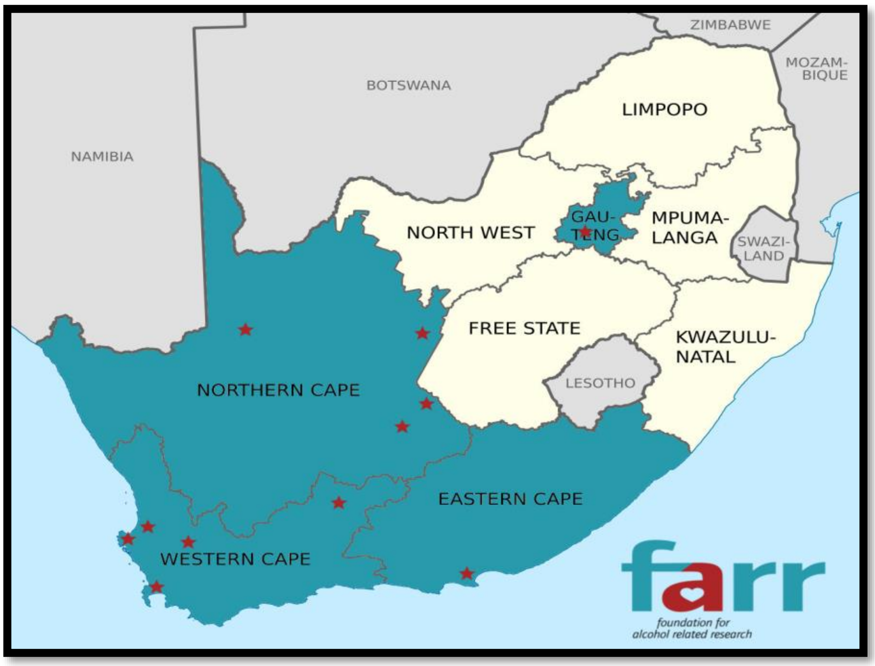


Figure 1. Sites of FASD prevalence studies mentioned in Table 2. (FARR SA 2018).

1.4. Pixley ka Seme District, Northern Cape Province

The Northern Cape geographically covers two fifths of South Africa (372,889km^2), but it is sparsely populated with only 2.2% (1,145,861 people) of the total South African population (Statistics SA 2011). The population density is only 3.1/km^2, the lowest in South Africa. The Orange/Garieb River flows through the province creating the borders with the Free State and Namibia. The Northern Cape is a semi-arid region with low annual rainfall and extreme temperatures (hot summers and icy winters).

Demographically, the population in the Northern Cape (white and red areas on the map below, Figure 2) consists of 50.4% African Black, 40.3% Coloured, 7.7% White and 0.7% other. Language distribution is 53.8% Afrikaans, 33.1% isiTswana, 5.3% isiXhosa, 3.4% English and 1.3% isiSotho. Other indigenous languages include Nama and Khwe. (Statistics SA 2011). Industry is limited to mining, small businesses in towns and to a large extent agriculture, including fruit and wine along the Garieb River, wool and livestock, as well as game and hunting. In recent years, renewable energy has become an industry of note in the Northern Cape.

Figure 2. Map: Pixley Ka Seme District within SA.

The Pixley Ka Seme District (red area in the map in Figure 2 above), one of five districts in the Northern Cape, is named after Pixley Isaka Seme, founder of the ANC in 1912 and quoted in the foreword of this thesis. De Aar, the district capital, has a population of 23,760 (Statistics SA 2011). The population comprises of 17% African Black, 72% Coloured, 1% Indian/Asian and 10% White as illustrated in the graph below, Figure 3. The language distribution includes 86% Afrikaans, 2% English, 9% isiXhosa, and 3% Other as illustrated in Figure 4.

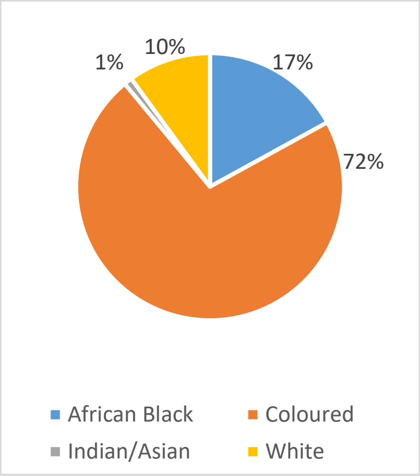


Figure 3. Demography of De Aar

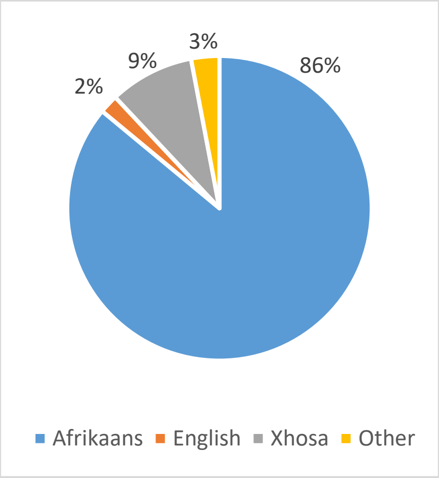


Figure 4. Language distribution De Aar

De Aar is an isolated town, situated halfway between the two major north-south highways, the N1 and N12, which serve to connect Gauteng to Cape Town. Although off the beaten track of major motor highways, it is situated on an important railroad. Historically, the two Friedlander brothers surveyed the farm De Aar and established the town during 1899 to serve the second largest railroad junction in South Africa (www.deaar.co.za). A thriving town grew around the railways and combined with affluent sheep farming in the area, De Aar was a bustling town in the 1950's – early 80's. Many South Africans hold fond memories of a stop-over in De Aar while traveling by rail. However, the national railway company's budget cuts since the 1980's led to a steady decline in employment. Currently, employment is limited to small businesses, especially that around renewable energy, as well as sheep and game farming, with seasonal hunting. Unemployment is as high as 80%, and 70% of the inhabitants live below the poverty line with an illiteracy rate of 20% (Stassen 2012).

The main source of income is from grants including childcare, old age pension and disability grants. Poverty impacts nutrition, and in addition, 68% of mothers in De Aar have mild to severe depression (Olivier 2012). This, combined with poor domestic circumstances, low educational levels and loss of hope, have a devastating impact on issues such as infant-mother bonding, child abuse, domestic violence, poor scholastic performance, delinquency, school dropout, crime and substance abuse. This ultimately culminates in an ever-increasing economic burden on society (Olivier 2012).

A nutritional study of pre-schoolers in South–Africa done by the NFCS (National Food Consumption Survey) found children in the Northern Cape to be more stunted (30%) and under-weight-for-age (24%) than in any other province (Olivier 2012). With the high alcohol consumption in the Northern Cape, these poor anthropometric measurements may be linked to alcohol consumption during pregnancy as well as poor nutrition. The Child Gauge (Delany, Jehoma & Lake 2016) reports that although the Northern Cape has a relatively small child population, child hunger is common. Only in Kwazulu-Natal is child hunger more common than in the Northern Cape.

Renosterberg is a neighbouring municipality which borders with the north of De Aar. The population of 10,978 (Statistics SA 2011) consists of 33% African Black, 57% Coloured, 9% White and 1% Other (Statistics SA 2011), as illustrated in the graph below, Figure 5. Language distribution is 71% Afrikaans, 1.5% English, 24% isiXhosa, 1% Sotho and 2,5% Other. Refer to Figure 6 in this regard.

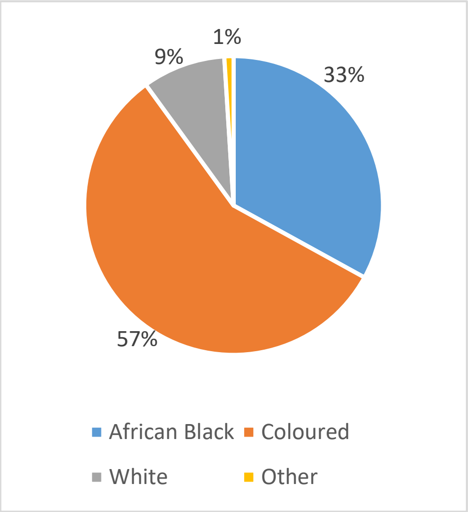


Figure 5. Demography Renosterberg

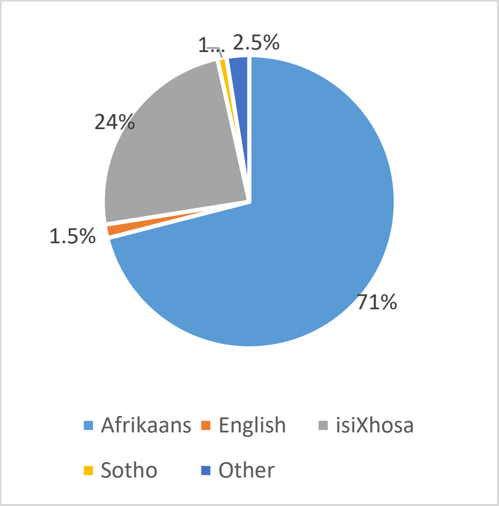


Figure 6. Language distribution Renosterberg

The Renosterberg Local Municipality is comprised of three small and very diverse towns: Philipstown, Petrusville and Vanderkloof, as shown in Figure 7 below. Philipstown is a small town 56km from De Aar with a population of 3,365 serving a farming community in the surrounding arid Karoo. Employment is limited to seasonal work on sheep farms and game hunting during the winter months (Personal communication with local farmer: Battenhausen, F. 2017). Petrusville, 45km from Philipstown, is closer to the Orange River where farms diversify into irrigation farms for crops such as maize, wheat and sunflower seeds. The third town in Renosterberg Local Municipality, Vanderkloof, is situated on the banks of the Vanderkloof Dam. This is the second largest dam in South Africa. The Vanderkloof hydro-electric power station provides limited employment opportunities. The dam is also used for touristic activities which generates some further work oppertunities. However, sheep and irrigation farms continue to provide the bulk of employment.

Figure 7. Map: De Aar and Renosterberg

Some of the highest prevalence rates of FASD have been measured in the Pixley Ka Seme District, with 12,2% in De Aar (2002) and 28% in Renosterberg (2017). However, as the next section will demonstrate, services do not match this challenge.

1.5. Services in Pixley Ka Seme District

In spite of the high prevalence rates in these areas, FASD is not prioritised by the Departments of Health, Education nor Social Development.

In De Aar, three primary health care (PHC) clinics and one day hospital provide primary health care including antenatal care. There is a primary health care clinic in each of the three towns in the Renosterberg Local Municipality: in Petrusville, Philipstown and Keurtjieskloof Clinic in Vanderkloof. These PHC clinics are supported by the District Hospital in De Aar. The De Aar District Hospital has a maternity unit with paediatric wards, as well as male and female wards. This district hospital offers the services of general medical practitioners, a rehabilitation team and limited specialists, including a paediatrician. Although it has recently been upgraded and moved to a modern facility, it does not offer a full complement of specialist services. Patients have to travel for most specialist services, including ginecology and psychiatry, to Kimberley, the provincial capital, which is 350 km away.

Children under the age of seven years with developmental delays, including those suffering with FASD, access health care services via PHC clinics. From here, they may be referred to a dietitian, occupational-, physio- or speech therapists. The therapist will assess the child and prescribe a home program supplemented by monthly or, in some cases, bi-monthly follow-up visits. The Department of Health employs a rehabilitation team, including five occupational therapists, three physiotherapists, one speech therapist, two dietitians (with one nutritional advisor in the Renosterberg region), a clinical psychologist and a paediatrician. This team serves the population of 186 352 people (Statistics SA 2011) over the vast geographical area of the Pixley Ka Seme District. Team members provide a monthly, and occasionally bi-monthly, service at the local clinics. In many cases, travel time for the rehabilitation team to clinics consume as much as half of the work day (Personal communication: Grundling, H.: Principal Dietitian, Pixley Ka Seme District 2018).

In South Africa, children have to attend school from the year they turn seven (SA Schools Act 84 of 1996). The Department of Health will hand treatment of children with developmental delays over to the Department of Education, unless the child has a confirmed medical diagnosis. (Personal communication: Koekemoer, L.: District Manager, Department of Health 2017).

The South African school's policy of inclusive education (Department of Education 2001) requires that children with the kind of deficits associated with FASD be included in mainstream schools. The White Paper 6 calls for the development of District-based Support Teams (DBSTs) to support learners with such deficits in mainstream schools, and aims to achieve inclusive education by 2021. Conversely, the Northern Cape is an under-resourced province with limited services for children with disabilities. In Pixley Ka Seme, the District-based Support Team within the Department of Education is limited to one occupational therapist, two learning support teachers and one social worker based in De Aar (Personal communication: Van Niekerk, M.: occupational therapist 2018).

The Department of Social Development employs community workers to supplement social workers, offering home-based care to clients in need. They encourage children to attend mainstream school and facilitate referrals.

The non-profit organisation, Foundation for Alcohol Related Research (FARR) has worked in De Aar for the prevention of FASD since 2000 and is now considered by the community as a service provider (Personal communication: Olivier, L.: FARR CEO). FARR focuses on raising awareness and prevention of FASD. This is supplemented by training of educators to assist learners with FASD and other learning difficulties in class. Occasionally, schools in De Aar refer learners to FARR for neurodevelopmental assessments by the in-house occupational therapist (the author of this thesis). Following assessment, the occupational therapist makes recommendations to the school and gives a home programme with monthly follow-up visits to the indicated learner and caregiver. However, these services are limited and cannot cover the needs of all learners on the spectrum of fetal alcohol disorders.

FARR and specifically the author, recognises the need to provide a service to people living with FASD and is exploring the most effective ways to support the large numbers of children with FASD to reach optimal life outcomes.

1.6. Rationale

South Africa, specifically the Pixley Ka Seme District in the Northern Cape has the highest reported rates of FASD worldwide (Urban et al. 2008; Olivier 2017). The challenges children with FASD live with affect their engagement in their daily self-care, leisure and productivity occupations (Nash 2012), as well as their occupational performance (Culshaw 2015). Challenges become particularly pronounced at pivotal points in the child's development, such as the adjustment to primary school, subsequently to high school and ultimately the transition into adulthood (Olson, Oti, Gelo & Beck 2009). In her current work context, the researcher has observed that many mothers successfully facilitate the occupational engagement of their children with FASD. The researcher engaged in this study to specifically unpack the ways in which mothers do this. The literature search did not reveal any South African studies exploring how mothers facilitate the occupational engagement of their children with FASD in the South African context. This study will give important insight in understanding mothers' strengths, challenges, needs, and hopes in order to inform the design of realistic, contextual intervention for children with FASD. In addition, describing the occupational engagement of individuals with FASD, from their mothers' perspectives, may enlighten their participation restrictions and how they integrate in society (in the form of social inclusion) in the long run as guided in the ICF (WHO, 2002).

Cloete's (2005; 2012; 2015) work on alcohol consumption as an occupation of women of childbearing age emphasized the significance of alcohol use during pregnancy in South Africa. Her research informed the prevention of FASD in South Africa. This study will augment her work by moving beyond the prevention of FASD into the reality of living with FASD in a rural South African community.

1.7. Problem Statement

Although the Pixley Ka Seme District has some of the highest FASD prevalence rates in the world, public services for individuals with developmental delay such as FASD are limited within the Departments of Health, Education and Social Development. Families with children with FASD face significant challenges, inlcuding but not limited to poverty, malnutrition and depression while raising children with developmental delays in this under-resourced district. Insight into the manner that mothers raise children with FASD in this rural community highlight ways to address some of these challenges. The ways in which mothers encourage occupational engagement, the facilitators that enable them, and the ways in which they overcome barriers form the focus of the study as set out in the following research question.

1.8. Research Aim and Objectives

This study aimed to answer the following research question:

How do mothers facilitate the occupational engagement of their children with FASD in a rural community in South Africa?

The intention of the qualitative study was to describe the ways in which mothers facilitated the occupational engagement of their children with FASD in De Aar and in the Renosterberg Local Municipality area, both within the Pixley Ka Seme District.

The objectives of the study were to:

- describe the ways in which mothers facilitated the engagement of their children with FASD in the occupations of productivity (work and school), leisure (play) and self-care;
- describe the personal, environmental and occupational factors which the mothers expressed as limiting their attempts to facilitate occupational engagement in their children with FASD in the above-mentioned occupations;
- describe the personal, environmental and occupational factors mothers reported as enabling them to facilitate occupational engagement of their children with FASD in the above-mentioned occupations.

1.9. Researcher Positioning

The researcher has worked with FASD since 1995, initially as a primary health care/community occupational therapist treating children with FASD. Currently, she works in De Aar, managing a FASD prevention project. Although her focus has shifted from treatment to FASD prevention, helping those affected, as well as their families, continue to be of interest.

Due to her background as an occupational therapist, the researcher is often called on to attend to the behavioural and learning challenges of children with FASD.

The researcher’s view of humans as occupational beings shapes her belief that positive engagement in occupations can influence health and well-being (Wilcock 2006). In line with this, the researcher has noted that, despite the many challenges they face, many mothers successfully promote the occupational engagement of their children with FASD.

1.10. Purpose of the study

The purpose of this study is to describe how mothers promote the occupational engagement of their children with FASD in their daily childhood occupations. The information generated gives important insight to design contextually relevant interventions for people with FASD in the Pixley Ka Seme District. The ways in which mothers facilitated occupational engagement of their children with FASD, the facilitators that enabled them to do this, and the ways in which they overcame barriers to do this forms the focus of the study.

1.11. Conclusion

This chapter provided the foundation for the study of FASD as a common barrier to occupational engagement. It placed the participants within their geographic context and, in so doing, explained the challenges they faced. The problem, rationale, purpose and research question were also introduced.

The next chapter will provide in-depth information on FASD and its effect on occupational engagement. It will address the theoretical lenses implemented in the research. Chapter three will outline the methods used for the study, followed by chapter four where the findings of the research are recorded. Chapter five interprets these findings and chapter six summarises the study, discussing the limitations of the study and makes recommendations for future research.

Chapter 2: Literature Review

2.1. Introduction

This chapter provides further information on FASD as it influences occupational engagement. It also explores the current focus of FASD research internationally as well as in South Africa. The chapter frames mothering as an occupation aiming to promote the occupational engagement of children. Finally, literature supporting the theoretical lenses drawn on in this study are introduced.

2.2. FASD and the Building Blocks of Occupational Engagement

FASD are a spectrum of birth defects resulting from alcohol exposure in utero. Alcohol may affect any organ in the developing fetus, including the heart, spinal cord, lip and palate, hearing, urinary tract and genitalia (Urban, 2017). However, the primary impact is on brain development (Urban 2017). The teratogenic effect of alcohol on the developing brain may result in poor attention, verbal learning and recall, auditory memory, auditory and verbal processing, abstract reasoning, language difficulties, problem solving and cognitive functioning. In addition, motor skills such as controlled movement, balance and posture may be affected (Kalberg & Buckley 2007; Franklin et al. 2008; Kodituwakku 2009). Lately, sensory processing challenges such as clumsiness, inattention, over- or under-sensitivity to stimuli and emotional reactivity of children with FASD has come to the foreground (Franklin et al. 2008, Densmore 2013; Nash 2012).

The intelligence of children with FASD vary considerably and although IQ scores are generally two standard deviations below the norm, only half of the children with full FAS have an IQ below 70 (Kalberg & Buckley 2007). On a functional level, the most significant neurological impact of prenatal alcohol exposure (PAE) seems to be on executive functioning, the ability to plan and sequence behaviour in order to achieve a goal (Kalberg & Buckley 2007; Kodituwakku 2009; Mattson et al. 2013). According to Nash (2012:19), executive functioning challenges are the "hallmark deficit" of FASD. Children with FASD struggle with complex working memory, problem solving, planning, organising tasks into a logical timeline, concept formation, reasoning and impulse control (Kodituwakku et al. 2009; Mattson et al. 2011).

Executive functioning challenges present cognitively as the difficulty to understand and remember sequences for activities of daily living and the academic process. Most people understand a daily routine and keeping on track requires very little cognitive effort. However, children (and adults) on the spectrum usually need external tools to follow their daily routine. Even the sequence of a simple task, like getting dressed, may become a complicated challenge for children with PAE.

Academic success, in a subject like arithmetic, requires an understanding of the value and sequence of the numbers used. These values and sequences must be held in working memory, a challenge for people with FASD: resulting in poor performance. Abstract reasoning is another challenge and PAE children may only acquire arithmetic skills through participation and incidental learning when abstract concepts are presented concretely. An example of this would include: in a vegetable garden with 5 rows of 5 carrots in each row, there would be a total equalling 25 carrots.

In addition, people with FASD find it difficult to acquire appropriate social behaviour which most children learn through observation and adult guidance (Kalberg & Buckley 2007). They therefore have to learn simple skills, such as how to approach and enter a group of children playing a game, how to take turns, and how to make small talk with a possible new friend. This must be learnt through active learning (Laugerson et al. 2003).

Emotionally, the executive functioning difficulties manifest in poor inhibition which in turn lead to inappropriate speech/actions and overactive behaviour. Children with FASD tend to act out because they lack the ability to control their emotions (Kalberg & Buckley 2007). In fact, Kalberg and Buckley (2007: 281) described impulsiveness or “acting before considering consequences as a hallmark of children with FAS.”

Impaired auditory learning and memory associated with FASD results in poor recall of verbal information and difficulty to follow verbal directions (Kalberg & Buckley 2007).

Symptoms of sensory processing disorders such as clumsiness, inattention, over- or under-sensitivity to stimuli and emotional reactivity have been clinically observed in children with FASD (Jirikowic, Olson, Kartin 2008). Poor sensory modulation (Jirikowic et al. 2008a) may manifest in sensory seeking behaviour such as overactivity and difficulty to calm down in order to concentrate during play or learning activities. Conversely, under-responsiveness to sensory input may also occur (Jirikowic et al. 2008a; Franklin et al. 2008) This can, for example, include not noticing when they are spoken to, being unaware of a disorganised work space, or dropping or losing personal items. In addition, difficulty filtering auditory input may affect their ability to follow an educator verbally in class (Jirikowic et al. 2008a; Franklin et al. 2008).

These studies concluded that the difficulties to modulate sensory information may contribute to behavioural challenges and externalising behaviour often reported by carers of children with FASD (Jirikowic et al. 2008; Franklin et al. 2008). Jirikowic et al. (2008) called for the use of sensory-based accommodations when addressing the behavioural challenges amongst children with PAE. Franklin et al. (2008) expanded by advocating for the empowerment of carers and educators to recognise and address the impact of sensory responses on the behaviour of children with FASD.

2.3. FASD and Occupational Engagement

The impact of PAE upon the ‘building blocks’ of occupational performance, such as intelligence, executive functioning and sensory processing have already been described.

All these symptoms affect the ability to engage in occupations required for development. Jirikowic et al. (2008b) observed significant deficits in the occupational engagement of children with FASD as measured by their adaptive behaviour in activities of daily life, social participation and school performance. They found that children with FASD scored significantly lower than their average developing peers in their social interaction and communication, as well as self-care and community living. In a different article, Jirikowic et al. (2008a) linked the poor adaptive behaviour observed in children with FASD to poor sensory regulation. In contrast, Jirikowic et al. (2008b) reported relative strengths for gross motor, personal self-care and domestic subscales as demonstrated in household chores performed by older children with FASD (teens and young adults). However, they found that younger children required more support with self-help skills such as dressing, toileting and taking meals. This differentiation between children's needs and relative strengths emphasises the importance of addressing functional skills for this sector as challenges emerge across the life span. Considering functional skills from an occupational perspective enables one to analyse the impact of task demands, caregiver expectations, environmental factors on children's performance. Jirikowic et al. (2008b) advocates for early intervention focused on functional skills and recommends that intervention has to include both the child with FASD and the caregivers.

Culshaw (2015) confirmed this deficit in occupational performance in her research exploring predictive factors for occupational performance amongst people with FASD. She described the complex nature of occupational engagement of individuals with FASD using the Canadian Model of Occupational Performance and Engagement (CMOP-E). Although her sample of pre-existing data in the retrospective study was limited, with insufficient data in some domains, she recognised the impact of personal components such as mental health, memory and executive functioning as well as environmental components, with examples such as a living situation and foster care and occupational performance factors such as school completion, employment status and self-care. Interestingly, she noted the positive impact of living with extended family, including parents or partners (as the case was for all participants in this study). Accordring to Culshaw (2015), the extended family had a positive impact on employment and financial security. She emphasised work and social relationships as challenges in occupational performance for this population (Culshaw 2015). These challenges impact participation and social inclusion as described by the ICF when considering FASD from a disability perspective (WHO 2002).

Exploring the deficits associated with FASD from an occupational engagement perspective enriches our understanding of the meaning a person attaches to tasks or activities (Culshaw 2015).

FASD affects not only the child but also the family (Urban 2017) and specifically mothers (Brown et al. 2008) as they facilitate the occupational engagement children require to develop towards relative independence. Brown et al. (2008) described the rewards parents felt as they raised a child with FASD, although their research with self-selected participants may not represent the perspectives of all parents. Parents in their study (Brown et al. 2008) took pride in their children's efforts with challenging tasks. They valued their children's positive attributes such as a sense of humour, perseverance and their ability to look on the bright side of things. Secondly, participants in the Brown et al. (2008) study felt appreciated as parents and described the rewards of parenting a child with FASD as similar to parenting any other child. In contrast to this, little is known about parenting a child with FASD, the way mothers engage with these children in various occupations or how mothers enable these children to engage in occupations in the Pixley Ka Seme District.

2.4. Parenting FASD

Various qualitative studies in the USA, Canada and Europe (including UK) explored the life experiences of people living with FASD, their care givers and service providers. These studies aimed to inform the development of programmes and services (Streissguth et al. 2004; Ryan & Ferguson 2006, Paley & O'Connor, 2009; Kalberg & Buckley 2007; Sanders & Buck 2010; Mukherjee et al., 2013). What follows is an overview of the findings of these studies.

Streissguth et al. (2004) emphasized the importance of a *stable caregiving home environment* to prevent secondary disabilities in people with FASD. Ryan and Ferguson (2006) confirmed the need for stability in their exploration of the person behind the 'face of FASD'. They recommended that competence in the person with FASD will be enhanced by a 'sense of stability and belonging' (Ryan & Ferguson 2006). Paley & O'Connor (2006) found that PAE children coped emotionally better and were more secure in their attachments when their mothers provided *suitable emotional support*.

Children with FASD who had been exposed to traumatic incidents scored lower on classroom and/or learning skills such as attention, memory and language as well as behavioural measures such as oppositional behaviour and social problems (Henry, Sloane & Black-Pond 2007). These findings seem to confirm Streissguth's emphasis on home stability. Similarly, Jacobson et al. (2004) found that a *stimulating home environment* may buffer some of the cognitive challenges associated with FASD.

In Canada, Sanders & Buck (2010) described the experiences of eleven parents raising children with FASD, searching for ways to promote successful family functioning where children with FASD can grow and reach their potential. The challenges participants in their study faced were varied and multi-factorial, with an accumulative effect on parenting. Amongst the themes they identified were conduct-related disorders such as violence and antisocial behaviour. Stress in families was related to externalized behaviour of children with FASD, such as hyperactivity, aggression and destructiveness. Sanders & Buck (2010) recommended that parents adopt self-care practices through community support structures. They did not propose strategies for the management and prevention of secondary disabilities associated with FASD.

Sanders & Buck (2010) continued to describe the disheartening and frustrating effect of cognitive and executive functioning deficits such as short-term memory challenges, organisation, learning, retention, regulation and social awareness. Parents in their study reported feelings of guilt when assuming their children's forgetfulness was purposeful or malicious. Their study lacked recommendations to assist parents. However, another research study by Kalberg & Buckley (2007) has shown effective ways to manage these challenges in cognitive and executive functioning which could assist in empowering caregivers.

Paley & O'Connor (2009) suggested that the IQ of children with FASD was not the main cause of concern for parents. The executive functioning challenges in planning and organizing, the inability to engage in effective problem-solving and the developmental delays in daily life were far more burdensome to parents.

Olson et al. (2009: 237) pleaded for the systematic research of "factors pivotal to family adaptation and developmental outcomes" to inform parenting and family intervention for children with FASD. The research for this dissertation aims to do just that.

Mukherjee et al. (2013) used mixed methods, including focus groups and questionnaires to study the influence of raising children with FASD on caregivers. They recommended training for parents on the needs of children with FASD paralleled with support from governmental departments and non-governmental organisations.

2.5. Research on FASD Intervention

There is a growing international literature on evidence-based interventions with FASD (Petrenko & Alto 2017; Riley et al. 2003; Nash 2012). Before embarking on the search for effective intervention for a person with FASD, one should recognise the variation within individuals with FASD. Rather than following a one size fits all approach, it is important to assess each individual and prioritise within the family the area most critically in need of remediation. Using these proprieties as a guide, one then has to find the most effective approach, implement, re-assess, adapt and move to the next intervention/challenge. This is an ongoing cyclical approach (Paley & O'Connor 2009).

Paley & O'Connor (2009) motivate strongly for educating parents to understand what it is like to live with FASD. They argue that when parents understand FASD, they are better able to support their PAE children in the long run. This approach is in line with the purpose of this study.

Paley & O'Connor (2009) summarise intervention in 1. Teaching strategies; 2. Classroom modifications; 3. Support to teachers; 4. Cognitive and academic skills training; 5. Parent-child interaction therapy; 6. Behavioural consultation; and 7. Adaptive skills training (social- and safety skills).

Petrenko & Alto (2017) analysed twenty-four intervention programmes and compared them in the following fields: Content, target age of child, setting (home/community/school), counsellor, format, frequency and duration as well as outcomes. In their analysis they looked at eight intervention programmes focusing on parent education and training. All eight of these were developed in the USA and Canada.

Only two of the twenty-four intervention strategies discussed in their article came from South Africa and both were implemented by experienced therapists. Cognitive Control Therapy (CCT) focussed on self-regulation and -observation and resulted in improvement in behaviour and adaptive functioning in the classroom. An experienced and trained therapist implemented individual therapy (Riley et al. 2003).

The second South African intervention described is the Literacy and Language Training (LLT) implemented by an experienced speech and language therapist. LLT focussed on language skills, phonological awareness and literacy to improve academic performance for groups of 9 – 10-year olds in the school setting (Adnams et al. 2007). As discussed in chapter one, the community where this study is based has limited resources in terms of therapists.

Petrenko & Alto (2017) concluded that qualitative studies exploring the cultural influences and risk factors associated with each unique country would add valuable knowledge to what is currently known about FASD. In addition, they recommended that intervention should stretch across the lifespan of PAE individuals. This qualitative research followed some of their recommendations, specifically relating to cultural influences and risk factors unique to rural Northern Cape and the impact of FASD across the life span.

A second theme, in the literature on evidence-based interventions, is training parents to manage the challenges that present in children with FASD at home. Such interventions include the Canadian Step-by-step programme (Denys et al. 2011) and American Good Buddies (O'Connor et al. 2012). However, these studies are all based in first world countries as discussed earlier. Little is known about the ways that mothers in the Northern Cape facilitate occupational engagement of their children with FASD in a rural setting. Understanding what mothers are currently doing and what they identify as their needs in relation to facilitating their children's occupational engagement, can inform effective, contextualised, remedial programmes to manage the challenges of children with FASD.

2.6. FASD Research in South Africa

South African research on FASD has focused mainly on quantitative studies describing FASD (Viljoen et al. 2005), it's prevalence (Chersich et al., 2011) and measuring the impact of therapist delivered intervention (Adnams et al. 2007; Riley et al. 2003). The author could find no qualitative research on raising children with FASD in South Africa.

Little is known about how mothers in the Northern Cape facilitate occupational engagement of their children with FASD in a rural setting. Understanding what they are currently doing and what they identify as their needs in relation to facilitating their children's occupational engagement, can inform effective, contextualised intervention.

2.7. Occupation of Mothering

As stated before, FASD does not only affect the person with FASD, but also the mother raising the child with FASD and facilitating the child's occupational engagement. The next section will explore mothering of a child with FASD, followed by a description of mothering as an occupation embedded in co-occupation.

Mothering a child with disability requires unique parenting that asks for "unusual child-care practices" (Bourke-Taylor, Howie & Law 2010: 127). Larson (1998) described the occupation of mothering a child with disability as a paradox. Firstly, she described the paradox within the mother who embraces her child despite the disability, while rejecting the disability to reach a more typical experience of mothering. She found that mothers were torn between the opinions other people held about the child's future and her own hopes for a miracle and progress in her child. This paradox may be aggravated for biological mothers of children with FASD who struggle with feelings of guilt because of the harm they caused.

Larson (1998) emphasised the importance of an optimistic view of possible progress and accepting the disability through this optimistic view. During her clinical work with children with FASD and their care-givers, the author has observed these paradoxes. Caregivers who were able to embrace their child in spite of the challenges that come with FASD and retain a hope for the future are usually agents of change for their children. This role continues well into adulthood as confirmed by Michaud and Temple (2013). The mothers interviewed, indicated that their children with FASD would be reliant on them well into adulthood for family support to participate in their daily occupations.

In a later article, Larson (2000) described the orchestration of mothers when facilitating child-sensitive occupations. She defined orchestration as the dance between mother and child as they engage with each other and create a rhythm of harmonious occupation. According to Larson, (2000) orchestration includes planning, organising, balancing, anticipating, interpreting, forecasting, perspective shifting and meaning making. Like children with severe physical disability, children with FASD may challenge mothers to similar orchestration. It is this dance, in the face of obstacles, that the author observed in some caregivers as they raise their children with PAE, that interested the author and lead to this study.

The dance of the mother creating child-sensitive occupations is also described by Pierce (2009), who identified that mothers have to create a play space with appropriate toys, structure and routine in order to facilitate child-sensitive occupations. She also emphasised the influence of cultural beliefs, norms, financial situation, neighbourhood, family and friends upon the occupation of mothering. This research in the context of a rural, semi-arid, mainly Afrikaans community with high levels of unemployment and poverty in South Africa explores some of these influences.

2.8. The Co-occupation of Mother and Child

The process of facilitating occupation in a child is embedded in co-occupation (Price & Stephenson 2009). Co-occupation implies active engagement from both mother and child while sharing intention and closeness on either a physical or emotional level (Pickens & Pizur-Berenekow 2009). For example, the game a mother plays with her baby as she pretends to gobble up the finger her baby pokes towards her mouth is initiated by the baby (Witcomb 2012). Both the child’s occupation and shared co-occupation with the mother are pivotal to develop the potential of the child with physical or learning challenges such as FASD (Price & Stephenson. 2009).

Witcomb (2012) described mothers’ attachment behaviour with young babies as occupation and she emphasised the active role played by the baby. Through her attachment behaviour, the mother creates a safe environment from which the baby can explore in order to develop motor skills and create symbolic meaning. As mother and child attach, mundane activities such as feeding gain meaning and become co-occupations supporting attachment. When feeding becomes a game for example, of an aircraft landing in the baby’s open mouth, it becomes a meaningful occupation, supporting attachment. Witcomb (2012) warns that insecure or disorganised attachment may be linked to attachment disorder, conduct disorder, ADHD, sensory processing disorder and higher-level cognitive functioning challenges. Many of these symptoms are associated with FASD (Kodituwakku 2009; Jirikowic et al. 2008) and are challenges that mothers of children with FASD face as they facilitate the child's engagement in occupations.

2.9. Theoretical Lenses Informing the Study

The following lenses guided the collection of data and analysis in this study.

2.9.1. Family Systems Approach

Various authors emphasise the importance of a stable home and family life to prevent secondary disability and enhance coping skills in children with FASD (Streissguth et al. 2004; Ryan & Ferguson 2006). From the USA, Olsen et al. (2009) advocates that parents of children with FASD should be trained in parenting practices such as positive behaviour support planning. They advocate that parents should understand the neurological impairment behind the challenging behaviour of children with FASD in order to manage behavioural challenges (Olsen et al. 2009).

The Family systems approach (Olsen et al. 2009) treats not only the person with disability, but offers direct treatment to family members, in order to impact the entire family system. Outcomes are measured for the family as well as the individual with disability aiming to influence not only the individual, but also the family involved. In addition, this approach considers the family culture when planning treatment. Intervention thus aims to alter systems to support families to adapt positively to challenges over time. Olsen et al. (2009) consider the family as the primary agent of change (Olson et al. 2009) for the child with FASD.

The author built on this concept recognising mothers as primary agents of change in the best position to help their children with FASD. In order to empower mothers within this Family Systems Approach, it is important to understand what mothers are currently doing to facilitate children's occupational engagement as well as the variables that mothers consider to be barriers and those that enable them in this process. In addition, the author recognises that treating an individual with FASD in isolation, is less effective than treating the individual within the family context. She supports the shift of focus from the individual to the family as consumer of intervention.

Although FASD may in some cases be an intergenerational problem, previous studies in the Northern Cape have demonstrated that many children with FASD are raised by mothers not affected by prenatal alcohol exposure (PAE) (Urban et al. 2008; Personal communication: Olivier 2017). Once mothers who are not affected by PAE are empowered to be the primary agents of change for their children with FASD, one can learn from their experience to also assist mothers who do live with intergenerational FASD.

2.9.2. The Canadian Model of Occupational Performance and Engagement

The aim of this study is to identify the factors which contribute to and/or hinder the mothers' ability to promote the engagement of their children with FASD in their daily occupations. In line with this focus, the

Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko, Townsend & Craik 2007) was drawn on as another theoretical lens to explore, understand and describe the ways in which mothers facilitate the occupational engagement of their children with FASD. The CMOP-E is an extension of the Canadian Model of Occupational Performance. The inclusion of the construct of '*engagement'* reflects the model's extended view of occupational performance. While occupational performance reflects the person's doing of an occupation, a person's engagement in an occupation reflects the value, importance and satisfaction a person places on their performance in such an occupation (Wong & Fisher, 2015). For the purpose of this study, the construct of engagement shed light on mothers' perspective of their children's occupations and the ways that they (the mothers) enabled these occupations. The CMOP-E is an occupation focused model and grounded on theory originating from social sciences, disability studies, social justice, human ecology and the International Classification of Functioning, Disability, and Health (ICF) (Townsend & Polatajko 2007; Kielhofner, 2008; Christiansen, Baum & Bass-Haugen,2005). It thus allows for consideration of aspects relating to social inclusion and social justice highlighted in the ICF. The extended views of this model allow for person-centered practice, a focus on creating supportive contexts and advancing justice, health and well-being (Polatajko et al. 2007).

Person: The CMOP-E places the person at the core of the model with spirituality at the person's core. Spirituality reflects not just religious beliefs but the core values and beliefs of a person, impacting the decisions they make. The CMOP-E also identifies three performance components: affective (feeling), cognitive (thinking), and physical (doing) which can shape how a person engages in their daily occupations.

Environment: The environment surrounds the person and includes not only the physical environment but also the institutional, cultural, and social environments. The person interacts with the environment through engaging in their daily occupations. Engagement refers to motivation and interest rather than completing an expected activity.

Occupations: Occupations include the domains of self-care, productivity and leisure. It is the engagement in occupation that brings purpose and meaning to life; engagement in occupation affects health and well-being (Townsend 2007). Importantly, occupation is specific to the person, allowing for the nuances, characteristics, and values of the person.

In this study, the CMOP-E allowed for the exploration of variables within the *person, environment* and *occupation* that both promote and/or hinder the mothers' ability to facilitate the engagement of their child in their occupations. The CMOP-E was chosen as it offers the opportunity to explore the relationships between the variables (person, environment and occupation) and how these variables shape occupational engagement. The components identified within each domain guided the analysis of the variables. While the Person-Environment-Occupation Model of Occupational Performance (PEO) (Law 1996) offers exploration of the transactional relationship between person, environment and occupation, the PEO Model emphasizes occupational performance (Wong & Fisher 2015). The value of the CMOP-E for this study lay in the added focus on the construct of occupational engagement. Occupational engagement adds a wider understanding of the emotional and cognitive experience of occupational performance (Wong & Fisher 2015). While occupational performance is the observable outcome of engagement, a person may engage in an occupation without active participation – such as a mother quietly enjoying her child's performance in sport or song. Understanding the varied patterns of engagement of a mother in her child's occupation offered insights into the way that mothers in this study facilitated children's occupational engagement. The CMOP-E recognizes the more nuanced aspects of occupational engagement moving beyond the quality of performance.

The CMOP-E assumes that occupations are influenced by the context adding value to the study of mothers and their children with FASD within a specific context (Wong & Fisher 2015). In addition, the model affirms the researcher's belief in client-centered practice (Polatajko et al. 2007). The model's recognition of spirituality at the core of the person allowed the researcher to explore the mother's values and beliefs and establish whether they influence the values, beliefs and decision of their children (Wong & Fisher 2015). This exploration allowed insight into if and how participants influenced the occupational choices (Dunbar & Roberts 2006; Galvaan 2010, 2014) of their children with FASD. The model also guided the researcher to explore the fit between the person and environment and how the various institutional and cultural factors of the mothers' contexts may facilitate or hinder their ability to facilitate the occupational engagement of their children.

The ICF frames participation as a range from individual to societal participation emphasizing inclusion and equality with aspects such as acceptance and access to resources (Larsson-Lund & Nyman 2017). However, participants in this study did not view their children as disabled. Therefore, the factors they described as resources or hindrances, in the way they facilitate their children's occupational engagement, corresponded with the environment (Larsson-Lund & Nyman 2017) as defined within the CMOP-E.

The author recognizes the limitations of the CMOP-E. These limitations, and the measures taken to overcome them, are presented below. The model is based on western perspectives of individuality, independence and autonomy (Wong & Fisher, 2015). The researcher kept this in mind and listened carefully for aspects of the collective society making reference to theoretical models such as the Kawa model (Lim & Iwama 2006 in Duncan 2006). These aspects are described in the environmental domain of culture. The CMOP-E is limited in the presentation of predetermined domains of occupations and the author was open to explore occupations mentioned by mothers that fell outside the domain of productivity, leisure and self-care.

2.10. Conclusion

The literature on FASD seems to make a conclusive case for parents as primary agents of change for their children (Streissguth et al., 2004; Ryan et al., 2006; O'Conner et al., 2006 and Olson et al., 2000). The challenge is to understand what mothers are currently experiencing as they facilitate the occupational engagement of their children on the spectrum of fetal alcohol disorders in Pixley Ka Seme. The factors that they overcome and facilitators, or bridges, which enable them to promote the occupational engagement of their children with FASD, will guide the recommendations for the design of contextually relevant and person-centred programmes aiming to empower mothers in the Northern Cape.

Chapter three will describe the study approach and design, motivating for the choice of a qualitative description through its strengths and weaknesses relevant to this research. It builds on the background described in chapter one by describing the specific study population and the sample selected for the study. Procedures for recruiting participants, collecting, storing and analysing data, as well as the ethical considerations are discussed.

Chapter 3: Methods

3.1. Introduction

This chapter will describe the methods employed for the research study. To commence the chapter, the assumptions of the researcher linked to her past and current experiences are presented. This orientates the reader to the researcher's viewpoints on the nature of reality and the construction of knowledge. The researcher then motivates the merits of a qualitative approach, and specifically a qualitative descriptive research study design, to answer the research question posed in this study. The process to obtain ethical approval, as well as selecting the research site and sampling is presented. This is followed by a description of the specific methods and tools used to generate and analyse the data. Lastly, the chapter argues that the processes, procedures and integrity with which data was generated secured the trustworthiness of the research process.

3.2. Researcher's Assumptions

This section explains the contribution of the researcher's prior knowledge and skills as occupational therapist, project manager and quantitative research assistant in shaping the current qualitative descriptive study.

3.2.1. Learning as an Occupational Therapist

The researcher has worked with FASD since the 1990's. Reflecting on her identity as a white female in post-apartheid South Africa, it was important to be mindful of the priveliges that the researcher held in terms of race and class in relation to her participants. This positionality was managed and negotiated through continuous debriefing with research supervisors, that allowed the researcher to bracket, firstly, the shift in role from an occupational therapist to that of a researcher. And secondly, how her presence could potentially influence how the participants responded to her. It is acknowledged that where this power did exist, it could not have been irradicated completely. As a primary health care/community occupational therapist in the Southern Cape/Karoo region, she met mothers of children with FASD for the first time in 1995. Although some of these mothers continued to battle with alcoholism, they faithfully brought their children with FASD to the occupational therapy clinics the researcher offered once a month. These mothers took much of what they learnt regarding early childhood stimulation to heart and took pride in their children's development. They taught the researcher, the importance of mothers as primary agents of change, early in her career, anchoring the researcher's point of reference (Elliot 2015).

During the late 90's the researcher started to search the literature on FASD for evidence-based management strategies for learners with FASD. Later (2004 – 2009) as an occupational therapist in Cape Town, she was able to apply and adjust these strategies for the few children with FASD she treated in her private practice. The private practice allowed the time for more intense treatment with fewer children and as the researcher worked closely with educators, and adoptive parents she continued to learn about FASD.

3.2.2 Learning while Managing a FASD Prevention Project

In 2010, the researcher returned to community work when she joined the non-profit organisation, Foundation for Alcohol Related Research (FARR), to work in De Aar. The ethos of FARR is to reduce birth defects caused by alcohol consumption during pregnancy through impactful, direct community interventions, whilst respecting human and child rights and seeking opportunities for research to improve practice.

Currently, the researcher works on a FASD prevention and community empowerment project for FARR in De Aar, Northern Cape. Within this project she plays various roles, including the supervision of a support programme for pregnant women encouraging them towards a healthy pregnancy in the belief that healthy children are the product of a healthy pregnancy. In addition, the project offers the researcher the opportunity to assess children with developmental delay, including FASD, and design home programmes for them and their care givers. In addition, she designs FASD intervention programmes at the FARR Centre. These programmes are implemented by trained community workers under her supervision. This work allowed the researcher to build trusting relationships with mothers of children with FASD who return to her from time to time seeking advice or sharing successes such as the child's progress in school or their achievement in other activities, such as athletics. These past experiences, and relationships that were formed, allowed participants to make an informed decision whether they wanted to join the research process or not when they were invited to participate in the study, thus negotiating the researcher's position of priveledge.

The researcher also runs workshops in the Northern-, Eastern- and Western Cape where she interacts with educators of learners living with FASD. This interaction reinforces her drive to find the best strategies to educate children with FASD.

The researcher's view of humans as occupational beings shapes her belief that positive engagement in occupations can influence health and well-being (Wilcock 2006). The FASD prevention work has taught her to respect mothers of children with FASD recognising that they, too, want the best for their children in spite of their battles with alcohol. The researcher developed tolerance of behaviour she does not always agree with, in order to meet and accept mothers where and as they are (Galvaan 2010). This tolerance enables her, and her team, to empower pregnant women to generate and implement solutions as they engage in alternative occupations (Cloete 2012). In a community with high levels of unemployment, the occupation of mothering is an obvious choice as alternative to the occupation of drinking (Cloete 2012). The researcher assumed mothers to hold the wisdom required to act as agents of change for their children with FASD. This assumption proved to be correct and appeared in glimpses during her interaction with them. She assumed that since mothers engaged with the children in co-occupation and facilitated occupation in their children, they hold knowledge that could contribute to designing effective interventions.

3.2.3. Learning from Previous Research

Prior to this study the researcher assisted in quantitative studies measuring the prevalence of FASD in various communities in the Northern Cape. Not only did the quantitative research emphasise the high prevalence of FASD in the Northern Cape, but counselling mothers upon hearing the diagnosis of their children challenged her to recognise them as agents of change for their children and to find contextually realistic interventions for their children. This research forms part of the search for such interventions.

3.2.4. Emerging in the community

The researcher lives in a small town (7, 000 inhabitants) which forms part of the municipality where the research was conducted, although 60km away. Life in this small town is integrated with people from different race- and income groups interacting freely. Although the researcher lives far enough from participants not to infringe on their privacy, life in the small town offers the researcher much opportunity to reflect on her relationship with clients in her clinical capacity and participants in her research capacity. The researcher has often observed families interacting as they walk past her, while working in her vegetable garden on a Saturday. These families might be on their way to the grave yard, visiting friends on a nearby farm, herding their goats or cattle, collecting kindle for their winter fires, or riding their horses bareback for an afternoon of fun. Observing these families with life conditions very similar to those of the study participants, grounded the researcher in her respect for the quality of life associated with this simple lifestyle. The researcher has often reflected on their enjoyment of chores and the time they spend together, questioning the privileged, busy Western lifestyle where family time together is limited and often involves financial expense. Although the researcher is committed to empowering members of the community and alleviating poverty through job creation, such as growing, drying and selling cancer bush, she also recognises the value of the time these families spend together which may be compromised with the demands of a more affluent lifestyle.

On the other hand, recognising the challenges of their life created a deep empathy for the alcohol consumption that so many of the participants continue to engage in. Such long-term engagement may cloud, rather than clarify, the research process. In order to bring unique findings (as an insider) to the foreground, it is important to acknowledge this subjective lens. An example of such ‘reflexive messiness’ (Elliot 2015: 136) is the comment made in chapter 5 of this thesis, and reads as follows:

> *A contentious aspect in the institutional environment is the high level of unemployment described in chapter one (80% in De Aar), leading to poverty, as 70% of inhabitants in De Aar live below the poverty line (Stassen, 2012). Yet, the flipside of unemployment is that mothers are at home with their children and able to engage in a variety of co-occupations with their children. However, the time unemployed mothers have may not be sufficient to facilitate occupational engagement of children with FASD.*

Debriefing to research supervisors and colleagues became important here to clarify the researcher’s ‘inner and outer voice’ (Elliot 2015: 138). In this way preparing for the research by clarifying the research protocol, by bracketing her own roles, and naming her positionality and privelige contributed to how data collection and reflection during data analysis became the researcher's own journey as her commitment to listen, learn, analyse, and reflect deepened (Elliot 2015).

3.2.5. Becoming a qualitative researcher

Clinical experience as an occupational therapist honed the researcher's ability to cultivate therapeutic reports, laying a sound foundation to engage with research participants (Elliott 2015). As she entered into the new role of qualitative researcher, she extended the 'therapeutic use of self '(Elliot 2015: 133). Nearly ten years' experience in this community with therapeutic groups and individual counselling around sensitive issues, such as drinking during pregnancy, guided the researcher to create a therapeutic space where participants felt safe enough to be honest about their experiences as they raise children with FASD. While the novice researcher had to tune into the ordinary and extraordinary recollected experiences of the participants (Elliot 2015), her previous clinical experience continued as reference point. The transition from clinician to researcher required a move away from the initial agenda of developing impactful, contextual intervention, towards focusing on participants' experiences and understanding (Elliot 2015). Presenting herself as the student wanting to learn from participants became critical in her development as researcher.

Paramount to the data collection during the semi-structured interviews, was the researcher's expressed desire to learn from mothers about the way that they raised their children with FASD. Acknowledging the participants' expertise in this way, shifted the power in the researcher-participant relationship towards participants. The educational aspect of the power dynamic in the researcher-participant relationship was the main consideration for this study. The research did not explore the interplay of race (current or historic) in a community where racial differentiation is becoming blurred in the light of professional people of colour serving the community as managers, doctors, dietitians and so forth; or on the other hand, poor white people living in conditions similar to the participants. The position of privilege that the researcher came from cannot be denied, but was underplayed by participants' familiarity with the researcher.

3.3. Research Approach and Design

This section presents the merits of a qualitative approach, specifically a qualitative descriptive research design, to gain insight into the way mothers facilitate occupational engagement of their children with FASD.

Qualitative description is theoretically embedded in naturalism (Sandelowski 2010). The naturalistic researcher (Lincoln 1988) views reality as multi-layered and socially constructed by a culmination of the wide-ranging experiences of an individual. This view resonated with the researcher in that it allowed her to explore the everyday reality of mothers as they raise children with FASD and facilitate their occupational engagement. The researcher acknowledges participants as persons with their own agency, and research as a process of mutual learning (Lincoln 1988). Her longstanding relationship with mothers of children with FASD both as occupational therapist and as project manager, reinforced this expectation of what she can learn from the study population. During the research process, she kept mutual learning in the foreground and encouraged participants to guide and prioritise topics, in particular during the photo-elicited interviews. The researcher reflected her understanding of contextual meaning and the constructions of other participants and presented these understandings as a wall to bounce off mothers' beliefs and to gain a deeper level of understanding. Moving between the role of teacher and learner helped her to make sense of the world of these mothers. The study intended to generate knowledge "grounded in human experience" (Sandelowski 2004: 1368) of mothers as they facilitate the occupational engagement of children with FASD.

The researcher (also a practitioner) is searching for effective ways to facilitate positive life outcomes amongst people with FASD living in under-resourced, rural communities. She recognises mothers as primary agents of change (Olsen et al. 2009) for their children with FASD. The inquiry used a qualitative descriptive research design to produce a broad description of the way mothers promote the occupational engagement of their children, as well as the meanings they attach to these methods (Sandelowski 2000). Qualitative description is argued to be essential in the search for answers to questions relevant to practitioners (Sandelowski 2000). During the study, the researcher, from time to time, had to set aside her search for effective intervention as a practitioner in a process of bracketing (Dunbar & Roberts 2006) in order to focus on mothers' perspectives. While analysing the data, the researcher became entangled in her clinician role as she drafted an intervention model. It took deep reflection, guided by the objective debriefing of research supervisors, to bracket the clinician's perspective and refocus on participants' perspectives. This shifting between clinician and researcher became part of the messiness of reflexivity (Elliot 2015: 136).

Recognising mothers as primary agents of change (Olson et al. 2009), the study focused on the manner mothers enable their children's occupational engagement as opposed to exploring the occupational engagement of the children themselves. Mothers make a valuable contribution towards the development of their children, however, mothers of children with FASD are often stigmatised (Corrigan et al. 2017). While focussing on marginalised voices of mothers, the study aims to describe rather than predict the manner in which mothers facilitate occupational engagement (Rosenau 1992).

This research is the first of its kind exploring the ways that mothers facilitate occupational engagement of their children with FASD in the Pixley Ka Seme District. In line with the limitations of naturalism, this study lacks finality as the knowledge gained here raised new questions in the way Lincoln (1988) explained that knowledge leads to more knowledge. The questions that arose from this study will be discussed in chapter six.

The second limitation of naturalistic inquiry is that it lacks what Lincoln (1988) refers to as 'elegance' because the search is not merely for evidence, but also counter-evidence. Chapter four sheds light not only on the evidence found, but also describes the counter-evidence and the implications thereof.

The next section describes the research process linked to collecting data.

3.4. Research Process

3.4.1. Study site, population and sampling

The study site is the Pixley Ka Seme District, in the Northern Cape, as described in chapter one. The researcher knows the community well as this is where she has lived and worked since 2010. She intended to generate knowledge to inform the design of interventions that are contextually relevant to people of this district. Her interaction with people here led her to believe that persons raising children with FASD are the best authority on the occupational engagement of their children. For this reason, purposeful sampling was implemented as the sampling strategy (LeComte & Preissle 1993; Stake 2008). Purposeful sampling (LeComte & Preissle 1993; Stake 2008) in qualitative description ensures that the participants chosen enlighten the phenomenon explored in the best possible way (Creswell 2013).

Although FASD is common in the area, few diagnoses are made outside of FARR. In order to find participants raising children with a confirmed diagnosis of FASD in the Pixley Ka Seme District, participants had to be accessed from previous research that FARR conducted in the district. Recruiting individuals outside of these research studies would have resulted in speculating about prenatal alcohol exposure. Another motivation for selecting participants from this population was the trust relationship FARR (and the researcher) had established with them. Thus, research participants were drawn from a population of mothers of children with FASD, living in the district, and identified in previous research. The following table summarises the selection criteria.

Table 3. Selection Criteria

Selection Criteria	
Gender	• Female: The study focused on mothers, as primary caregivers, to fit into the FASD prevention work with pregnant women the researcher is already involved in. These are the women she has observed since 2010 and with whom she has collectively built a relationship. The emphasis was on mothers, although the researcher does not disregard the important role of fathers and the extended family, including grandparents.
Accessibility	• Live in De Aar or Renosterberg, within the Pixley Ka Seme District, in the Northern Cape - as does the researcher. • Participants had to be accessible in terms of their time and proximity to the researcher.
For the interest of the study, participants must:	• Raise a child with FASD as diagnosed by FARR • Show an interest and willingness to join the study • Give informed consent • Express interest to facilitate occupational engagement in their child by participating in previous studies. • Be able to give a cohesive account of their child's development.

Additionally, the researcher wanted to understand the promotion of occupational engagement as seen and understood by various mothers of children with FASD in this context. For this reason, the principle of maximum variation was added to the sampling strategy to maximise participant diversity relevant to the research question (Sandelowski 2000). Maximum variation addressed two sets of elements, namely, that of the child and, secondly, that of the mother.

Olson et al. (2009) described the turning points in the life of a child with FASD as: entry into primary school, the transition from primary to high school and the often-prolonged transition into adulthood. In order to clarify different aspects of facilitating occupational engagement across the life span of children with FASD, the researcher selected mothers with children at these turning points in their life. Mindful of these criteria for maximum variation regarding the child with FASD, mothers who had participated in the following research, were included in the study population:

1. The De Aar FAS prevalence study (Urban et al. 2008): Children who were in grade 1 during 2001 when they were diagnosed, and are at the time of the study young adults (Olson et al. 2009).
2. The universal awareness raising study: 2003 – 2006 (Chersich et al., 2011) in De Aar. Children who were 9 months of age in 2003 or 2006, and are at the time of the study making the transition from primary to high school (Olson et al., 2009).
3. The De Aar FASD prevention programme: 2009 – 2012: This was the start of FASD prevention with pregnant women in De Aar. In spite of decreasing or ceasing alcohol intake, some women gave birth to a child with FASD. These children were diagnosed with FASD at 9 months and are in early primary school (Olson et al 2009).
4. FASD Renosterberg prevalence study (Olivier 2017): Children who were in grade 1 during 2015 when they were diagnosed, and are at the time of the study in early primary school (Olson et al. 2010).

The elements of variation are outlined in the table below:

Table 4. Elements of variation

Age of affected child being raised, include turning points (Olson et al. 2009)	• Early primary school (2nd to 4th grade) • The move from primary to high school (grade 7 or 8) • The prolonged transition into young adulthood (young adults aged 23 years)
Employment status of the mother	• Employed or unemployed
Housing of the family	• Formal or informal housing
Educational level of the mother	• None to Grade 12 (No-one in the study population had higher education)
Relationship to the child	• Foster/biological mother
Marital status of mother	• Single/married/cohabitating

The diagram below gives a visual overview of the process of sample selection which started with purposive sampling, then implemented maximum variation for the children and lastly followed maximum variation criteria for the mothers.

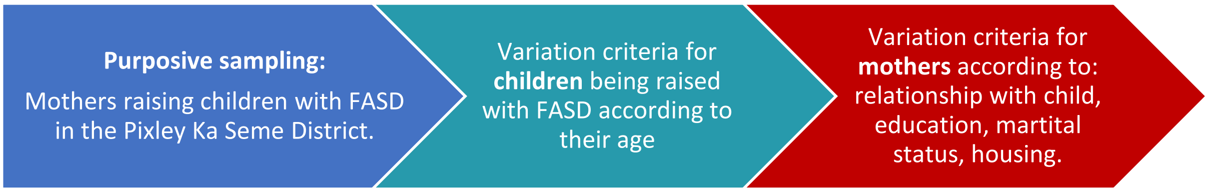


Figure 8. Process of sample selection

3.4.2. Obtaining stakeholder and ethical approval

Initial approval for this research was granted by FARR for: (a) the researcher as an employee to embark on the study, and (b) access to participants from previous research done within FARR (Addendum A: Letter of Approval). The participants were all familiar to the researcher who has offered some therapeutic service to participants of all the previous studies. The researcher adhered to all ethical considerations to ensure that the confidentiality and anonymity of the participants was not compromised. The participants engagement in previous studies also assured them that these aspects would be respected. Next, ethical approval was sought and granted from UCT, Department of Health and Rehabilitation Science and UCT's Health and Science Ethics Committee (Addendum B: Ethical Approval). Finally, approval was gained from participants via community workers acting as gate keepers (Creswell & Poth 2017). This process will be addressed in the following section.

3.4.3. Recruitment

Once ethical approval was granted by the Faculty of Health Science and Human Research Ethics Committee at the University of Cape Town, recruitment followed the process below:

- The researcher called on community workers in FARR, who are familiar with the study population, to recruit mothers to participate in the study. She met with two community workers in their respective towns, and provided them with all the necessary information regarding the study and the recruitment process. In their current work for FARR, the community workers are familiar with the process of recruitment and gaining informed consent. Acting as gate keepers (Creswell & Poth 2017) they identified mothers meeting the selection criteria, invited them to join the study and obtained their verbal consent. Power dynamics between the community workers and researcher (who is also the supervisor of one of the community workers) is avoided, as community workers have access to a counsellor/human resource manager to address issues that may arise with the researcher. FARR gave written permission for this study and community workers recruited participants as part of their daily work.
- FARR community workers recruited mothers incrementally who are already known to them from previous work.
- Community Workers emphasised that participants' choice whether or not to participate in the research would not affect their access to services by FARR in any way.

- All the participants were clients of FARR and well known to the Community Workers. FARR clients have open access to the FARR Centre where the researcher met with participants. Access to the FARR Centre includes visits for anything from support during pregnancy, support with their children, counselling, training, participation in community awareness programmes, a meal when they need it, or merely a cup of tea or quick chat as clients walk past on their way to town. FARR clients are used to freedom of choice to join programmes that FARR offer. In some cases, a client may verbally accept an invitation to join a FARR programme, but then not show up for the agreed appointment, without affecting future opportunities to access services offered by FARR. This open access to the FARR Centre and service balanced any possible position of power the researcher may have held over participants who have consulted her before. Recruits had freedom to refuse participation even if only by not showing for arranged appointments, but all recruits chose to participate in the study and did attend appointments. One participant from Renosterberg could not make her initial appointment and sent a message asking to reschedule her appointment.
- Community Workers introduced participants that indicated an interest in joining the study to the researcher.

Introducing Participants

Community workers, acting as gatekeepers, recruited nine participants to the study. A tenth participant did not meet the criteria, and, although she met the researcher, no interview was conducted with her. She had fostered a 15-year old boy since his mother passed away. On her request, the Department of Social Development placed her foster child in the care of his biological father. This occurred shortly before she met the researcher. Although the participant was very familiar with the child and still had regular contact with the child, she did not meet the criteria for raising a child with FASD and was excluded from the research. Thus, all the data gathered from all nine participants were included (Green et al. 2007) in the research.

Participant 1

Magret (39) is the biological mother of two children with FAS. She lives with her own mother and four children in a brick house in a residential area of De Aar, close to the FARR Centre. She has a long standing and stable relationship with the father of her children, although they do not live together. She takes on piecemeal jobs of cleaning or doing laundry in her neighbourhood.

Magret was one of the first clients in FARR's focussed FASD prevention programme with pregnant women in De Aar during 2009. When she joined the programme, she was already 16 weeks pregnant and a harmful drinker. Although she tried to cut down on her alcohol consumption, she was unable to stop drinking. Her baby daughter, Joe, was born in the middle of 2009 and diagnosed with FAS during a nine-month assessment clinic by a paediatrician/geneticist.

At the time of her pregnancy Magret already had four other children and requested a sterilisation when Joe was born via caesarean section. Unbeknown to her, through a misunderstanding at the hospital, she was not sterilised. A year later, she was pregnant again. Being under the impression that she was sterilised, she only realised that she was pregnant during the final trimester. She immediately sought support from FARR's prevention programme. Her son was born at the end of 2010 and also diagnosed with FAS at 9 months.

Magret tried to help her daughter, and later her son by participating in an early childhood stimulation programme offered by the researcher at the time. Stimulation groups were offered once a quarter in the first year of life and once a semester during the second and third years of life. Magret attended these groups with mothers and babies born in the same quarter as Joe. During this time, the researcher came to know Magret and her children well, although they had less contact after her son's third birthday.

During 2017 Magret had her drinking under control and fell pregnant for a final time. Her youngest daughter was born at the end of 2017 and Magret was sterilised. At nine months of age this daughter was declared healthy, without any trace of FASD by the paediatrician/geneticist.

Participant 2

Like Magret and Joe, the researcher has known Clavina and her mother since 2010 when they participated in the early childhood stimulation programme described above. This was a follow up of the focussed FASD-prevention programme her mother joined at 20 weeks gestation. At the time Clavina's mother was alcohol-dependant and never conquered her drinking habit. During this time, Clavina and her sister (now 12 years old) lived with their mother in a shack behind Doreen's brick house. Doreen's brother fathered both children before his death. In 2017, Clavina's mother also passed away asking Doreen to care for her children after her death. Doreen participated in the research study as the foster mother of Clavina, a child with FASD, whom she has known since birth. Doreen (46) is unemployed and lives in a brick house in a residential area in De Aar with the father of her own children, two children of her own and the two foster children. The Department of Social Development has not yet formalised this fostering arrangement and Doreen only receives the childcare grant and not yet a foster-care grant. The researcher facilitated this process after the first interview and by the time of writing this, Doreen should be receiving the foster-care grant for the children she fosters. Doreen welcomed the opportunity to discuss her experience of raising a foster child with FASD and did not seem to be bothered by the differences between herself and the researcher, such as that of education. She spoke with confidence and authenticity and provided detailed, yet at times, disjointed information.

Participant 3

The researcher met Marie through the community worker who recruited her for the study. Marie (59) is a widow whose 23-year old biological daughter Filida was diagnosed with FAS during the 2001 FAS prevalence study while she was in grade 1.

Marie used alcohol to cope with domestic violence before Filida's birth. She stopped drinking after Filida was born prematurely and struggled to survive. School was difficult for Filida, and after she failed a couple of years, she finally gave up after grade 4. Since leaving school Filida has stayed home with her mother, two older sisters and their children. She plays an active role in housekeeping and cooking and gave birth to a daughter of her own in 2017. She lived for three months on a farm with the father of her baby but returned home when she was pregnant. Filida participated in FARR's prevention programme during her pregnancy and did not drink alcohol.

Marie has retired and lives in a brick house close to the FARR community centre in De Aar. The household income is from childcare grants.

Participant 4

Sylvie (36) fosters her nephew André, placed in her care by the Department of Social Development because of his mother's alcohol dependency. André, while in grade 1, was diagnosed with FASD during the Renosterberg prevalence study in 2016. When the community worker who recruited her introduced her to the researcher, Sylvie questioned the need to participate. Although she gave consent for the prevalence study, she was now concerned about the stigma that only '*dom' (stupid)* children were seen by FARR. The purpose and requirements of the current research was discussed with her and she decided to participate. At the end of the second interview she expressed her gratitude for the opportunity to talk about her son:

Ek laaik rerig vir [van] hom te praat.

I really enjoy talking about him.

Sylvie stays with her mother, another sister and 5 children in a brickhouse on a large plot in the historical part of town in the Renosterberg area. She has two children of her own. The household income consists of childcare and old age grants.

Participant 5

Sophie's biological daughter, Anna, was diagnosed with FAS during 2001 when she was in grade 1 and part of the FAS prevalence study in De Aar. She lives with her adult daughter and son in a shanty on an open field close to her family, where she had to move after the death of her brother when she was forced to leave the family home. Sophie (56) returned from Cape Town five years ago, where she was employed as a domestic worker, to retire. She continues to drink alcohol when she can afford it, or when alcohol is offered to her, and at times she also drinks with her daughter. All three members of the household do occasional domestic or gardening work for a limited income and occasionally receive financial support from family members.

Participant 6

At the start of the study, the community worker over-recruited clients from the 2009/2010 FASD prevention programme because she was concerned that participants would withdraw from the study. When Zelda chose to join the study and met the criteria, the researcher did not turn her away.

Zelda (29) joined the FASD prevention programme in the last trimester of her pregnancy during 2010 while she was alcohol-dependant. Her son, Nathan was born towards the end of 2010 and diagnosed with FAS at 9 months. Zelda has battled with her alcohol addiction ever since, although there was a period of four years when she abstained and was healthy. During this time, she was married to an older man whom she nursed when he became ill. Since the death of her husband, Zelda returned to a pattern of occasional drinking.

She moved back to her mother’s home where she lives in a neat tin Wendy house in the back yard. Her three children, ages 17, 12 and 9, live with her and sleep either in the main house with the grandmother or with their mother in the Wendy house. Zelda receives a childcare grant for all three children. Zelda’s mother is actively involved with her children. Like Magret and Clavina’s mother, the researcher met Zelda in the early childhood stimulation groups 2010-2013, although she did not attend regularly.

Participant 7

The author first met Vikki (37) in 2016 during a counselling session when she gave feedback to mothers whose children were diagnosed with FASD in the Renosterberg prevalence study. The author counselled her when disclosing that her daughter Princess (now 11 years) was diagnosed with FASD. Vikki was a social drinker during her pregnancy and was unaware that casual drinking could harm her unborn baby.

Vikki was the only participant with full time employment in the study. She works shifts at a small grocery store. Apart from Princess, she has two older daughters (ages 18 and 13) and the family lives in an RDP house on the edge of town, overlooking the veld. Vikki’s adult niece and her new born baby also live with the family.

Princess repeated grade 1 and participated in the FASD prevalence study during her second year of grade 1. She is now in grade 3.

Participant 8

The gatekeeper/community worker introduced Lya (46) to the author at the FARR Centre. Lya is the biological mother of twelve-year old Rico who was diagnosed with FAS as a baby in 2006. At the time Lya was alcohol-dependant and has never overcome her drinking habit. She lives with Rico, his older brother, their father and two dogs in an RDP house in one of the residential areas of De Aar. Rico's father works three days a week as a gardener and Lya is unemployed. The household income is supplemented by childcare grants. She expressed her concern about her son's occupational engagement in games of chance (blikkie-blikkie), sniffing glue and the fact that he has dropped out of school.

Participant 9

Maryna is a mother of three daughters and a son between the ages of three and seventeen years. Apart from her own children, she fosters 14-year old Ali (diagnosed with FAS in 2006) and her older sister. Both Ali's parents died and she has been in Maryna's care since she started school. The gate keeper/community worker introduced the author to Maryna at her home one morning during the data gathering process of this research study. The family lives in a brick house in a residential area of De Aar and Maryna is a full-time mother to her children. She is married and her husband works at a local business in town.

3.4.4. Data collection methods and tools

Following recruitment, the researcher met with the participants who expressed an interest in participating in the study. All the participants recruited for the study voluntarily attended the meeting. She revisited the details of the study with each of them, encouraging them to ask questions and then gained their informed consent (Refer to Addenda C and D). Once informed consent was obtained, interviews were scheduled at a time convenient for each participant, such as after work for those participants with employment. Interviews were conducted in a private and comfortable lounge in the FARR Community Centre either in De Aar or in the Renosterberg Centre. The FARR Community Centre is well known to the participants. FARR offered transport to the Centre and back home again, but most participants chose to walk.

The researcher met the participant, built rapport over a cup of tea or coffee and again explained the purpose of the study, reiterating that the participants had the right to withdraw at any time. The researcher presented herself to the participants as a student. She explained that her engagement in the research was motivated by her desire to learn from participants who she considered to have expert knowledge in raising their children with FASD. This was done to shift the balance in the research-subject dynamic which often places the researcher in a position of power in relation to the participant (Elliot 2015).

At the end of the first semi-structured interview, the researcher explained in detail how photographs would be used in the following interview. Participants were offered the use of a borrowed digital cell phone camera by the researcher, but all participants preferred to use the cameras on their own cell phones (McCoy et al.

2014). However, after this arrangement some of the participants asked the gate keeper who had recruited them to assist in taking photographs. Participants brought these photos or photos they already had to the second, photo-elicited interview (PEI). The photos were used as prompts to encourage them to reflect on and describe how they facilitated their child's engagement in occupations, as well as the specific hindrances and facilitators they had to overcome to allow them to do so (McCoy et al. 2014; Mitchell 2008). Assent for the pictures taken was obtained from the children involved. (Addenda E and F).

Audio recordings of the interviews were transcribed within 3 days of the interview by the researcher. Transcriptions were confirmed by the researcher who listened to the audio recording while reading through the transcription. The researcher met with the participant again once the interview was transcribed. This interview followed a semi-structured approach with the aim to both confirm the data generated in the previous interview and allowed the researcher to ask further questions. In addition, this interview allowed participants to talk about the photographs they brought to the PEI. Using analysis of all interviews ensured data saturation was achieved.

3.4.4.1. Semi-Structured Interviews

The primary source of data collection was semi-structured, separate interviews (45-60 minutes duration) with each participant. An interview allows the researcher to gain understanding of people's experiences and the meaning they make of these experiences (Dunbar & Roberts 2006). A semi-structured interview guided the researcher with specific pointers to discuss (Rubin & Rubin 2012), although not every participant was asked the same questions in the same way (Holloway, 2010). A limited number of questions were prepared in advance (Rubin & Rubin 2012). Semi-structured interviews allowed participants to tell their stories and reflect on how they facilitate the occupational engagement of their children with FASD. Questions and probes were used to determine what factors facilitate or hinder their ability to do this.

Interviews commenced with demographic information, for example, age of participant, age of child and the child's school, in order put the participants at ease (Poole, Willer & Mendelson 2009). The researcher proceeded to ask the mother to describe a day with her child. This was done to unpack the nature of the child's occupational engagement (what, with whom, where, when) and to explore the additional demands on the family including stressors and daily challenges. Participants were encouraged to talk about the child with FASD and prompted to describe his/her friends (Watson et al. 2013), how the child spends his/her time, ways in which the participant perceives the child with FASD as different from other children, and to describe behavioural- or learning difficulties they find challenging to deal with. Prompts allowed continued exploration into the details of the structure and routine relating to participants' mothering role (Watson et al. 2013). This line of questioning prompted the mother to describe the things that are special about the indicated child and what she enjoys about the child. The aim was to find the strengths/positive aspects of the child with FASD (Olson et al. 2009). The researcher asked about support structures, trying to identify resources and coping strategies (Watson et al. 2013; Olsen et al. 2009), as well as the skills participants think would empower them in facilitating occupational engagement in their child.

Interviews were conducted in Afrikaans, the mother tongue of all the participants and the researcher. Afrikaans is the primary language in De Aar and Renosterberg area. Once transcribed and analysed, the researcher translated the main themes with the quotes illustrating them in English. Observations made during the interviews were recorded as field notes (in English) and added to the transcriptions. Interview observations included hesitations, confidence in answering questions, tone of voice and shared experience of participant and researcher were noted (Green et al. 2007). Please refer to Addendum G: Semi-structured interview guidelines in this regard.

Most participants were familiar with the researcher even if they had no direct contact with her. This prior familiarity added to participants' ability to give or decline informed consent as they knew who they were meeting. Although participants had not directly consulted with the researcher since she embarked on the study, they trusted her sufficiently to join the research and to come to the FARR Centre for the interview. This relationship added to the quality of the interview (Rubin & Rubin, cited in Galvaan 2010) and guided the format and flow of the interview (Christensen & James, 2017). In this way the researcher's prior knowledge, such as that Magret's last born child (now 16 months old) had no signs of FASD and the positive conversation about her ability to abstain from alcohol during that pregnancy, set the tone for their interview.

The semi-structured nature of the interviews allowed the researcher to use prompts to productively inquire (Argyris, 1999) and explore the assumptions informing their action. For example, Zelda described her son as busy and the productive inquiry revealed busy to include distractibility, hyperactivity and playfulness.

Pierce, (2003) advises the interviewer to be flexible and to include questions as ideas emerge during the interview, with examples including exploring how the baking of bread with Marie revealed how she taught her adult daughter to read time and recognise monetary value. This required the researcher to explore thoughts in a flexible, interactive and continuous manner (Rubin & Rubin 1995 cited in Galvaan 2010).

The researcher had to carefully navigate her position as "expert" familiar to participants due to previous interactions such as facilitating early childhood development groups that some of the mothers participated in from 2010 – 2012. She placed great emphasis on participants' "expert" knowledge as the mothers who know their children better than anyone else. In this way, the researcher encouraged participants to engage with her as experts in their own right, while maintaining the alliance they developed over the years. The photos mothers brought to the PEI empowered the participants with the agency to prioritise the topics of discussion. Thus, the researcher's prior contributions became of secondary importance.

Lastly, the researcher's history with the pregnant women and mothers, allowed her the sensitivity to carefully observe, listen and interpret the participants view of themselves and the issues they face (Green et al. 2007).

3.4.4.2 Photo-Elicitation Interviews

The researcher sought participatory ways of data collection to promote agency of the participants (Graue & Walsh 1998 cited in Galvaan 2010). She is well known to this study population and her past role, as an expert, had to be underplayed in participatory data gathering methods. Photo-elicitation is such a strategy, promoting participation and advocacy while gathering data (Mitchell et al. 2005). Before embarking on this inquiry, the researcher had observed mothers using their digital cameras on cell-phones to capture memorable moments during their participation in FARR's programmes. This observation opened the possibility of using photo-elicitation. Qualitative research is concerned with content and context of photographs. Participants can describe and read their photographs in order to tell the story in photo-elicitation.

Pierce, (2005) emphasised the benefit of visual images to study a topic as complex as occupation. Such visual research places participants in their own context, and generates a deepened engagement with the social world of the participants (Halford & Knowles 2005). Visual images, such as photographs, allow insight into the personal-social and space dimensions, adding powerful images to the time dimension exposed in participants' stories (Clandinin, 2006).

Visual images allow for fuller description of experiences when compared to exclusively verbal interviews (Mitchell 2008). These descriptions include both the physical and emotional experiences. Messages communicated by visual images influence both viewer and those captured by the image. In this way, visual images offer marginalised groups a voice to advocate for appropriate policies or services (Ewald 2005; Wang et al. 2004).

Photo-elicited conversation encourages participants to take the lead in the inquiry, share their views, perspectives and experiences and make full use of their expertise in raising children with FASD (Mitchell 2008). In this study, PEI allowed the researcher and participant to explore the photographs together while participants had the agency to decide what is worth remembering and discussing (Wang et al. 2004). Reading the photographs involved the participant in the analysis and interpretation by critically reflecting on the intent and meaning of messages.

PEI proved useful in this study as the visual image became a door to engage with participants on a deeper level while discussing their children with FASD. In addition, as a participatory data gathering method, PEI respected the diversity and complexity of the way mothers facilitate occupational engagement, while attempting to understand the phenomenon (McCoy et al. 2014).

The semi-structured interviews described in the section before were therefore followed by a second interview where self-generated photographs provided prompts in the PEI visual methodology. Mothers were asked to bring pictures of their children engaging in occupations in and around the home as well as in other contexts. At the end of the first interview, the researcher offered them the use of a digital cell phone camera. However, all participants opted to use the cameras on their own cell phones (McCoy et al. 2014). After this arrangement some of the participants asked the community worker, who had recruited them, to assist in taking photos. Participants brought the requested photos to the second PEI. These were then used as prompts to reflect how they facilitated their child's engagement in occupations, and the specific barriers and facilitators they had to overcome to allow them to do so (McCoy et al. 2014; Mitchell 2008). The PEI also allowed for continuity between the first and second interviews as it offered a tangible reminder of discussion conducted in the previous interview and facilitated a "full flow" of conversation (Mitchell 2008: 369).

Ethically, photo-voice may lead to challenges such as considering ownership of photographs taken (De Lange, Mitchell & Stuart 2007). For the purpose of this study, photographs were used to elicit discussion during data gathering interviews. During the PEI, participants consensually selected a few of their images to be used in the illustration of themes in the thesis. Although the pictures mothers selected were valuable illustrations of occupations the children engaged in, the children could easily be identified in all the pictures. In the light of the stigma associated with FASD, the researcher refrained from publishing these pictures in the thesis with the exception of one picture as an example. The participants were in agreement with this decision. Care was taken to protect the identity of participants in this image. Thus, the generation of data was shaped by the need to promote agency of the participants who are the real experts at raising children with FASD.

The process of gathering data is visually illustrated below in Figure 9.

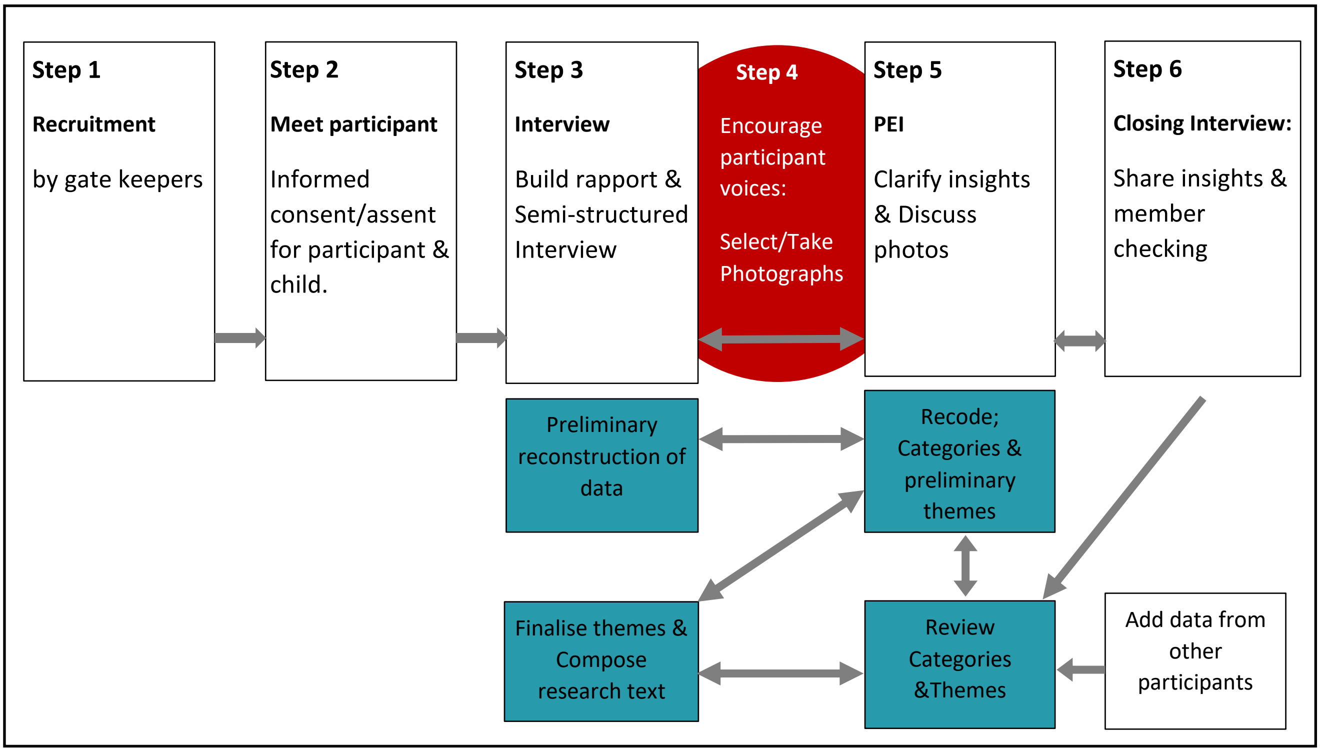


Figure 9. Process of gathering data

3.5. Data Management

Audio recordings and transcriptions were stored on a password protected computer in the researcher's locked office and were deleted from the audio-recorder once downloaded. Transcribed data and audio recording files only contained a study number to connect different sets of data from the same participant. Research participants selected pseudonyms for themselves, and their children, and these were used when writing about them.

3.6. Data Analysis

The next section will describe the process of analysing data in order to give the reader insight into the process of interpreting the data (Green et al. 2007). It also explains how the themes are anchored in both the data and theory.

The data generated during the research was analysed using an inductive approach. Raw data was reviewed using thematic analysis to identify and report themes based on what emerged from the data. This form of analysis aligns with the research question which aims to describe the manner in which the mothers facilitate the occupational engagement of their children with FASD (Creswell 2013).

The next section accounts for the steps of thematic analysis followed throughout the data analysis process: familiarisation of data, generation of initial codes, identifying mutually exclusive and inclusive categories, discovering themes, reviewing, defining and naming themes.

Step 1. Familiarisation: The researcher conducted the interviews, transcribed the raw data and analysed the data sets. Her involvement in these steps was undertaken to ensure a deep familiarity with the data (Green et al. 2007). Familiarisation continued as she immersed herself in the data by listening to audio recordings several times, as well as reading and re-reading the interview transcriptions with and without listening to the audio recordings. In this manner, meaning was constructed whilst mentally noting possible interpretations. The researcher's familiarity with the participants and their culture laid the foundation for accurate meaning fields (Ewald & Lightfoot 2001). Through the immersion in the data, the researcher gained a deeper understanding of the data collected. She considered the interview in its entirety before analysis of parts to generate codes.

Step 2. Generation of codes: The researcher re-read the transcripts in order to generate preliminary codes. The preliminary codes were embedded in the context of statements, and not mere labels for segments of data (Green et al. 2007; Ewald & Lightfoot 2001). Field notes made through observations during the interviews (Creswell 2013) were added to the transcriptions, making deductions from the timing, tone and gestures observed during the interviews (Ewald & Lightfoot, 2001). Following analyses of several segments, colleagues provided peer debriefing to ensure awareness into researcher bias. Preliminary reconstruction of the first interview was checked with participants during the second PEI as form of member checking (Ewald & Lightfoot 2001).

Based on the familiarisation, preliminary codes and field notes, the researcher then started to formulate codes for the descriptions the participants provided about the ways in which they facilitate the occupational engagement of their children. These codes were considered in relation to the research question, aim and objectives, as well as the literature reviewed (Creswell 2013). In some instances, initial transcripts were re-coded. In this way, coding involved a circular moving between transcripts and codes. This circular process allowed the researcher to gain deeper insight and understanding (Green et al. 2007).

Step 1 and 2 were done following each interview and not left until all data had been gathered (Green et al. 2007). Subsequent interviews added information, and as new codes were added, the meaning of codes were refined and previous codes revisited to verify whether those codes still applied in the light of new information. As interviews were added and coded, previous transcripts and codes were reviewed and, in some instances, recoded (Green et al. 2007), keeping the research question and objectives in the foreground (Green et al. 2007; Sandelowski 2000).

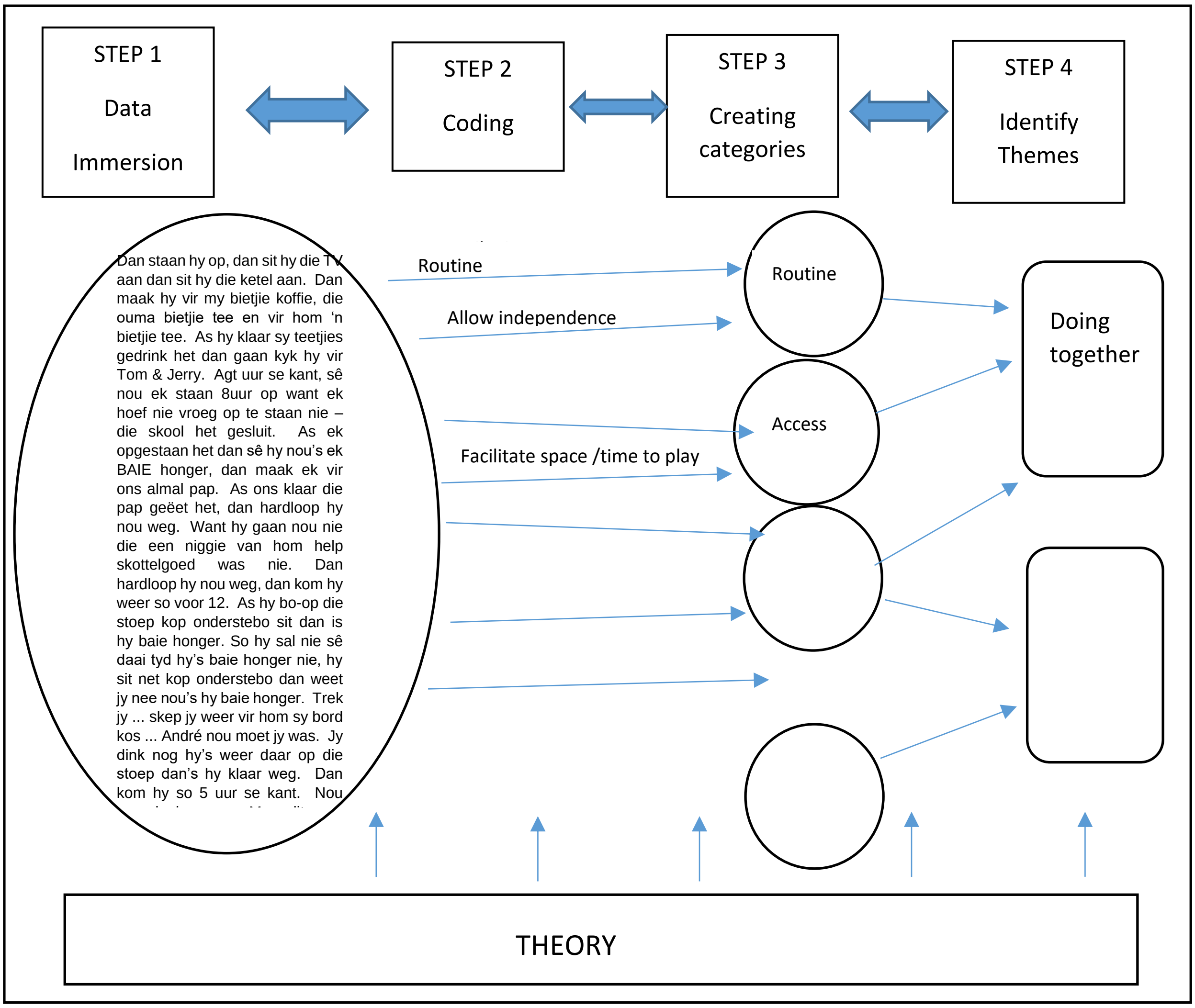
Moving back and forth in the analysis allowed the researcher to test the fit of codes as new data was integrated into the analysis, as well as to follow up on emerging ideas and build in new questions during the research. This ensured that there were no missed opportunities once interviews were completed (Green et al., 2007). The second, photo-elicited interview provided the opportunity to follow up on such emerging ideas, including the way Vikki facilitated her daughter's knitting.

Step 3. Identifying mutually exclusive and inclusive categories: Once the codes were generated, the researcher grouped these in various categories and subcategories with colour codes, which later lead to the generation of themes (Creswell 2013). Where suitable, categories were given a descriptive label using direct quotes from interviews (Watson et al 2013). Saturation was reached when no new categories emerged and mothers' experiences became coherent and explicable within the framework that emerged (Green et al. 2007).

Step 4. Discovering themes: Finally, the researcher interpreted the colour coded categories (with reference to the line in the transcription the code was taken from), searching for explanations and themes (Green et al. 2007). Again, there was a moving back and forth between the transcripts, codes, categories and themes. Transcriptions were revisited several times in order to ensure that data was placed in the appropriate themes.

Step 5. Reviewing, defining and naming themes: Themes were tested against the data and theory, linking the results of the interview with what is known about occupational engagement, FASD and raising children with FASD. Data was coded and recoded with refined codes until saturation of themes was reached. Once data saturation was reached, recruitment of study participants ceased.

Figure 10 is adapted from Green et al. (2007) and illustrates this process of analysing data.



Dan staan hy op, dan sit hy die TV aan dan sit hy die ketel aan. Dan maak hy vir my bietjie koffie, die ouma bietjie tee en vir hom 'n bietjie tee. As hy klaar sy teetjies gedrink het dan gaan kyk hy vir Tom & Jerry. Agt uur se kant, sê nou ek staan 8uur op want ek hoef nie vroeg op te staan nie – die skool het gesluit. As ek opgestaan het dan sê hy nou's ek BAIE honger, dan maak ek vir ons almal pap. As ons klaar die pap geëet het, dan hardloop hy nou weg. Want hy gaan nou nie die een niggie van hom help skottelgoed was nie. Dan hardloop hy nou weg, dan kom hy weer so voor 12. As hy bo-op die stoep kop onderstebo sit dan is hy baie honger. So hy sal nie sê daai tyd hy's baie honger nie, hy sit net kop onderstebo dan weet jy nee nou's hy baie honger. Trek jy ... skep jy weer vir hom sy bord kos ... André nou moet jy was. Jy dink nog hy's weer daar op die stoep dan's hy klaar weg. Dan kom hy so 5 uur se kant. Nou

Figure 10. Process of data analysis (based on Green et al. 2007)

3.7. Data Gathering within Qualitative Description

The researcher in qualitative description forms an integral part of the research process and needs to investigate not only the experiences of the participants but also that of the researcher, as well as their co-constructed experience/story (Clandinin 2006). The journey of the researcher thus becomes part of the research (Elliot 2015). The stories are explored on three dimensions, being time (the continuum between present and past), space (place) and personal-social (Clandinin 2006). The dimensions are recorded in field notes, but at some stage the researcher leaves the field and field notes to process the inquiry and start composing the research text. Although there is a flow between the field - and research text, tension may develop as the researcher moves from the close relationship with participants to a more objective view while creating the research text for a more objective, detached audience.

This move between the field and text is illustrated by the following reflection recorded after the analysis of the initial interview with Lya:

> *"The disappointment that the interview, at first glance, contributed little to the theme of* **doing together** *was overwhelming. However, as I analysed the interview, I realised that the counter-evidence (Lincoln, 1988) confirms the evidence. In this interview, the lack of* **doing together** *coupled with Lya's concerns regarding the occupations her son engaged in was the counter-evidence that confirmed the evidence from previous interviews. With this revelation, I look forward to the second PEI with a renewed expectancy to learn from Lya."*

The flow between the dimensions of person, space and time came to the foreground during the following interaction with participants from the Renosterberg area. The researcher is not as familiar with this community as with De Aar where she lives and works. Vikki's account of her daughter's knitting was surprising because the children familiar to the researcher in De Aar do not knit by choice. When she expressed interest, Vikki invited her into her home to see the knitting. As the researcher entered Vikki's home, the simple beauty of Vikki's light-green kitchen in her small RDP house on the edge of town overlooking the Karoo veldt, gave a much deeper dimension to what she understood about Vikki and her daughter. Vikki's choice to change the 'scene' (Elliot & Bonsall 2018) and invite the researcher to the private space of her home may reflect the trust she held for the researcher and her positive experience of the research process, although the researcher did not explore her feeling by asking her about it.

Upon reflection, the researcher realised that including such participant observations in the initial protocol would have added value. However, as ethical approval for this method of data gathering was not sought, it could not be included for other participants.

3.8. Trustworthiness

Various criteria determine trustworthiness within qualitative research (Creswell & Poth 2017). Truth is multidimensional (Riesman 1993) and constructed by discussing and interpreting people's views and actions (Kvale 1996). Truth is grounded in current world views and perspectives of class, race, gender and group affiliations (Creswell & Poth 2017). The truth value (LeCompte & Preissle 1993) of qualitative research relies on the philosophy and values of the researcher as well as on the methods used to generate and analyse data. The confidence in the truth of the findings (Lincoln & Guba 1987) in qualitative research is expressed as *credibility* and built through prolonged engagement, peer debriefing and member checking where meanings and intentions are clarified (Carspecken & Apple 1992).

Credibility in this research was attained through *prolonged engagement*. The investigation in the way that mothers enable the occupational engagement of their children with FASD was conducted in a setting where the researcher has lived and worked for nine years, allowing ample time to observe, communicate and develop relationships in *prolonged engagement* (LeCompte & Preissle 1993). On the basis of these established relationships, participants needed little encouragement to join the study. The understanding and trust that the author brought to the research enabled her to explain the research process to participants in a way they could understand and appreciate. The researcher's history in this community laid a solid foundation of interpersonal communication and intersubjectivity required for rigor (Moss 2004).

In addition, the researcher worked closely with colleagues based in Cape Town. They regularly visit the research site allowing for similar prolonged engagement, although living away from the research site allows for detachment. This combination of prolonged engagement and detachment proved valuable in the peer debriefing they offered the researcher. *Peer debriefing* facilitated clarification as the themes of ***doing together*** and ***varying access to engagement*** emerged and was debated (Creswell & Poth 2017). *Peer debriefing*, from colleagues and the research supervisors, allowed a space where the researcher could express and discuss her assumptions. Where necessary, she could bracket assumptions to avoid them from interfering with the research analysis and interpretations. The researcher also compiled a list of assumptions and wrote them in her research journal to ensure reflexivity (Creswell & Poth 2017; Primau 2003). This peer debriefing added to the credibility of the study. For example, discussing one of Vikki's interviews with a colleague clarified the category 'Involving others' in the theme 'Doing together' as illustrated by the following comment in the research journal:

> *Improving safety for children with FASD requires supervision. Mothers are not with their children fulltime. It takes a village to raise a child. Who are the 'others' that the mother involves for supervision etc.?*

The use of direct quotes from participants explaining their processes of facilitating the occupational engagement of their children added another layer to *credibility* (Denzin & Lincoln, 2005).

Confirmability [the degree to which results can be confirmed by others (Creswell & Poth 2017)]: The researcher confirmed that the findings generated are supported by data collected through methods of member checking, peer debriefing and reflexivity (Krefting 1991). The researcher met with each participant following data analysis to discuss her interpretation as a form of *member checking*. During this meeting, the researcher reminded the participant of the interviews she participated in, and briefly described the process of analysing the data, generating codes, categories and themes. She explained that the themes were a way of capturing the essence of what the mother expressed and that the researcher needs to ensure that the findings are a true reflection of what the mothers expressed during the interview. Each participant verified the themes that emerged as a true reflection of her voice.

Reflection during the research involved conscious examination of how the researcher, as active creator of knowledge affects the data gathering, analysis and representation (Galvaan, 2010). This *reflexivity* positioned the author in the text (Denzin & Lincoln 2005), declaring her subjective involvement while maintaining a sense of purpose and process (Denzin 1989) and adding to confirmability.

Dependability that results would be stable over time (Creswell & Poth 2017) was obtained by consistency across all the different aspects of the research process (Marshall & Rossman 2011). The researcher maintained a detailed record of the practical aspects of the research process in a journal as an audit trail (Watson 2013). The decisions made during the data collection and analysis process was documented in the study journal (Creswell & Poth 2017). An example of such a decision was the definition of learning:

> *I thought learning would reflect school work, but learning needs to include household chores, reading time, handling money.*

Transferability refers to the external validity of the findings, that is, the extent to which the findings of the study can be applied to other contexts (Lincoln & Guba, 1985). A thick, rich description of the participants, their children and the contexts in which occupational engagement took place ensures that the reader can draw comparisons between their contexts and the contexts in which this research has taken place (Creswell & Poth 2017). This allows the study's findings to be extended to similar contexts in South Africa or even other countries.

3.9. Ethical Considerations

Participants were sampled from previous research conducted with ethical approval:

Table 5. Sample from previous research

Study Title	**Ethics Reference No.**	**University**
De Aar Epidemiological screening for FAS and FASD	M00/11/14	WITS
De Aar: Identifying pregnant women who drink and intervening to reduce their alcohol consumption	N09/03/080	Stellenbosch University
Renosterberg: Epidemiological screening for Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder	N13/01/008	Stellenbosch University

For this Masters study, the Faculty of Health Sciences Human Research Ethics Committee granted ethical approval HREC REF: 275/2018 (Addendum B). The World Medical/Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects (2013) were consulted to inform the following ethical considerations:

Beneficence: According to the Health Professions Council of South Africa (2008), beneficence refers to acting in the interest of the participants even when it contradicts one's own personal interests. The study adopted a person-centred stance in that it aimed to seek out the voices of mothers and draw on their experiences to inform the design of an intervention which will support their ability to promote the occupational engagement of their child with FASD. In line with FARR protocol, participants received an incentive at the completion of both the semi-structured and PEI interviews. Incentives were given in the form of a gift voucher to a local grocery store where participants could buy either food or stationery for school. The voucher was not valid for the purchase of alcohol or tabaco products. FARR often uses this kind of incentive and shop owners and assistants are familiar with the procedure.

Non-maleficence: This refers to taking care not to cause harm to the participants (Health Professions Council of South Africa 2008). Although the study was considered to be low-risk, care was taken to create a support network for participants who may need it, tapping into existing resources. The researcher referred a participant with an orphaned FASD child in her care, to the Department of Social Development, in order to formalise foster-care for the child. This was done with her consent. Another participant and her daughter were referred to the mental health services unit at the local hospital to adjust the medication of her adult daughter with FASD. A third participant declined a referral to a psychologist, but continues with counselling from the FARR community worker with whom she has a longstanding relationship. Together they will address the psychology referral.

The study drew on participants from previous research, this being their second time participating in research. The previous studies were done 2 – 17 years ago, although they received incentives during those studies, research incentives offered more than two years apart cannot be seen as a source of income, but remains an incentive.

This study made no new diagnosis, limiting the risk of stigmatisation. Current diagnoses were handled with confidentiality to avoid stigmatisation. Participants were recruited from previous research done by FARR, but all participants were known to the gate keepers in a service delivery capacity. In this way, confidentiality of previous research participants was not compromised. The FARR Centre is accessed by members of the community with and without FASD. Therefore, participation in the research did not add stigmatisation.

Autonomy refers to respecting the individual's ability to make independent decisions (Health Professions Council of South Africa 2008). The first step of ensuring autonomy was gaining informed consent, by providing detailed information to the potential participants regarding the focus of the research and the nature and extent of their required participation. This may present a challenge particularly when engaging with people from vulnerable communities, with low levels of literacy.

In this study, the researcher made considerable efforts to achieve informed consent. Participants were invited to join the study by gate keepers (community workers well known to them) and could at any time decline their appointed interviews. At this stage, they were unaware of any incentives being offered. At the initial interview, each participant was presented with an information sheet clearly and simply describing the study and what would be required of them (Addendum C: Information letter). They were informed that they could choose to not participate or withdraw from the study at any time. They were also informed that they had the right to refuse to answer any questions if it made them uncomfortable. Participants were informed that refusing to take part, or withdrawing from the study would not influence the current or future inputs that they would receive from FARR. In the informed consent form, participants were asked whether or not they consent to having the interview audio recorded. There was also a check-box option so that the participants could explicitly agree or disagree to audio recordings of the sessions.

Confidentiality refers to the measures taken to ensure the privacy and confidentiality of the participants in the study. In this study confidentiality was maintained in the following ways:

a) Raw research data was securely stored in a locked cupboard in the researcher's office. All digital data was stored on a password protected computer and on a VULA project site. All data will be kept for five years.

b) The researcher committed to not disclosing or sharing any confidential information with outsiders.

c) Community workers agreed to ensure confidentiality of all persons taking part in the study. Their confidentiality is confirmed as part of their signed employment contracts with FARR.

d) Audio-recorded interviews were listened to using headphones to avoid the data being heard by a third party.

e) The transcription was done by the researcher alone to ensure confidentiality.

f) The content of the interviews was regarded as privileged at all times.

g) In all publications relating to this study, no identifying details will be used to ensure that no information can be traced back to a participant.

h) Confidentiality was also ensured by initially using study numbers to link different sets of data and then pseudonyms when writing about participants. Participants are known to the community workers and researcher who will treat them confidentially.

i) Justice: Participants were all treated equally during the study. All participants had access to transport, the incentives they received had equal monetary value, all had access to similar referrals and equal value was ascribed to data from each participant. Participants will be given equal opportunities to participate in any follow up from the study.

3.10. Conclusion

In conclusion, this chapter claimed a qualitative descriptive study design to be most suited to the inquiry described in this thesis. The influences of past experiences on the researcher's perspective was clarified and the process of obtaining ethical permission, sampling, data gathering as well as inductive, thematic analysis was detailed. Lastly, the chapter argued that the process, procedures and integrity with which data was generated secured the trustworthiness of the study.

Chapter 4: Findings

4.1. Introduction

This chapter will describe the themes and categories that emerged from analysing the data gathered in the study. Two themes emanated from the analysis and captured the description of how mothers facilitated the occupational engagement of their children with FASD. These two themes were ***Doing together*** and ***Varying access to engagement***. The theme of ***Doing together*** illuminates the value mothers and children ascribe to *Doing together* and is supported by the underlying categories of *Doing with the child*, *Flexible expectations*, *Grading support*, and *Involving others*. The theme ***Varying access to engagement*** with its categories of *Creating access*, *Maximising access* and *Limiting access* describes the way mothers manipulate children's access in order to facilitate their occupational engagement. The image below, Figure 4.1., visually presents the themes and categories.

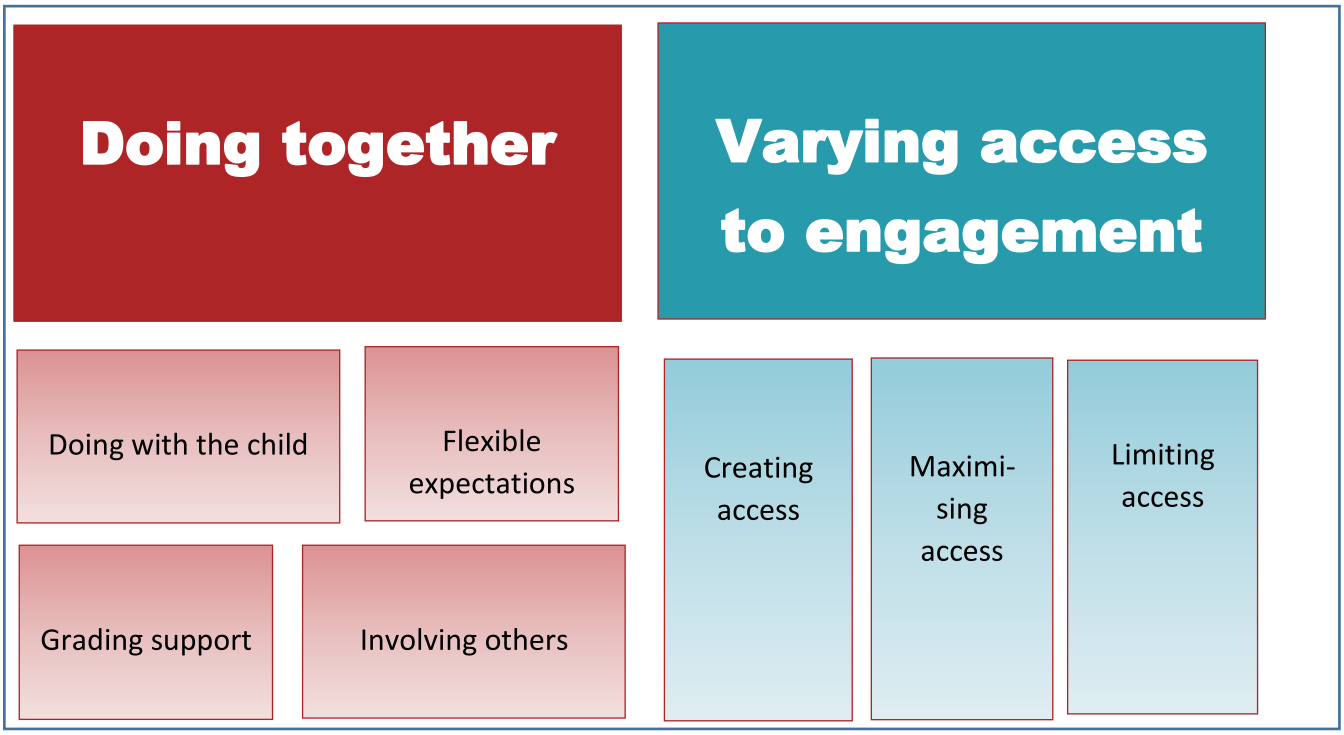


Figure 11. Themes and categories

4.2. Theme 1: Doing Together [*saam 'n ding doen*]

Participants in this study described "Doing together" as a central aspect of how they facilitated the engagement of their children in various occupations. Participants fondly described the collective nature of the ways in which the facilitation of their children's engagement in occupations took place. As participants either share in their children's playful occupations, or allow their children to join in their own occupations in and around the house, these mundane activities become meaningful. This sharing of daily chores adds meaning to mundane tasks which enables mothers to facilitate their children's engagement in occupations of leisure, self-care and productivity.

Nested in the theme of *Doing together*, are the four categories, *Doing with the child*, *Flexible expectations*, *Grading support* and *Involving others*. In the category *Doing with the child,* mothers expressed their joy in sharing occupations with their child and found this a successful way to engage their children in these shared occupations. However, the sharing of an occupation does not suffice to engage a child over an extended period of time. The other three categories in this theme, play an equally important role.

The way that mothers adjust their expectations to the child's ability as well as the pride they take in a child's attempt, cannot be underestimated and is described in the categories: *flexible expectations and grading support*. *Grading support* describe the manner in which mothers grade their own involvement from initially playing an active role in their engagement with their child. Over time, the mother gradually withdraws, allowing the child to engage in these occupations on their own, if not independent. The final category of *involving others* place emphasis on the role of the collective society as mothers involve others (siblings, extended family, teachers, neighbours, friends and similar others) to facilitate their children's occupational engagement.

The theme of *Doing together* is grounded in the value mothers ascribe to sharing occupations (*Doing together*) with their children. This section will describe the worth mothers attach to *Doing together*.

> *Magret:* *Vir my is dit die beste as ons saam 'n ding doen.*
>
> *Lian:* *Soos wat?*
>
> *Magret:* *Sy help my baie met die kombuis skoonmaak…. En Saterdae … weet sy ek was skoolklere en as ek inkom dan het sy die badkamer skoon gemaak.*
>
> **Magret:** **For me, the best is when we do a thing together.**
>
> **Lian:** **Like what?**
>
> **Magret:** **She often helps met to clean the kitchen … And Saturdays … she knows I am washing school clothes and when I come back in, she has cleaned the bathroom.**

In the second, photo-elicited interview, Magret selected two favourite photographs of her daughter, Joe, helping with the washing and the cooking. Magret washed the family's laundry by hand in the front yard where her children were playing. She was thrilled that her daughter freely joined her in this occupation. Her daughter's free choice to join her mother may indicate that the *doing together* provides mutual pleasure.

> *Lian:* *Daai ene .... vertel vir my hoekom is dit so spesiale foto?*

Magret: Daar't ek nou saam ... Ek het gewas toe kom sy en toe kom help was sy vir my.

Lian: So jy het nie vir haar gevra: 'Kom help my ....?"

Magret: Nee ek het haar nou nie gevra. ...

Lian: En dan is dit .. dis baie spesiaal né.

Lian: That one? Tell me why it's such a special photo?

Magret: There I was together ... I was washing and then she came and then she came to help me to wash.

Lian: So you didn't ask her: "Come help me ...?"

Magret: No, I did not ask her...

Lian: Then it is ... It is very special, hey?

The following quote was documented in the research journal after this interview with Magret. It reflects the unfolding of this theme.

> *Magret obviously enjoys the simple, ordinary chore that she shares with her child. I expected her to go through the motions of a chore like this as quick as possible, and then enjoy quality time with her child... maybe the ball game she also told me about. Yet, this chore becomes their quality time! What a surprise, I must explore this idea.*

Another mother, Sylvie, confirmed this delight in the *doing together* with the child:

Sylvie: Ek laaik saam met hom huis skoonmaak.

Lian: Hoekom?

Sylvie: Ons kry gou klaar, of hy sal sê as daar 'n vriend van my kom, "Moenie so lank praat nie ons moet klaar werk of ek gaan nou vir jou los dan loop ek." So is hy. Hy gee my altyd steam.

Sylvie: I like cleaning the house with him.

Lian: Why?

Sylvie: We finish quickly, or he will say when a friend of mine comes: "Don't talk so long, we must finish working or I will leave you now, then I will go." He is like that. He always gives me steam.[2]

---

[2] Sylvie is referring to the energy and motivation she gains from working with André.

Vikki, emphasized the value of *Doing together.* She was the only participant with full time employment, allowing her less time to do things with her children, although she described these moments as precious. She described the positive experience of sharing domestic chores with her children and the way that they sing together as they work. She explained these treasured moments in the following way:

> *Vikki:* *Dis vir my lekker want ek is eintlik meerderheid by die werk as wat ek, so die bietjie wat ek met hulle kan saam wees is vir my baie kosbaar.*
>
> **Vikki: I enjoy that, because actually I am mostly at work, so the little I can be with them is very precious to me.**

Speaking about her favourite moments with her children, she described their ball game and concluded with this statement about her participation.

> Vikki: *Veral as hulle so buite speel ... Dan sal ek altyd daar tussen hulle. Dan sê ek is albei se kant [lag] ek is op altwee kante.*
>
> **Vikki: Especially when the play outside ... Then I will always be there with them. Then I say I am on both sides. [laughing]**

With fondness she described the way the family sings together as they clean their small four roomed house.

> *Vikki:* *Dan Saterdag oggend dan maak ons nou weer die huis skoon. Dan sal ek nou miskien in die kombuis wees. Hulle sal miskein in die kamer begin, die ander een sal miskien die voorkamer se vertek vat. Dan sal een van hulle sommer uitbreek met 'n koortjie.*
>
> **Vikki: Then Saturdays, then we clean the house. Then I will maybe be in the kitchen. They will maybe start in the bedroom and the other one will maybe take the lounge. Then one will start a song.**

Maryna's affectionate description of early evenings when the family relax together under the shade of a tree with board games, confirms the value mothers ascribe to *Doing together*.

> *Ons het so bord [ludo] daar in die huis in. Sien mevrou, en as hulle so begin vervelig raak dan sê ek vir hulle kom ons gaan sit daar by onder die koelte dan speel ons. Dan speel ons almal saam.*
>
> **We have a board like that [Ludo] at home. You see ma'am, when they get bored, then I say let's go sit there in the shade and play. Then we all play together.**

In contrast, two mothers struggled to describe things they did with their children. These were the same two mothers who also expressed concern about the occupations their children engaged in.

Lian: *Is daar iets wat julle saam doen behalwe by die huis?*

Sophie: *By die huis? Nee niks em-m ... ek en sy nou nie. Ek wil net hê sy moet werk...* [by die huis]. *Ek wil maar net hê sy moet haar besig hou want ek sê vir haar ek was 18 jaar toe gaan werk ek. Nou sê ek vir haar jy is nou al so groot jy gaan nog 'n ouma raak.*

Lian: **Is there anything you do together other than at home?**

Sophie: **At home? No nothing em-m ... not she and I. I just want her to work ...** [at home] **I only want her to stay busy, bacause, I tell her, I was 18 years then I went to work, I tell her. Now, I tell her, you are already so big... you're becoming a granny.**

Sophie fet that because her daughter was already 23 and not working, she was like a granny who simply sat in the sun doing nothing. Yet, unlike most other participants, she was unable to describe any occupations she shared with her daughter.

Another participant, Lya expressed concern about her son's choice of occupations, which included sniffing glue, playing games of chance (blikkie-blikkie), as well as occupations he may potentially engage in if he goes to town, like robbery. Like Sophie, she was unable to name anything she does with her son.

Lian: *En Lya sê vir my is daar iets wat jy en Rico saam doen?*

Lya: *Soos ... werk?*

Lian: *Soos werk of soos speel of ...*

Lya: *Uh-u.*

Lian: **And Lya, tell me, is there anything that you and Rico do together?**

Lya: **Like … work?**

Lian: **Like work, or play or …**

Lya: **Uh-u (meaning 'No')**

Sophie and Lya were the only mothers who expressed concern about their children's occupational engagement. They were also the only mothers who were unable to describe things they did with their children. The possible reasons which may have contributed to these participants limited occupational engagement with their children were not explored within the limits of this qualitative descriptive study. However, their concerns in the absence of doing things with their children, underlines the importance of *Doing together* to facilitate children's engagement in desirable occupations.

Having introduced the theme of *Doing together* by describing the value mothers attach to sharing occupations, the following section will continue to explore the categories of *Doing with the child*, *Flexible expectations*, *Grading support* and *Involving others.* These categories emerged from analysing the manner in which mothers facilitated the engagement of their children in the occupations of leisure/play, self-care and productivity (work and school).

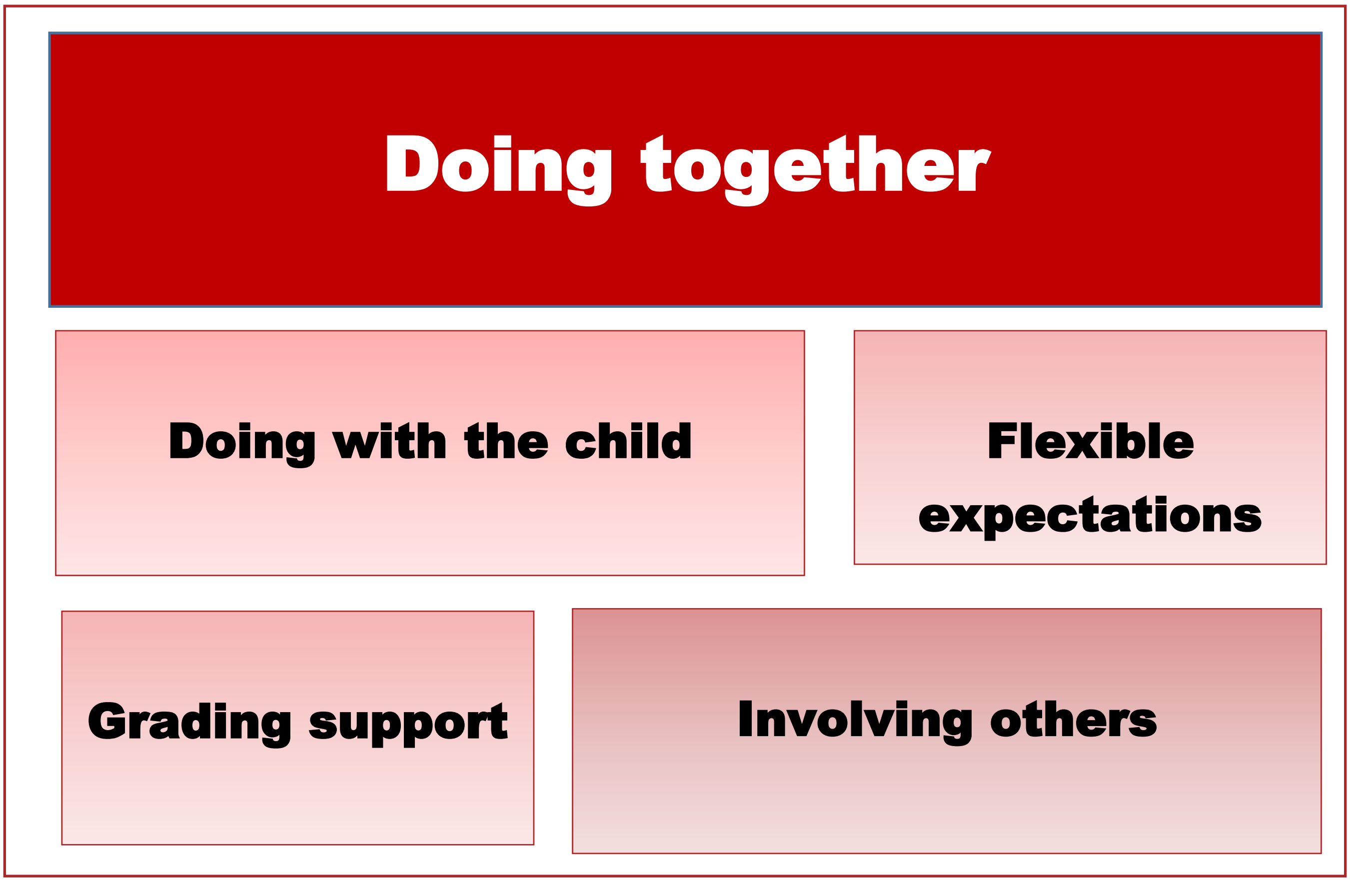


Figure 12. Theme: Doing together with categories

4.2.1. Doing with the Child

This section will unpack the shared participation of mothers and their children as a way for mothers to facilitate their children's engagement in the occupations of play, self-care and productivity (domestic chores and school work) taking place inside, as well as outside of the home context. This category clarifies how mothers facilitate occupational engagement in spite of the challenges associated with FASD when they *do with their child,* and how they create opportunities for learning when engaging together with the child in their occupations.

Zelda shares how she plays along with games initiated by her son, such as hide-and-seek.

Zelda: As ek hom soek, as hy hoor ek soek hom, hy laaik my speel ook. Dan kruip hy vir my weg.

Lian: Speel hy met jou wegkruipertjie?... En dan, gaan soek jy hom?

Zelda: Ja, ek kama-kama, dan weet ek waar hy is maar ek sê vir hom niks. Dan roep ek hom… is jy op die kas, of so? Dan lag hy net. Dan sê ek, ek weet waar's jy. In die hangkas in? Em-m hy's nie hier nie… Dan sê, ek weet nou waar's jy … nou dan soek jy by die bed se poot. Dan bars hy uit van die lag

Zelda: When I look for him, when he hears I am looking for him, he likes to play me and hide from me.

Lian: Does he play hide and seek with you? … And then, do you go looking for him?

Zelda: Yes, I pretend, then I know where he is, but I say nothing. Then I call him … Are you on the wardrobe, or so? Then he just laughs. Then I say, I know where you are. In the wardrobe? Em-m ('no'), he's not here. Then, say, now I know where you are, now then you look at the bed's leg. Then he bursts out laughing.

Later in the interview, Zelda talked about her son's dream of becoming a preacher in Church and reported that she is part of his fantasy game.

> *…. en hy's baie lief vir Kerk speel... En so. Hy preek, sommer vir ons ook ... Meestal vir my: "Zelda! Jy moenie so baie rondloop nie!" So as ek nou miskien net geloop het... al het ek nie geloop nie. Dan mors hy met my: "Zelda ek het jou gesê my ma sê jy moenie so baie baie rondloop nie." Dan lag hy my uit. Vernaam as hy sien ek stress.*
>
> **... and he loves playing Church... And so. He preaches, for me also ... Mainly for me: "Zelda! You shouldn't go out so much!" Like, maybe if I'd been out ... even if I was not out. The he teases me: "Zelda I told you, your mother said you should not go out so much." Then he laughs at me. Especially when he sees I stress.**

Vikki plays an even more active role in her daughter's occupation of play by joining in a ball game with her peers and adopting an impartial role to ensure all parties feel a sense of success in the game.

Vikki: Veral as hulle so buite speel, miskien die vriende dan is hulle veral daar in daai jaart ... jy sal altyd 'n klompie meisiekinders sien. Hulle spring tou of hulle speel daar met 'n bal en hierdie .. wat is die ander ding se naam wat hulle noem wat hulle die stene omgooi . .. e... omstoot en dan jaag hulle ... is nou opgedeel in groepe dan jaag die een groep met 'n bal nou op hulle *uit gevang sodat hulle kan uit is . Dan sal ek altyd daar tussen hulle aangaan dan sê ek is albei se kant …* [lag]

Lian: *Jy speel alkant?*

Vikki: *Ja ek is op albei ... ee groepie se kant . Dat hulle nou nie dink hier word nou die een voorgetrek of so.*

Vikki: **Especially when they play outside, maybe with friends then they all are in that yard. You will always see a group of girls. They are skipping or playing with a ball and this ... what do you call it, the thing they call that they throw over the bricks … e… push over the bricks and then they give chase … they … are divided in groups and then one group chases the other with a ball to catch** [throw] **them out so that they can be out. Then I will always be amongst them, then I say I am on both teams' side …** [laughing]

Lian: **You play on both sides?**

Vikki: **Yes, I play on both sides ... ee.. groups' side. So that they don't think one is being favoured or so.**

Magret described this same game Vikki plays with her daughter in more detail, calling it 'Three-tins' (*Drie-blikke*). At her home, tins are used in the game rather than the bricks Vikki's family uses. Magret continues to explain how she facilitated this game by creating access to the equipment needed for the game.

Magret: [Blaai foto] *Doer het hulle nou drie-blikke gespeel.*

Lian *Hoe speel hulle drie-blikke?*

Magret: *Hulle pak blikke bo-op mekaar dan gooi hulle die ball. Dan hol hulle nou weg. Ene moet die ball vang.*

Lian *OK, hoekom hol hulle weg?*

Magret: *Want dis amper ... dis ok soos die touch* [a game where one child tries to throw another with the ball while the children run away]*. Dan gooi hy nou vir jou maar as jy uit is. As almal weer bymekaar is. Die een wat laaste is, dan moet hy nou die ball vat om te gooi*

Lian *Ok. En met watse ball speel hulle dit?*

Magret: *Met 'n tennis ball*

Lian *…'n Tennis ball. OK, en hulle moet dan nou die blikke omgooi?*

Magret: *Ja ... laat hulle omval.*

Lian *OK …* [Blaai foto]

Magret: *Daar hol hulle.*

Lian *Daar hol hulle. Is dit 'n speletjie wat jy gespeel het toe jy groot geword het, Magret?*

Magret *Ja, ons het baie dit baie gespeel*

Lian *Baie dit gespeel. So wie't vir Joe geleer om dit te speel? Het jy vir haar geleer of het sy dit by die maatjies geleer?*

Magret *By die maatjies geleer ok.*

Lian *En waar kry sy die blikke?*

Magret *Hulle tel hulle sommer op.*

Lian *OK, so sy vra nie vir jou vir die blikke of so nie?*

Magret *Nee, maar dan hou ek ... as ek miskien blikkies goed oopmaak of so dan hou ek dit altyd vir haar.*

Magret: [Pages through the pictures] **There they were playing three-tins.**

Lian **How do they play three-tins?**

Magret: **They stack the tins on top of each other and then they throw the ball. Then they run away. One must catch the ball.**

Lian **OK, why do they run away?**

Magret: **Because it is almost... it's also, like touch** [a game where one child tries to throw another with the ball while the other children run away]. **Then he throws you but then you are out when everyone is together again. Then last one has to take the ball to throw.**

Lian **Ok. And what ball do they play it with?**

Magret: **With a tennis ball**

Lian: **…A tennis ball. OK, and they have to throw the tins over?**

Magret: **Yes ... so that they fall over.**

Lian: **OK …** [Change photo]

Magret: **There they run.**

Lian: **There they run. Is that a game you played when you were growing up Magret?**

Magret: **Yes, we often played it.**

Lian: **Often played it. So, who taught Joe to play it? Did you teach her or her friends?**

Magret: **From the friends also.**

Lian: **And where does she find the tins?**

Magret: **They pick them up.**

Lian: **OK, so she never asks you?**

Magret: **No, but I do keep it for her … when I maybe opened tins or so then I always keep for her.**

During a PEI, Doreen spoke in a playful tone of voice as she described photos of children's games of hide and seek. She became so annimated in her account, that it sounded as if she was playing with them. Later, the author's entry in the study journal reflected:

Doreen talks in a playful voice and is so involved as she tells the story that it sounds as if she is playing with the children.

> *Doreen: Wegkruip , wegkruip . Maak toe jou oë moenie sien waar kruip ek weg nie... Waar's hy?.... Hier's hy!* [spelerige stem] *. Sy oopgaan haar oë* [lag]
>
> **Hide away, hide away. Close your eyes, don't look where I hide ... Where's he?... Here he is!** [playful voice]**. Her eyes open** [laugh].

Play was not the only shared occupation. Domestic chores also emerged as a team effort shared between the participants and their children. Mothers facilitated engagement in occupations of productivity by presenting chores. Such chores include doing the dishes, doing laundry and making a bed, and these are occupations that can be done together. Children learn to play their part in the team, by observing what needs to be done as this story from Sylvie depicts:

> *Sylvie: Hy is 'n ander mens, hy sal altyd in die kombuis bly as jy daar werk. So hy sien sommer nee jy't so gemaak, jy't so gemaak. Hy sny vir ons almal brood hy sit rama op of wat ever hy kan.*
>
> *Lian: So hy kom in die kombuis en dan staan hy en kyk wat jy doen?*
>
> *Sylvie: Hy kyk so wat jy doen ja. Of more sal hy sê: "Jy moet weer daai ding maak, wat jy netnou gemaak het of wat jy gister gemaak het." Maar nou nie kook of iets swaar doen nie. Maar die brood.*
>
> *Lian: Brood smeer en tee maak?*
>
> *Sylvie: Ja, dit sal hy nou doen.*
>
> **Sylvie: He is another one, he will always stay in the kitchen when you work there. So, he sees you did this, you did that. He cuts bread for all of us, he spreads it with Rama[3] or whatever he can.**
>
> **Lian: So he comes into the kitchen and watches what you do?**
>
> **Sylvie: He watches what you do, yes. Or he will say: "You must do that again, what you just did or what you did yesterday." But not heavy stuff like cooking. But the bread.**

---

[3] A brand name for margarine

> **Lian:** **Cutting bread and making tea?**
>
> **Sylvie:** **Yes, that he will do.**

Later Sylvie continues to describe her son André's contribution.

> *En hy rakie moeg nie. ...Hulle* [haar eie kinders] *is baie lelik en hulle is lui jy weet 'ie hulle is ... hulle sal altyd terug praat ook of 'n ding. Nie hy nie. Jy kan vir hulle sê gaan sny brood em-m . Hy staan op dan gaan doen hy daai selle ding. Maar hy't hulle so geleer want hy vat altyd hulle se part. My een gaan haal nie eers sy skool skoene nie, want hy weet Andre gaan hulle nou gaan haal. Hy's so. Kom kom eet nou of kom vat gou julle se tee. Hulle* [skud haar kop]*... Hy het vir hulle so gebederf.*
>
> **And he never grows tired .... They** [her own children] **are really nasty and they are lazy, you don't know they are ... they will always talk back or something. Not him. You can tell them to cut the bread em-m. He gets up and does that same thing. But he taught them that because he always takes there side. My one does not even fetch his school shoes, because he knows André will fetch them. He's like that. "Come, come eat or come take your tea." They ...** [shaking her head no] **he spoilt them.**

Mothers seem to facilitate occupational engagement by sharing occupations with their children, and the shared occupations also provide opportunities to teach skills within an occupation. Marie's description of teaching her daughter to read the time while baking bread illustrates this.

> *En as jy hom 12 uur of five past, of ten past, ... die twee is mos nou 'n tien sê ek vir haar. "Ja my ma, ek onthou," sê sy "dis reg". Nou OK as jy sien hy's ten past dan sit jy dit in en as hy, dan gaan hy om. Dan loop die horlosie mos nou om, wéér tot by twee dan isit sê tien oor, dan kom hy mos nou oor, dan kom hy weer oor tot by twee dan isit tien oor twaalf of nee tien oor een … dan is dit 'n uur, sê ek vir haar dan kan jy die brood uithaal. Sy doen dit alles.*
>
> **And when you… 12 o'clock or five past, or ten past, … the two is now a ten, I tell her. "Yes, my mom, I remember," she says, "it's all right." Now OK, when you see it is ten past, then you put it in, and when it… then goes around. Then the clock runs around, again to the two then it's say… ten past, then it goes around, again to the two then it's ten past twelve or no, ten past one. Then it is an hour, I tell her then you can take out the bread. She does all that.**

Marie's 23-year old daughter, Filida, briefly lived with her boyfriend on a farm. After the birth of her baby, Filida found she could not cope and moved back home. Marie helped her to care for the baby and as mother and daughter engaged in this occupation together, Filida learnt to nurture her young baby. Over time she became more independent in caring for her baby, although Marie continues to play a supervisory role.

Marie: Mm-hmm sy weet wannner die kind eet as die kind klaar geëet het dan, dan gee sy vir die kind, dan gee sy vir die kind bottle. Eers laat sy die kind wind breek, dan gee sy vir die kind medisyne. As die kind klaar medisyne gekry het, daarvandaan dan maak sy die kind aan die slaap, dan lê sy hom neer. Sy maak hom saans aan die slaap, sy bad hom, sy smeer hom uit en so ... Sy doen dit alleenig

Lian: OK, en hoe het sy geleer om dit te doen?

Marie: Ek het haar gewys. Ja hoe word die kind gebad ek hoe smeer jy hom uit en as die kind klaar is dan moet jy hom eers oor jou skouer hou en so onder sy stertjie sus. [illustreer die beweging] *En dan dat hy wind breek en as hy slaap maak dan lê jy hom op sy magie neer. So het ek haar gewys. En van daai tyd het sy ... rerig dit kop toe gevat en sy soos ek sê sy onthou nou. Sy onthou nou rerig, sy onthou nou. As mens vir haar iets sê sy vergeet nie sy doen daai ding of sy onthou daai ding. Partykeer vergeet ek, dan onthou sy weer vir my.*

Marie: Em-m, she knows when the child eats, then she feeds the child and when the child has eaten, she gives him the bottle. First, she winds the child, then she gives the child medicine. When the child took the medicine, she puts the child to sleep, then lays the child down. She puts him to sleep in the evening, she bathes him, and puts cream on … She does all that.

Lian: OK… and how did she learn to do that?

Marie: I showed her. Yes, how the child is bathed and rubbed with cream and when the child is finished you must hold him against your shoulder and soothe him under his bottom [demonstrates the movement]. And then when he breaks wind, and sleeps, then you lay him down on his tummy. I showed her. And since that time, she … really took it to heart, like I said, she remembers now. She really remembers, she remembers now. When, one tells her something, she does not forget that, she does that or she remembers that. Sometimes I forget, then she reminds me.

Occupations of productivity outside the home were also facilitated by 'doing with the child', as Lya described. She wishes for her son to work in a garden, like his father does, but realises that he lacks the ability to plan his day according to a schedule and he will probably not arrive for work. Her solution to this inability to plan a day (a challenge often associated with FASD), is for her to find a domestic job where there is also work for a gardener. In this way, she hopes to take her son to work and keep an eye on him while he works. Once again, the theme of 'doing together' underpins her plan to do with him, to facilitate his engagement in an occupation of productivity.

> *Uh-u ek het al gedink ek wil vir my joppie kry. Dan wil ek by daai mense soek is daar nie werkies vir hom nie. Ek moet lat hy elke dag saam met my inval en so aan...*
>
> **No, I thought, I want to find me a job. Then I will ask those people** [employers] **for jobs for him. I must let him come to work with me every day and so let him fall in with me and so.**

Participants described their children's impulsiveness and acting out behaviour. While sharing occupations, mothers use the opportunity to address behaviour they find unacceptable. Sylvie disciplines her son using a variety of strategies including corporal punishment, time-out and withholding privileges such as watching TV, before she engages him in another occupation, modelling acceptable behaviour.

> *Want ek gee vir hulle elkeen 'n pakslae. As ek daai dag voel julle is te stout dan slaan ek vir hulle of ek sit hulle uit by die deur. "Gaan sit julle op die stoep, toe gaan sit op die stoep, gaan sit op die stoep." So. Ek sit vir hulle uit. Of: "Sit af daai TV julle gaan nie vandag hier TV kyk nie, want giser toe's julle te lui of julle willie gewas het nie. Sit af daai TV." So. Ons verstaan mekaar ek en hy.*
>
> **Because I give them each a smack. If I feel that day, they are too naughty then I smack them or I put them out the door. "Go sit on the veranda, go sit on the veranda, go sit on the veranda." Like that. I put them outside. Or, "switch off that TV, you're not going to watch TV today, because yesterday you were too lazy or you didn't want to wash. Switch off that TV." So we understand each other, the two of us.**

Later she added:

> *... Daai tyd tot ek weer besluit nee maar hy sit nou lank daar buite. Dan sê ek: "Kom nou in." Of "Kom maak gou vir ons tee."...*
> *...Hy's baie lief vir tee. Hy sal sommer vir jou vra ok. "Moet ek nou vir ons tee maak?"*
>
> **That time, when I decide OK, he's been outside long enough. Then I say: "Come in now." Or "Come, make us some tea."... He really loves tea. He will even ask to make you tea: "Shall I make us some tea?"**

While doing homework with their children, participants observe the challenges associated with FASD (such as poor concentration) and accommodate these, as the following transcripts demonstrate:

> *… jy gaan vir hom hier 'n ding sê dan gaan hy net 'n bietjie luister en dan sê hy ja. Maar dan's hy weer weg of weer besig met 'n ander ding.*

> **... you will tell him something here then he will listen only a little bit and then say yes. But then he's off again or busy with something else.**

A little later Zelda adds:

Zelda *Dan help ek hom, maar daar kom 'n tyd wat hy nou net nie weer konsentreer...*

Lian: *En wat doen jy dan? As jy sien hy konsentreer nou nie?*
Zelda: *Dan los ek hom so vir 'n rukkie, dan nou begin ek weer.*

Zelda: **Then I help him, but there is always a time that he just does not concentrate anymore.**
Lian: **And what do you do then? When you see he no longer consentrates?**
Zelda: **Then I leave him for a while, then I start again.**

The way that mothers *do with their children*, create opportunities to facilitate occupational engagement and to manage some of the barriers associated with FASD.

4.2.2. Flexible Expectations

This section will address the category *Flexible expectations*, embedded in the theme of *Doing together*. As children mature, their skills improve, but younger children, especially children with FASD may not gain the same level of competence as their mothers. Irrespective of their child's ability, mothers described the value they attach to their child's participation and attempts at participation during occupational engagement. Mothers' adaptability, in their expectations of their children, is an important aspect of facilitating occupational engagement as reflected in Sylvie's statement below:

> *Ek vat die een s... ek vat die sitkamer, hy vat my kamer dan vat hy weer solank die kombuis. Maar hy maak hom nou nie SO skoon nie, jy moet maar weer terug gaan maar hy gee jou krag want hy doen die ding amper reg so jy gaan maak net op.*
>
> **I take the one ... I take the lounge, he takes my room and then in the meatime he takes the kitchen. He does not clean THAT well, you always have to go back, but he gives you energy because he does it almost right, so you just have to add the final touch.**

Children with FASD often find it difficult to adjust to others' needs or expectations. The participants were able to work within the boundaries of their children's stubbornness in ways which allowed them to facilitate their occupational engagement.

Sylvie: Hy droo skottelgoed af, hy was skottelgoed. So ek sal enige tyd sê: "Gaan was gou die skottelgoed. Droë af die tafel," dan gaan hy. Maar as hy voel ok nee, nie vandag nie dan sê hy: "Nee man, ek gaan nie die skottelgoed in pak nie." Dan los ek hom.

Lian: Jy druk hom nie dan en sê kom ek het nou gesê jy moet...

Sylvie: Nee ek los hom want hy is nie vandag lus nie.

Lian: More doen hy dit weer?

Sylvie: Ja, more doen hy dit regtig weer.

Sylvie: He dries dishes, he washes dishes. So I can tell him any time: "Quickly go wash the dishes. Wipe the table," then he goes. But when he feels like, 'not today,' then he says: "No man, I am not going to pack the dishes away." Then I leave him.

Lian: You don't push him then and demand that he must ...?

Sylvie: No, I leave him because he really does not feel like it today.

Lian: And tomorrow he will help again?

Sylvie: Yes, tomorrow he really does help again.

Similarly, Sophie is flexible enough in her expectations of the meal her daughter prepares, to eat it, even if it is not to her taste:

> *Nee sy maak dit alleen al maak sy dit ok nou so partyker dat ek nou nie dit...* [lag] *Ek meen nou dat dit nou nie vir my so is dat ek dit nou gevoel het wil hê nie. Dan laat ek dat sy maar aangaan.*
>
> **No, she does it alone, even if she does it that I don't …** [laughs] **I mean, that it is not the way I felt it should be done. Then I let her be.**

Marie embraces her daughter's fastidious approach to cleaning the house, allowing her to clean in her own way. She even obliges when her daughter sends her outside. In this case, Marie's flexibility allows for her daughter's individual approach to cleaning, rather than insisting that the cleaning be done in the way Marie always cleans. The end result of her daughter's independent approach is more important than dictating the way it should be done.

> *Filida, sy's 'n vreeslike kind, Filida ...ene, sy hou van netheid. En elke ding moet reg wees soos sy dit wil hê. Ons almal werk mos nou nie dieselfde nie, nou as sy sien daai ding issie regie dan gaan sy vreeslik uitlaat en dit kan hulle* [susters] *nie vat nie. Ene dan word ons almal nou uitgesit: "Gaan, uit, gaan uit, gaan uit." Dan moet ons nou buite loop sit en dan nou vat sy daai vier vertrek dan maak sy hom van agter af skoon tot voor. Dan loop die*

mense in dan sê hulle hooee, maar jou huis is lekker koel skoon. 'n Mens kan sien Filida is hier. Ja, so sê hulle.

Filida, she is another one, Filida, she likes cleanliness. And everything must be the way she wants it. We do not all work the same way, and when she sees that this is not right, she will go off and they [her siblings] can't take it. And then we all are sent outside: "Go, out … out." Then we have to sit outside and she takes that four roomed house and she cleans it from back to front. Then people come in and say: "Oooo, but your house is clean and fresh. We can see Filida is here. Yes, so they say…"

When Maryna sends her daughter, Ali, to the shop and she forgets what she has to purchase, Maryna gives her an opportunity to try again.

Maryna: So nou en dan is daar 'n dingetjie wat ek moet miskien vir haar vra dan sal sy miskien nou sê sy het vergeet of so, ja. Of winkel toe stuur, dan sal ek vir haar sê ek het dan vir jou gesê bring brood en dit saam dan sê sy sy het vergeet maar sy gaan nou gou weer terug gaan. So...

Lian: So, is dit maar die manier hoe julle dit oplos? Sy gaan gou terug en dan gaan haal sy...

Maryna: Ja dan bring sy die regte ding.

Maryna: Sometimes there is something I have to remind her, then she will maybe say she forgot or something like that. Or I will send her to the shop and say I asked you to buy bread and that. Then she says she forgot but she will quickly go again. So…

Lian: So, is that the way you manage it? She goes back to fetch…

Maryna: Yes, then she brings the right thing.

Sophie extended this flexibility in expectations to include her daughter's social behaviour. She takes her daughter's mood swings in her stride and stays unconfrontational.

Sophie: Ja en dan staan sy maar weer op en dan was sy haar dan maak sy weer vir haar skoon en dan is sy maar daar. Maar dan is sy baie kwaai. Niemand moet so baie met haar praat nie . Jy moet haar ook net so los. So is sy.

Yes, and then she gets up again and washes herself, then she cleans herself and then she is just there. But then she is very moody. Nobody must talk much to her. You must just leave her alone.

This theme of flexible expectations describes the way mothers adapt their expectations to their children's competence, in order to encourage their engagment in various occupations.

4.2.3. Grading Support

Apart from flexible expectations, mothers facilitate occupational engagement by downgrading their own involvement in the doing together over time. This category of *grading support* will describe the ways in which mothers facilitate occupational engagement by doing for their child, allowing them to observe as the mother engages in the occupation, doing together and then withdrawing into a progressively more supervisory role. Supervision lasts into adulthood upholding the theme of doing together.

Dressing was learnt effortlessly by the children. Magret reports that her daughter learnt to dress herself without any fuss. Although, she says her daughter observed something once only, before doing it, she may have forgotten the many times she dressed her daughter as a baby and toddler.

Magret: *Ek was hulle mos in die aand. Dan maak ek hulle ... as dit winter is dan maak ek hulle vir half sewe wakker. Sy trek haarself aan. Dan sal ek haar net met die hare help en so. Skoene het ek vir haar geleer hoe trek mense skoene aan en kouse. Hoe trek jy vir jou aan. Van bo af aan*

Lian: *Het jy gesukkel om dit vir haar te leer*

Magret: *Niks nie… Sy sien een keer 'n ding en die ander tyd ... doen sy dit self*

Magret: **I wash them in the evening. Then I wake them … in winter I wake them at half-past six. She dresses herself. Then I only help her with her hair and such. Putting on shoes, I taught her to put on shoes and socks. How you dress yourself from the top.**

Lian: **Was it difficult to teach her?**

Magret: **Not at all… She sees something once and then she does it herself.**

Zelda described how she facilitated André's engagement in the selfcare occupation of dressing:

> *Ek leer hom aantrek, en ek was hom mos maar in die aand in. In die oggend vee ons mos maar net uit dan help ek hom om aan te trek. Hy weet nou ook al hoe om aan te trek die kouse, die hemp. Miskien as hy 'n t-shirt of 'n ves onder aan het. Dan trek hy eerste dit aan. Hy willie eers weer hê ek moet hom help nie. So ek is nou maar net by laat ek nou maar kyk.*

> **I taught him to dress, and I wash him in the evening. In the mornings we only wipe off and then I help him to dress. He knows how to put on the socks, the shirt. Maybe if he wears a T-shirt or vest underneath, then he puts that on first. He does not even want me to help him anymore. So now I am just around to watch.**

Doreen provides a little more detail of the supervision she offers her daughter when dressing:

> *Sy trek self aan. Ek sal nou miskien die collar regmaak en kyk of als reg is.*
>
> **She dresses herself. I only fix the collar and check that everything is right.**

Although mothers gradually withdrew their support, Doreen stayed actively involved when her 9-year old daughter took a bath on a Sunday evening. This ensured that merely washing her face the next morning would be sufficient, and preparing for school on a Monday morning was a little easier.

> *Party more is sy het nou miskien nie vir jou .... reg gewas nie. Is maar soos op Sondagaande. Dan sal ek nou sal ek self vir hulle was… Dan weet ek nou vanaand was ek miskien nou aan. More oggend kan hulle net afvee jy weet so ... en die mond uitspoel…*
>
> **Some mornings maybe she did not … wash properly. Like maybe on Sonday evenings. Then I will wash them myself… Then I know maybe tonight I wash all. Tomorrow morning, they only have to wipe off, you know, and rinse the mouth**.

And later in the same interview she added this concern:

> *Soos ek sê sy sal altyd sien as iets nie reg is nie dan sal ek altyd vir haar sê: "Kom." Dan moet ek haar self was so …*
>
> **Like I said, she will always see when something is not right and then I will always tell her, "Come." Then I have to wash her myself so…**

Although selfcare seems to be an activity that quickly evolves from doing together to doing alone, mothers continue to supervise their adult children with FASD. Marie took the responsibility to ensure that her adult daughter, Filida, used birth control after her baby was born. Marie was able to control Filida's family planning, even while she lived with her boyfriend on the farm.

> *Sy het die depo gevat. Sy't aanvaar ... als. As ek vir haar sê mammie nou dit is vir dit en party jong manne gee vir jou eerste kind.*

She took the depo. She accepted … everything. If I tell her mommy this is for this and some young men give you your first child.

Mothers seem to facilitate engagement in occupations of productivity at home, in the same way that they grade their involvement of 'doing together'. Initially, mothers allow the children to observe while they are doing, occasionally adding verbal guidance and then gradually withdrawing their support to allow the child to do on their own. Vikki illustrates this process well:

Vikki *Soos hulle mos nou maar rondom my sal staan aan die begint as ek miskien nou dit gedoen het. Het sy natuurlik opgelet ook OK 'n mens moet so maak, jy gooi water in en die skottelgoed water, em. Skottelgoed seep of wat ook al so ek dink sy het maar gesien ... ek weet nie rerig nie.*

Lian: *Het sy gesien of het jy spesifiek vir haar gesê onthou, as jy nou skotelgoed was moet jy eers dit doen...?*

Vikki: *Ja partykeer het ek gesê ja, veral so soos ek glo daaraan die glase moet eerste gewas word dan die borde wat bietjie vetteriger is as die glase of as die koppie ... ja ja so ek het daar 'n bietjie gesê wat was julle eers daai gedeelte en dan agterna die dalk die... borde en dan die potte wat moet gewas word.*

Vikki: Like they are with me, maybe at the beginning when I did it. She obviously saw 'OK, one should do this, you add the water and the dishwashing water, em. Dishwashing liquid, whatever ... so I think she watched ... I do not really know.

Lian: Did she watch or did you tell her specifically, remember when you do the dishes, you must first ...?

Vikki: Yes, sometimes I did tell her, especially like I believe one should first do the glasses, then the plates that are greasier than the glasses or cups ... yes, yes, so I did say a little, first wash that part and aferwards, this, maybe the plates and then finally the pots must be washed.

Sylvie described how André learnt to make his bed while she gradually withdrew her support.

OK maar gestaan en kyk. Maar hy doen dit self... hy't sommer skeef en ... Nou haal ek weer die komberse af. Dan sê ek nou moet julle kyk van dit.

Also stood watching. But he does it himself ... even lopsided and ... now I take the blankets off again. Then I say you now have to watch this.

Filida, Marie's daughter learnt to bake bread by first watching, then participating and finally baking on her own, without supervision, when her mother is not at home.

Lian: *En waar het sy die eerste keer geleer om brood te bak? Hoe het sy dit geleer?*

Marie: *Ek het haar gewys hoe om ... ek maak die ronde oondkoeke, rolletjies dan sit ek dit ... smeer ee .. was eers die pan, dan smeer ek die panne, dan wys ek haar hoe moet jy die broodjies rol, en in die pan sit ...so*

Lian: *So aan die begin het sy net die broodjies gerol, jy het die deeg aangemaak en jy't geknie en ...*

Marie *Sy het geknie. Ja, en as ek geknie het dan het ek dat sy by my kom staan dan wys ek haar hoe moet sy knie, die sout is sôveel en die meel is sôveel en dan knie sy en dan is dan wys ek haar. Toe laat ek haar vir die tweede keer toe staan ek net by haar ....*

Ja ons bak roeshdoe dan sit sy dit mos nou in die oond in. Dan sit, dan wys ek vir haar hoe moet sy die oond stel. Dan draai ek dit vir haar aan en dan wys ek haar. Nee nou weet niggie hoe word die stoof gestel. Dan sê ek die stoof moet eers lou raak en dan sit ons hom brood in en dan maak ek hom eers weer dood die oond. Sodat die brood hitte kry dat dit die pan vol rys...

... Sy onthou, nee sy onthou nou rêrig. Sy onthou. En ek het, sy kan maar gaan .. sy kan allenig ek kan maar ry of so...

Lian: **And where did she learn the first time to bake bread? How did she learn?**

Marie: **I showed her how to ... I make the round oven rolls then I put it ... spread ... first wash the pan, then butter the pans, then I show her to form the rolls and put it in the pan ... like that.**

Lian **So initially she only formed the rolls, you mixed the dough and kneaded it.**

Marie **She kneaded. Yes, and when I kneaded, she was with me and I showed her how to knead, she must add so much salt and so much flour and then she kneads and then I showed her. Then the second time I let her [knead] while I stood with her.**

Yes we bake roeshdoe, then she puts it in the oven. Then puts ... then I show her how to set the oven. Then I turn it and show her. Now she knows how to set the oven. Then I say the oven must warm up first and then we put the bread in to get the heat and then I turn the oven down so that the bread can rise into the pan ....

> **.... She remembers, she really remembers. She remembers. And I did, she can go ... she can cope on her own, even when I leave ...**

Similarly, Marie facilitated her daughter's engagement in teaching Sunday School. Just like she graded her involvement when facilitating her daughter's cooking, she allowed her to watch while she taught Sunday school, gave verbal guidance, then observed her teaching the children before finally allowing her to take the class while Marie stayed home.

> *Ek... ek leer vir haar hoe om die kinders op te lei by die Sondagskool… Maar nou sê* [ek vir haar] *kom nou … ek gaan nou sit en kyk hoe jy die kinders ... ek het mos nou klaar vir jou gelei ... gewys. Eers maak ons met 'n gebed oop né dan vat jy een van die kinders om die kinders oop te maak met 'n gebed, dan doen sy dit. En as klaar die kinders gesê het die kinders moet oopmaak met gebed, dan sê ek dan begin sing julle aanbiddingslied, eers 'n opgewekte drie liede en dan is dit die aanbiddingsliede. Dan doen sy dit enne partykeer dan stuur ek haar alllenig. Dan sê ek jy moet nou gaan ek kan nou nie vanmore gaan nie want e ek voelie lekker nie. Dan gaan die ou dan gaan hou sy Sondag skool. Dan sê ek jy moet nou die pen vat dan skryf jy die kinders se name, wie het geopen in die Sondag skool dan skryf jy die naam en hoeveel kinders vandag in die Sondag skool is en dan merk jy dit reg merkies sê ek vir haar. Dan doen niggie dit... So*
>
> **I … I teach her how to train the children in the Sunday school… But now I tell her come … I will sit and watch how you [teach] the children … I guided you … showed you. First, we open with a prayer, then you take one of the children to open the children with prayer, then she does it. And when that is done, the opening in prayer, then I say, then you sing a worship song, first three upbeat songs and then the worship songs. Then she does it and sometimes I let her go alone. Then I say you must go, I don't feel well this morning. The she goes and teaches Sunday school. Then I say you must take the pen and write the children's names, who opened the Sunday school and then you write the name and how many children were at Sunday school today and then you tick their names, I tell her. Then she does it… Just like that.**

When Marie teaches Sunday school, she reads a story from the bible. However, her daughter is unable to read, so when she conducts the class, her mother guides her to ask one of the children to read. Marie therefore engages her daughter, in spite of the learning difficulties her daughter experiences as a result of FASD.

> *Lian:* *Nou sê nou maar jy is nie daar nie en Filida doen alleen die Sondagskool, kan sy die stukkie lees uit die Bybel?*
>
> *Marie:* *Sy laat een van die kinders lees.*
>
> **Lian:** **Let's say you are not there and Filida does the Sunday school on her own, can she read from the Bible?**

Marie: She lets one of the children read.

As mothers are facilitating occupational engagement, they seem to downgrade their involvement in the doing together to facilitate the child's occupational engagement while the mother is busy with another task or even in the mother's absence. This grading is well illustrated when Magret shared the laundry with her daughter and by the cooking shared between Marie and her daughter.

Magret: Ek vou, en die klein goedjies vou sy. En dan pak ek weg … [wys na foto] *Daar het hulle* [Joe en 'n tjommie] *nou die klein goedjies afgehaal. Daardie draad is bietjie platter.*

Lian: OK en sy kan dit alleen doen? … Jy hoef nie vir haar te help nie?

Magret: Nee daar help ek nou nie.

Lian: En hier? [wys na 'n volgende foto]

Magret: Daar het hulle nou ingegaan en dit op die bank eers gesit… Dan gaan ek nou inkom dan gaan ek nou vir haar sê die kleintjies moet jy nou vou en dan vou ek die grootes.

Lian: Wat doen jy terwyl sy die kleintjies vou?

Magret: Dan gaan ek nou solank die waters buitekant uitgooi.

Magret: I fold and then she folds the small things … and I pack it away … [point at the photo] … There they [Joe and her 'tjommie'/friend] took the washing down. That line is a little lower.

Lian: All right, and can she do it alone? … You needn't help her?

Magret: No, there I am not helping her.

Lian: And this one? [points to the next photo]

Magret: There they have gone inside and put it on the couch … Then I will come and tell her to fold the small things and I will fold the big ones.

Lian: What do you do while she folds the small things?

Magret: Then I will empty the water outside.

Once children gained proficiency in an occupation at home, mothers progress to facilitate occupational engagement in a different context, as this story by Magret illustrates.

En dis nie net by die huis wat sy dit [skottelgoed was] doen nie, want sy doen dit by die ander ouma se huis ook.

> **And it is not only at home she does it [wash dishes], because she also does it at the other granny's home.**

In conclusion, mothers grade their involvement in the *doing together* in different stages. By firstly allowing children to observe as they do, secondly, by guiding the child verbally to do, and thirdly, by observing as the child does and then allowing the child solitary engagement in the occupation while the mother engages in another occupation close by. Finally, the mother facilitates occupational engagement in a different context, for example, at a grandmother or aunt's home.

4.2.4. Involving Others

This category describes the way that mothers include other people to support their children. Most participants in this study live in family homes with a familial composition of the maternal grandmother, siblings and often the extended family. If the extended family are not living in the home, they live close by. The close proximity of immediate and extended family allows increased opportunities for d*oing together*. The openness of the community, and easy access of the children to the neighbourhood, means that children play in the streets, and adults interact with each other. The social interaction that occurs in these spaces are contextual factors supporting the process of doing together.

Mothers are not constantly with their children and the participants in this study draw from their close-knit social environment to include others in the support of their children. Thus, they implement a collective approach to facilitate their children's occupational engagement.

Sylvie recognises the role of friends and/or siblings to facilitate social engagement:

> *Sylvie: Baie lekker mevrou, maar hy willie verloor ie. Hy het sy dae van verloor. Vandag wen hy, more dan moet hy maar net aanvaar hy het verloor. Al wil hy nie verloor het nie, hy het verloor.*
>
> *Lian: OK ... wat maak hy as hy verloor en hy willie verloor nie?*
>
> *Sylvie: Hy gooi die tol weg of hy speel nie meer ball nie dan kom hy terug huis toe. Dan kom sit hy bo-op die stoep of hy gaan kruip weg in die kamer. Dan moet my groot seun hom nou weer kom soebat: "K om speel nou weer, kom speel nou weer". Dan moet ek sê: "Nee nou moet julle weer verloor laat hy moet kan wen." So sê ek ...*
>
> *Lian: En wat sê die ander tjommies? Raak hulle kwaad omdat hy altyd wil wen?*
>
> *Sylvie: Ja hulle raak kwaad, ek sal ok kwaad geraak het want jy kan nie altyd wil wen nie. En jy moet verloor. So, maar dan breek hulle sommer weer op as hy te kwaad is dan gaan hulle weer bietjie huis toe. Maar netnou kom hulle weer. Kom hulle weer by mekaar uit. Dan speel hulle .... weer almal saam.*

Sylvie: Very nice, ma'am, but he does not want to lose. He has his days of losing. Today he wins and tomorrow he just has to accept he loses. Even if he does not want to lose, he has lost.

Lian: OK ... what does he do when he lost and he didn't want to lose?

Sylvie: He throws the top away or he no longer plays ball and then he comes home. Then he sits on the veranda or hides in his room. Then my older son has to come and plead with him: "Come play again, come play again." Then I have to say: "You must lose, so that he can win." That's what I say.

Lian: And what does the rest of the friends say? Do they get angry because he always wants to win?

Sylvie: Yes, they get angry, I would also get angry because one cannot always win. And you have to lose as well. So then they break up when he gets too angry and they go home for a while. But just now they will all get together again. Then they play ... all together again.

In the second, photo-elicited interview, Magret shared how she involves friends in a playful way to get a mundane chore done. In this example, she wants her daughter to take off her school clothes before playing outside and turns it into a game with friends.

Magret: Daar trek sy nou vir haar uit. Dan vou sy dit… [Blaai foto] *Daar het die een tjommie nou vir haar gehelp die een kous uittrek en sy die ander.*

Lian: [Laggend] *So hulle maak sommer 'n speletjie daarvan*

Magret: Ja … [lag]

Magret: There she is undressing. Then she folds it … [Turn the picture] **There a friend helped her take off a sock and she takes off the other.**

Lian: [Laughing] **So they made a game out of it?**

Magret: Yes [laughing]

Vikki described the important role of an older, unaffected sister who organises afternoons at home when the children arrive from school and Vikki is at work.

Nee, soos ek sê die grote [ouer suster] *sal sorg dat hulle eers alles doen dan sal hulle mekaar help met die huis goete soos in skottelgoed was. Die ene kry ... Die grote doen eintlk ... gee eintlik meer die ... die werk uit. Ek gaan dit doen en dit doen ... julle twee ... maar sy gee altyd vir hulle die maklikste dele om te doen. Jy sal miskien die skottelgoed was en die ander een sal nou miskien weer afdroë en wegpak of so, dan draai sy net weer die volgende dag*

> *dit om. Of so maar sy sal nooit laat hulle die meerderheid werk doen nie. Sy sal altyd die meerderheid werk doen.*
>
> **Like I said the older** [sister] **will see to it that they finish everything and then they will help each other with the chores like doing the dishes. This one does ... The older will actually ... she distributes the chores. "I will do this and this ... and the two of you ..." But she always gives them the easy things to do. You will do the dishes and the other will dry and pack away, and the next day they swop around. Or something like that, but she will never give them the bulk of the work, she will always do the most.**

In Sylvie's home, the grandmother plays an important role.

> *Nee, die ouma het altyd skottelgoed gewas, dan het hy so buite by die ouma gesit … Dan sê die ouma jy kan nie so sit nie, jy moet sommer leer skottelgoed was, more gaan ek dood dan kan jy ook skottelgoed was. So het hy sy vadoek gevat al is dit ok papnat skottelgoed in die kas gedruk, so. Hy het maar aangegaan tot hy nou regkom.*
>
> **The granny always did the dishes and then he sat outside with the granny … Then granny said you can't sit like that, you must learn to do the dishes, tomorrow I die and then you can also do the dishes. So, he took his tea towel, even if it is wet, he packed the dishes in the cupboard, like that. He carried on until he got it right.**

Maryna described the role of unaffected children in the home, sharing how they assisted her foster daughter with FASD with her school work.

> *Ek het em vier kinders, my oudste meisie is nou matriek die jaar. En my seun... die 2e oudste is een graad 9 .... Ek dink dis hulle wat... vir hulle wat nou daai ...wat vir Alie so motiveer om skool toe te gaan sien mevrou. Elke middag by die huis te kom, eet, uittrek, vat bietjie jou boeke en kyk bietjie vir die dag se skoolwerk wat hulle gedoen het en so aan . ....*
>
> **I have, em, four children, my oldest is in grade 12 this year. And my son ... the second is in grade 9 ... I think it is them, they ... motivate Alie to go to school, you see ma'am. Every afternoon when they get home, they eat, undress and take their books to check the days school work, like that ...**

When mothers and the rest of the people at home are unable to help with schoolwork, the support network circles widen as Vikki demonstrated. However, even when including others to support her child, Vikki wants her daughter to eventually work by herself in class.

> *Dan sal ek nou vra watse huiswerk het jy? En dan gaan ons dit na. Dan sal sy vir my sê my ma ek haak nou hier vas en dan help ek haar daarmee en as ek nou weer nie verstaan nie, sal ek nou weer iemand anders vra wat verstaan. "Help my gou hier. Ek sukkel nou om vir haar dit maklik te ver.. e... verduidelik." Of by haar reg te kry want waneer sy mos nou in die klas is is sy alleen dan moet sy mos nou alleen kan regkom sonder my en my kennis of ook ... so...*
>
> **Then I will ask 'what homework do you have?' And then we check it. Then she will say, 'my mom, I am stuck here' and then I help her and when I do not understand, I will ask some one who does understand. "Quickly help me here. I battle to explain this to her in an easy way."... Or help her to do it ... because in class she has to do it on her own without my knowledge.**

Sylvie specifically mentioned teachers when she described others who assist in supporting her child. She seeks a teacher's help with her son's maths and facilitates his engagement in extra maths classes by reminding him to prepare and go to extra classes. In addition, Sylvie is willing to play an even more active role under the guidance of the teacher.

> *Ja hy flop so nou en dan by sy wiskunde.... Dan flop hy so nou en dan maar juffrou gee vir hulle so middae klasse of naweke. As juffrou nou in die mood is dan sal sy briefie stuur, hulle moet by haar huis wees so laat of so laat. "Maak nou vir jou reg, lat jy nou gou gaan." Dan so...*
>
> *Nee sy kan net kom sê* [met huisbesoek] *wat hy doen of nie doen by die skool nie. Of wat sy verwag van my af om te doen. Dan sal ek vir hom help. Sy kan naweek klasse ook aanbied. Dan's dit nog beter so, dan help dit mos nog. Dan hoef juf nie meer huisbesoek te doen nie, dan sal ek dit doen. Maar dan moet juf weer vir my ok monitor sy roep weer vir my en ek gaan wys vir haar dit het ons die naweek gedoen of dit het ons die dag weer gedoen.*
>
> **Yes, sometimes he fails maths ... He fails once in a while, but then his teacher gives them extra classes in the afternoons or weekends. When his teacher is in the mood, she will send a letter that they must come to her home at this or that time. "Get ready that you can go." Then, like that.**
>
> **No, she should only come and tell me [with a home visit] what he does or does not do at school. Or what she expects me to do. Then I will help him. She can also give weekend classes. That is even better, that will help more. Then the teacher needn't do home visits, I will do it. But then she should check my progress and call me in and I will show her what we did over the weekend or what we did that day.**

Zelda also monitors the help teachers provide in class:

> *Want hy is nogal nie in die klas besig nie... want ek het haar gevra hoe is hy in die klas. "Nee, nee hy's gehoorsaam, hy's rustig"... maar daar's 'n tjomiie van hom wat sy gesê het wat so wat vir hom nou so* ...[sy aandag aflei] *Ja, toe maak sy hulle uit mekaar uit ... toe skuif sy hulle uit mekaar uit.*
>
> **Because he is not that busy in class, ... because I asked her [the teacher] how he is in class. "No, no, he is obedient, he is calm" ... but he has a friend, she said, that ... [distracts him]. Yes, so she seperated them ... then she moved them apart.**

The role of others concludes this section on the first theme of "Doing together" as a means to facilitate occupational engagement. A visual summary of the first theme is included in Addenda H and I, in the form of a poster to promote the value of shared occupations to mothers of children with FASD.

4.3. Theme 2: Varying Access to Engagement

When data was analysed to uncover how mothers facilitate occupational engagement of their children with FASD, a second theme of ***Varying access to engagement*** was uncovered. This theme explores how mothers manipulate their children's access to occupational engagement. Three categories emerged: C*reating access***,** *Maximising access and Limiting access.* Mothers facilitate occupational engagement by creating access to friends, to safe spaces, toys (real and make believe) and to real life experiences children act out in fantasy play. Mothers maximise access to friends and family to facilitate social engagement. Ultimately, they serve as a buffer in limiting access in order to protect their children from physical and social harm.

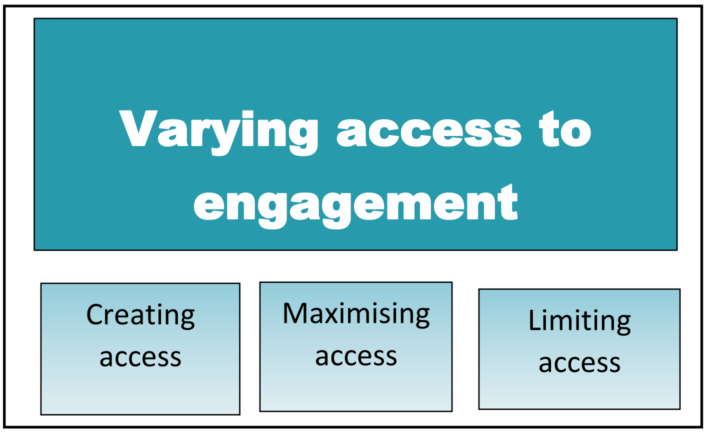


Figure 13. Theme: Varying access to engagement with categories

4.3.1. Creating Access

This category describes the way mothers create access to friends, toys or other equipment, and experiences to facilitate play. Creating access to space and time also play a role in the way mothers facilitate engagement in occupations of productivity in and around the home.

For some participants, friends are readily available, as Sylvie described when asked who her son plays with.

> *Met my twee seuns is sy maatjies en dan het hy ses ander maatjies wat ook sommer rondom ons bly.*
> **With my two boys, are his friends and then he has six other friends living close by.**

In the second PEI, Sylvie explained how she created access to these friends by welcoming them to her home and serving them meals:

> *Hy sal sommer sê skep nou laat ons* [André en sy vriende] *kan gou eet want hy wil gaan speel as ek sien...* [pause] *nee hy't nou weer tjommies op die stoep. Nou skep ek maar gou vir al die tjommies ... Jy moet skep in 'n groot bak, hulle eet saam.*
> **He will say dish up now that we [André and his friends] can quickly eat because he wants to go and play, when I see [pause] he has friends on the veranda. So I quickly dish up for all the friends... You must dish in one large bowl, they all eat together.**

Other participants had to be more directive in creating access to friends. After initially stating that her daughter had no real friends, Marie described her daughter's friends at Church. Marie created this access to friends by taking her daughter to Church and engaging her there in occupations, such as teaching Sunday School and lead singing.

> *En e sy is 'n persoon, sy kom by die huis en daarvan af worrie sy nie ... Sy het ook nie eintlik rerig tjommies nie. Tot nou nog toe. By haar is dit by die kerk as sy daai tyd by die jeug, saam met die jeug tjommies is sy [te]vrede. Maar sy is 'n persoon as sy klaar is dan gaan sy hui... huis skoonmaak* [gewigtige fluister].
>
> *... die Kerk is net so oorkant die pad. Dan gaan sy dan nou maar daar tussen die ander tjommies* [van haar eie ouderdom] *en gesels en so aan.*
>
> **And, e... she is one, she comes home and then she doesn't care … She has no real friends. Even now. With her it is the church and that time at the youth, with the friends there, she is happy. But she is a person when she is finished, she will … clean the house** [heavy whisper].

> **… the Church is just across the road. Then she goes there between the other friends (of her own age) and chats and so on.**

Creating access to real life experiences, which children can act out in fantasy play, is another way to facilitate play. During her second PEI, Zelda showed me a family picture taken before Church. Taking her son to Church, Zelda created access to the idea for his make-believe preaching.

> *Ja, dis die oggend toe ons oppad Kerk toe is... Ons almal was Kerk toe ....*
>
> *Hy's baie lief vir Kerk speel...*
>
> **Yes, that's the morning on the way to church ... We all went to church ... He loves playing church.**

Creating access to toys, real and pretend, facilitates play. Examples of this include how Magret gives her daughter, Joe, a blanket to wrap around the brick which becomes Joe's make-believe baby. Magret showed me a picture of Joe carrying the make-believe baby on her back, as well as a photograph of Magret and Joe cooking together. While cooking, Magret has Joe's baby sister on her back in the same way Joe carries her make-believe baby. Just like Zelda's 'preaching' son uses real life experiences in his fantasy play, Joe acts out the occupations her mother engages in daily.

> *Daar het sy nou die baksteen gevat om te maak soos haar babatjie. Hier draai sy hom nou toe…. Daarso word hy nou geabba.*
> **There she's taken a brick to make believe like her baby. Here she is wrapping him up … There he is carried on her back.**

Mothers facilitated play by creating access to toys which they bought when money was available, or which children received from donors. Children also improvised with the little that was around them. Magret continues to create access to the fantasy game of playing house by giving the children food to use in their game.

> *Magret:* *Hulle vat mos sommer die bakstene dan pak hulle so en so. En dan sal sy vir my sê gee vir my iets. Dis dan kos en so ... en dan speel hulle nou* [huis].
> *Lian:* *En waarin gee jy dan vir haar die kos?*
> *Magret:* *Dan skep ek nou in die huis in 'n bakkie vir haar en dan vat sy nou haar speelgoedjies dis nou hulle se borde ... en so en dan gaan hulle aan.*
> **Magret:** **They take the bricks and then they stack them like this. And then she will ask me for something. That is food and so … then they play** [house].
> **Lian:** **And in what do you give her the food?**

Magret: **I dish up inside for her in a bowl and then she takes her toys, those are now their plates and so and then they carry on.**

Access to material/equipment is a further way that mothers create access in order to facilitate occupational engagement. Vikki allows her daughter to cut up old clothes and re-model them into clothes for her doll. Vikki has never actually taught Ali to sew, she learnt by observing her mother. Vikki shared this anecdote about her daughter's sewing.

> *Dan sal sy altyd hierdie ou sweaters van hulle wat hulle nou nie meer aantrek of wat ook al nie. Dan sal sy kleertjies maak sommer met regte naald werk, naaldwerk. Ek het haar nie geleer naaldwerk doen nie, maar dan sien ek daar word 'n nou 'n toppetjie of nou 'n skirtjie gemaak vir die pop.*
> **Then she will always take those old sweaters they no longer wear or whatever. Then she will make dolls clothes with real needle and thread, sewing. I never taught her to sew but then I just see there a top or skirt is made for the doll.**

Later Vikki explains ways she can facilitate her daughter's sewing as well as how her daughter initiated the sewing of dolls clothes: Vikki is also considering access to better equipment that will refine her daughter's sewing, and may then become an occupation of productivity. Although Ali has observed her mother sewing, Vikki has never taught her daughter, Ali, to sew.

> *Ek moet haar net meer aandag, meer aandag gee aan dit wat sy doen dat sy meer, beter werk. Ok die steke wat gedoen word is nou maar nog nie heelwat soos ek dit sou perfek doen nie maar e net dat dit dat die ee aanmekaar is.*
>
> *… Laat dit aanmekaar is ... soos daai e... naaldwerkmasjientjies wat 'n mens kry wat ook sommer maar plestiek is want eke dink ek het ook enetjie gehad toe ek kleiner was maar dit was baie lank terug. Ek weet nie kry 'n mens nog so iets nie? Dan sal ek vir haar dit kan ... dit koop as ek kan. Dan dink ek dit sal haar ook meer beter push en ... ja... Ek doen dit ... sy sien ek doen die naaldwerk, maar sy kom sit nie en kyk presies hoe doen ek dit nie. Ja ek het haar rerig nie geleer nie ek sien ook maar net...*
>
> **I need to be more attentive, more attentive to what she does, so that she can work more, better. Also, the stitches made is not quite like I would do it perfectly, but it is sewn together. …**
>
> **Like those, e… sewing machine that one gets even the plastic ones, because I think I had one when I was little, but that was a long time ago. I don't even know if one still gets them. Then I will buy it for her if I can. Then it will encourage her even more and … yes... I do it, … she sees me sewing, but she**

> **does not sit with me and watch exactly what I do. Yes, but I did not really teach her, she also just watched.**

Children in this study helped themselves to sandwiches and tea or coffee from a young age. Sylvie described how her son, André rises early during the school holidays to help himself to tea, because she had created access by setting things within his reach. Apart from helping himself, he also made his mother coffee, returning to the theme of 'doing together'.

> *Dan staan hy op, dan sit hy die TV aan dan sit hy die ketel aan. Dan maak hy vir my bietjie koffie, die ouma bietjie tee en vir hom 'n bietjie tee. As hy klaar sy teetjies gedrink het dan gaan kyk hy vir Tom & Jerry. Agt uur se kant, sê nou ek staan 8 uur op want ek hoef nie vroeg op te staan nie, die skool het gesluit. As ek opgestaan het dan sê hy nou's ek BAIE honger, dan maak ek vir ons almal pap.*
> **Then he gets up and switches on the TV and the kettle. Then he makes me a little coffee and a little tea for the granny and for him a little tea. When he finished his tea he watches Tom & Jerry. At about eight o'clock when I get up, because I don't get up early, schools are closed. When I got up then he will tell me he is VERY hungry and then I make porridge for all of us.**

She explains how she facilitated his engagement in this occupation:

> *Ek het vir hulle almal geleer tee maak. Ons het emm groot kombuis. Toe dink ek nee, kom ek skuif die kombuis dat hy die kaste bietjie nader bring en die ketel bietjie plat sit soos by daai plug.* [wys na 'n lae muurprop] *Ek sit die ketel daar ek sê vir hulle: "Die ketel word nie aangesit as hy nie water inhet nie. Julle moet altyd water in die ketel ingooi. En as jy klein bietjie water wil ingooi, gooi maar twee koppies in. As jy vinnig wil vir jou wil tee maak." So het ek vir hulle almal geleer. Daar's 'n skinkbord bo-op die tafel. Die ketel staan as hy af is, is hy daar* [wys na denkbeeldige skikbord op lae tafeltjie]. *Jy haal hom uit die skinkbord uit jy gaan plug hom in ... die koppie, die suiker en die tee wat hy wil hê bly daar in die skinkbord in. Hy moet net daar in die skinkbord tee maak. So.*
> **I taught them all to make tea. We have a big kitchen. So I thought, let me move the kitchen to bring the cupboards a little closer and the kettle a little lower, like at that plug** [points to a low electrical plug in the wall]**. I put the kettle there for them and I tell them: "The kettle does not get switched on when it has no water in. You always have to put water in the kettle. And if you want to boil a little water, put two cups in. If you want to make yourself a quick cup of tea." I taught them like that. There is a tray on the table. That is the place for the kettle when it is off** [points to an imaginary tray on a low table]. **You take the kettle**

> **from the tray and plug it in... the cup, the sugar and tea, everything you want stays there on the tray. He should make tea right there in the tray.**

However, the context of André's independence, is the doing together discussed earlier in this chapter.

> *Hy is 'n ander mens, hy sal altyd in die kombuis bly as jy daar werk. So hy sien sommer nee jy't so gemaak, jy't so gemaak.*
>
> **He is another one, he will always stay in the kitchen when you are working there. So, he sees, you do this or you do that.**

Vikki was the only participant with full time employment. Her work, as a shop assistant, involved alternative weekend shifts. Vikki has to plan her routine carefully to create access to family time on the Saturday mornings she has free. She tries to finish her laundry on a Friday morning while her children are at school. Vikki and her daughters clean the house on Saturday mornings. In this manner, the chore is completed, while enjoying family time together. She narrates:

> *Ek sal byvoorbeeld soos in nou al klaar Vrydag oggend voor ek werk toe gaan* [teen 14:00] *sal ek sorg dat onse wasgoed ... dat ek die wasgoed klaar uit die pad uit kry. Dan Saterdag oggend dan maak ons nou weer die huis skoon. Dan sal ek nou miskien in die kombuis wees. Hulle sal miskien in die kamer begin, die ander een sal miskien die voorkamer se vertek vat. Dan sal een van hulle sommer uitbreek met 'n koortjie ...'*
>
> **I will for example on a Friday already, before I go to work** [at 14:00] **then I will see to it that our washing is done ... that I get the washing out the way. Then on Saturday morning we clean the house. Then I will maybe be in the kitchen. They will start in the room and the other one in the lounge. Then one of them will spontateously start a song.**

Sylvie described how she encourages her son to go to school on mornings when he doesn't feel like it. In this way, creating access to the occupation of school work.

> *Sylvie:* *Ek push hom skool toe. Ek ondersteun hom skool toe, ek sal als doen om hom by die skool te kry*
>
> *Lian:* *OK so wat doen jy as jy hom push skool toe?*
>
> *Sylvie:* *'n Mens die... 'n mens het mos jou dae ... vandag voel jy nee nie vir die skool nie nee weer more. Ek sal vir hom sê nee man, staan nou op dan gaan jy skool toe. Vanmiddag as die skool uitkom dan kom lê jy of dan kom doen jy die ding wat jy wou gedoen het.*

Sylvie: I push him to school. I support him to school, I will do everything to get him at school.

Lian: OK, so what do you do to push him to school?

Sylvie: One, the … one has one's days … today you don't feel like school, I will go again tomorrow. I will tell him, no man, get up and go to school. This afternoon when you come from school then you can come and lie down or do what you wanted to do.

The routines, before and after school, play an important role in the way that mothers facilitate their children's engagement in school work. Zelda explains the morning routine when asked what time her son wakes up:

Zelda: Sê maar so voor 7. Nie eintlik voor 7 al nie So past 7. Daar is dae wat hy 'n klein bietjie laat lê.

Lian: Is dit? So jy hoef hom nie wakker te maak nie. Hy word self wakker?

Zelda: Nee, ek sien hy lê nou in die tydjie in. Noudat hy seker moeg gespeel... dat ek hom moet wakker maak. Hy hou om ook eintlik aan die slaap... Ja, dis vir die koue, maak hom weer toe as ek hom oopmaak...

Zelda: Let's say before seven. Not really before seven, maybe past seven. There are the days he lies in a little...

Lian: Really? So you needn't wake him? He wakes on his own?

Zelda: No, I see he lies in a little. Now that he is probably tired from playing ... then I have to wake him. He actually pretends to be sleeping ... Yes, in the cold he covers himself up again when I take the blankets off...

In contrast with the routines in the above two homes, Doreen struggles to establish a routine for the orphaned child she fosters. Clavina appears to come and go as she pleases, often staying with family of her deceased mother.

En as sewe uur daar is, ek roep ek soek ook. Dan gee ek vir haar so een of twee rapse: As ek sê ses uur is ses uur.

And when seven o'clock comes, I call and search also. Then I give her a smack or two. When I say six o'clock it's six o'clock.

Earlier in the interview Doreen gave a more detailed account of her battle to establish a routine. She spoke about how Clavina would go out and sometimes only return the following morning:

> *Dis al wat ek mee sukkel en ... Sy slaap versKRIKlik uit. As sy nie by die ouma slaap nie dan is daar 'n vrou af in die straat waar sy slaap. Op die hoek. Nie ver van my af nie... Dan sal daai vrou vir haar hou en nie vir daai kind sê kom huis toe nie. Dan kom die kind more oggend huis toe. Dan wil daai kind nog kom lê. O, dis vir my baie moeilik daai. Ek het vir daai vrou geconfront, nou die aand toe sê ek jy's 'n groot vrou, jy's 'n groot vrou… week en naweek, jy weet wat is dit vir 'n meisiekind .... Maar net daai, sien jy daai ek weet nie of sy vergeet om huis toe te kom of wat nie, maar ek sê dan daai mense…. en ek gee nie om as sy naweke by haar ouma slaap nie. Maar daai huis is so vol.*
>
> **That is the only thing I struggle with and … She sleeps out a lot. Maybe she sleeps with the granny or a woman down the street. On the corner. Not far from me … Then, that women will keep her and not send her home. Then the child only comes home the next morning. Then she wants to get into bed. Oh, it is really hard, that. I confronted that woman, the other night, "you are an adult, you're an adult" I said, "week and weekend." You know what it is like for a girl child. That is the only thing, you see, I don't know if she forgets to come home or what, but I say those people … And I don't care if she stays with her granny, weekends. But that house is so full.**

Lya allowed her son to find his own routine, even though she was dissatisfied with it. This is the same mother who complained that her son dropped out of school. Both, the presence and the absence of routine appear to emphasise the importance of establishing one, in order to facilitate engagement in occupations of productivity such as work and school work.

> *Lya:* *Enige tyd as hy net 'n draai loop dan kom hy terug kom eet hy*
>
> *Lian:* *So daar is nie 'n spesifieke tyd nie*
>
> *Lya:* *Nee daar's nie tyd nie. ... Hy kom laat saans in huis in ...Sê as die hoenders kraai eerste hoenders. As hy inkom dan hoor ek hier kraai die hoenders*

> **Lya:** **Any time, even if he goes a little way and then returns, he comes to eat.**
>
> **Lian:** **So there is no specific time?**
>
> **Lya:** **No, there is no time...He gets home late at night... Maybe at the first crow of the rooster. When he comes in I hear the rooster crow.**

Another important aspect contributing to mothers' facilitation of play was creating access to a safe play space, which encompassed social as well as physical safety. Magret shared the following about keeping her daughter safe and off the street

Magret: *Dan bly sy uit die straat uit*

Lian: *En hoekom wil jy nie hê sy moet in die straat wees nie?*

Magret: *Want die karre ry rof en party kinders baklei met haar. Dan voel ek sy moet maar net by die huis is.*

Lian: *OK… En hoekom kom sy eerder … na jou toe? Hoe kry jy dit reg dat hulle by jou in die jaart speel en dat sy nie in die straat gaan speel nie?*

Magret: *Omlat my ma voel ook soos ek voel. Dat sy maar liewerster in die jaart speel dat ons sien sy is veilig in die jaart. Dat sy nie seerkry nie want partykeer is daar woorde.*

Magret: **Then she stays out of the streets.**

Lian: **And why do you not want her on the streets?**

Magret: **Because the cars go wild or sometimes other kids fight with her. Then I feel she should rather just stay at home.**

Lian: **OK … And why does she rather come … to you? How did you manage to get them to play in your yard and keep her off the street?**

Magret: **Because my mother also feels that way. That she should rather play in the yard where we can see that she is safe in the yard. That she does not get hurt, because sometimes there are squabbles.**

Maryna confirmed the importance of creating a safe environment as she shared her opinion on the difference a stable home has made for Ali, her foster daughter. Ali's parents died and in spite of the disruption caused by such a loss, Maryna and her husband provided a stable home, thus curtailing the impact of FASD.

Maryna: *Maar dit lyk nie vir my rerig Alie is so baie aangetas nie. Want ek het ok al iets ek het ok al iets opgelet. Want ek dink kinders wie se ouers beide gesterwe is, of veral as die ma wegval en die ma is gesterwe dan isit mos amper so die hele huishouding omvou. Ja daar is nou nie weer 'n hand wat nou vir hulle op die straight en narrow paadjie hou nie en dan los die kinders die skool en wat dit... Maar in die geval van hulle tweetjies mm-m....*

Lian: *Omdat hulle in elkgeval by jou bly ... so ma het weggeval maar jy het hulle in elk geval toe nou al versorg en*

Maryna: *Ja … Mevrou kyk hulle, ek dink hulle tweetjies was nie so klein ek dink hulle was al by hulle se verstand toe hulle by hulle se ma gebly het. Toe sien hule in watter omstandighede bly hulle, verstaan mevrou. So toe hulle nou na my toe kom toe sien hulle nou die verskil by my huis en daar waar hulle gebly het by hulle oorlede ma.*

Sien mevrou? En daar het ek en my man vir hulle geleer ... Ons maak ... ons doen dinge so en op so manier ja.

Maryna: **It does not seem to me that Ali is that severely affected. Because I have observed something. Because I think children whose parents both died or especially if the mother passed away then it is almost as if the whole home collapses. Yes, there is no longer a hand to keep them on the straight and narrow and then the children drop out of school and whatever. But in the case of these two ... mm-m....**

Lian: **Because they were already staying with you and you were already caring for them so when their mother passed away, you were aready there.**

Maryna: **Yes, ma'am, see, they, I think these two was not that small, I think they were already of sound mind when they stayed with their mother. Then they realised what context they were staying in, you see. So, when they came to me, they saw the difference in my house and where they were. You see, mam? And then my husband and I taught them there … We do things … we do things like this and in that way.**

The category of creating access described the importance of access to friends, experiences, material, equipment, time and routine as well as physical and emotional safety when mothers facilitate the occupational engagement of their children with FASD.

4.3.2. Maximising Access

Apart from the access mothers create as described in the previous category, children also find access to sport and games, such as through their schools and with their friends. This category describes the way mothers maximise the access created by themselves or others, for their children to engage in occupations of leisure such as sports and games.

Vikki and Sylvie, within the Renosterberg area, shared their experiences of watching their children participate in sport. This support for the child's occupational engagement encourages continued participation.

Vikki: *Rerig dis vir my lekker om vir hulle dop te hou en te kyk hoe's hulle in aksie. [*Lag]

Really I like watching them and seeing them in action. [Laughs]

Sylvie: *Ja... ek willie hê hy moet voel maar my ma is dan nie hier nie want more oor more dan sê hy nee ek doen nie meer daai ding nie. Al'ie mammas skree , my ma issie daar om te skree nie. So ek glo as hulle 'n ding doen, ek moet daar wees.*

Yes, I don't want him to feel my mother is not here because tomorrow or the day after he may decide he no longer wants to

> **do that thing. All the mothers cheer, my mother is not there to cheer. So I believe when he participates, I have to be there.**

Later, when asked to describe a time she felt proud of her son, Sylvie shared this story about André winning a wire-car race (*draadkar resies*). He surprised her with an achievement she did not think he was capable of. However, he often observed his siblings engaging in such a race and followed their lead. This, combined with his mother's regular support at sport events, seem to have motivated his engagement in this race.

> [Lag] *Hy het my nou die dag verras met die draadkar kompetisie... [mmm] Hy't mos nog nooit deelgeneem nie. Dis net my kinders wat altyd aan [die kompetisie] deelgeneem het, dan wen hulle, dan wen hulle. Dan sê hy ek gaan ok vir my inskrywe. Dan sê ek nee, nee jy kan nie hardloop nie. U-e moenie vir jou in die skande gaan steek nie. Nou, Nou die dag met die draadkar kompetisie die 8e Sept toe sê hy ek gaan nou vir jou wys. Ek gaan nou wen as ek kom. Maar hulle het sommer so aan die voorkant van ... daar by die hof se kant gehardloop Toe skree hulle kom kyk jou kind hy wen nou! Toe's dit hy wat daar aankom: "Ek het jou gesê ek gaan wen." Toe sê ek nou kan jy hardloop! Toe spog ons die heeldag met hy't nou gewen!*
>
> [Laughs] **He surprised me the other day with the wire-car race. Usually only my children enter in** [the race]**, then they win. Then he asked to also enter. So I said no, no you can't run. U-e, don't put me to shame. So the other day with the race on 8 Sept, then he said now I will show you. I will show you I can win. But they ran only in the front of ... they ran there in front of the court. Next thing they called me: "Come look, your child is winning! So he came past and he shouted "I told you I'm gonna win!" So I said now you can run! So we bragged with him all day, with his victory!**

Hot summer afternoons in the Karoo are a time for families to relax in the shade of a tree enjoying a cool evening breeze. Mothers use this opportunity to engage their children in board games. Using this to teach and refine social skills such as that of taking turns, following rules, as well as winning or losing without alienating other players.

Maryna shared how she initiates these games:

> *Hulle speel mos nou die kaarte en dan speel hulle die Ludo bord, wat ons almal, ek speel saam met hulle die ludo bord ... Ons het so bord daar in die huis in. Sien mevrou? En as hulle so begin vervelig raak dan sê ek vir hulle kom ons gaan sit daar buite onder die koelte dan speel ons. Dan speel ons almal saam ... Ja hulle almal speel saam. Of die straat se kinders kom join ok dan speel almal lekker saam.*

They play cards and then they play ludo, because we all, I also play Ludo with them... We have a board there at home. You see ma'am? And when they get bored then I say come lets go play in the shade under the tree - then we play. Then we all play together... Yes, they all play together. Or the children of our street also join in and we all play nicely together.

Magret also plays Ludo with her daughter and during her first interview Magret told this story about moulding her daughter's social engagement during this game.

Magret:	*Partykeer speel ons miskien Ludo bord dan speel hulle saam.*
Lian:	*… en raak sy ooit kwaad as julle dit speel?*
Magret:	*Net as sy verloor dan raak sy nou kwaad.*
Lian:	*En dan? Wat maak sy as sy kwaad raak?*
Magret:	*Dan sê sy nee julle speel nou vir my skelm. Dan sê ons nee Joe ons issie skelm nie* [lag]
Magret:	**Sometimes we play Ludo and they join us.**
Lian:	**… and does she ever get upset when you play?**
Magret:	**Only when she loses, she gets upset.**
Lian:	**So, what does she do when she is upset?**
Magret:	**Then she says, no you are cheating. But we say, no Joe, we are not cheating.** [laughs]

These stories by Magret and Marie illustrates how they maximise access with the board games they play together. This assists in reinforcing academic concepts such as number concept and matching.

Magret:	*Partykeer speel ons miskien Ludo bord dan speel hulle saam…. Ek en sy en die broertie en die pa. En dan leer ek nou weer vir hulle daar ook en die nommers en so ….*
	Sometimes we play Ludo and they join us … Me and the little brother and their father. And then I teach them there about the numbers and so …
Marie:	*Met die kaart speel .... sy en die nommers, sy weet wat op wat is, is, is ... sê ons speel vyf kaart. Dan weet sy dis twee sewes, en sê maar sy't sy het twee sewes dan het sy by die twee of twee vywe. Dan weet sy daar kort nou een twee vywe. Dan kort daar nog 'n een vyf. Dan is die ander ene mos miskien 'n J of 'n K, dan*

> *weet sy nee daai is die name. Nou vat sy net dan sit sy net 'n K by die ... dan weet sy haar dinges is vol.*
>
> **Playing cards, she and the numbers, she knows what is on the cards. Let's say we play five cards. Then she knows these are both sevens and maybe she has two sevens or two fives. Then she knows she needs another one, two fives. Then one more five. Then the other is maybe a J or a K, then she knows their names. Then she only adds a K then she knows her things are full.**

This category of maximising access describes the way that mothers make the most of occupations their children engage in to encourage further engagement and to develop skills, such as social skills.

4.3.3. Limiting Access

Just like mothers create and maximise access to facilitate occupational engagement, they control and, in some cases, limit access as a buffer to harmful occupational engagement. The following will explain how mothers do this in order to protect their children physically and socially.

Zelda waited for her son after school and walked him home in order to protect him from harmful occupations such as fighting. Sylvie declared that she would protect her son from unwelcome friends who may facilitate engagement in occupations she does not approve of, like drinking.

> *Zelda: Maar ek gaan haal hulle as die skool uitkom* [om saam huis toe te stap]*. Die kinders is baie bakleierig deur daai vlak.*
>
> **But I fetch them when they come from school** [to walk them home]**. The children often fight coming through that area.**

> *Sylvie: Ek ja daai vriende weg van hom af . Ek sal daai vriende wegja van hom af want ek sal vir hom sê daai vriende van jou pas nie by jou nie. Want ek soekie 'n drink kind nie. Ek sal rerig sy vriende weg ja of waar hy is waar snaaks is .. ek sal hom gaan haal daar.*
>
> **I will chase those friends off. I will chase the friends from him, because I will tell him they do not suit you. Because I don't want a drinking child. I will really chase those friends off or go fetch him when he is with them.**

Lya explained the manner in which she limits her son's access to an environment and friends who may engage him in risky occupations. She does not want him to go to town and never sends him there on errands.

Lya: *Nee, hy lopie dorp nie ... ek stuur hom okie eers nie em-m ek willie dat hy dorp toe gaan nie. Nee hulle kry stout maniere .... Stoutigheid ... kwaad doen ...mense ook roof. Tjommie verraai [versoek] jou mos gou ... ene ene "Kom ons gryp daai ding" "Kom ons doen daai ding" Dan loop doen hulle daai ding ja. En ek willie so nie.*

He does not go to town, I never send him there. Em-m, I don't want him to go to town. No, they get bad habbits there. Friends quickly lead you into temptation and... and... "Come let's grab that. Let's do that." Then they do that, yes. I don't want that.

Marie recalls her daughter's distress when others teased her for not remembering. Ultimately, supporting her daughter in her decision to drop out of school, and thus, protecting her from being teased in this way.

.... Partykeers daai tyd nou né daai tyd, dan-dan doen sy ee...eee.. sê sy kan nou nie daai ding doen nie .... Nou gwarra die kinders haar en dis seer vir my gewees altyd. As hulle so, sê sy doen nou nie sy kan nou nie reg skryf nie, sy kan nie onthou nie, sulke goed sien mevrou, dit was vir my baie seer gewees. Toe kon sy nie eers geonthou het nie. En dat die kinders vir haar gegwarra het altyd ooo Filida jy kan nie eers lees nie. Sy's so sy kan nie eers in die skool klaar maak nie, sulke goede ai. Dan kom sy, dan kom sy huis toe dan sê ek vir haar moenie worrie nie, dan leer ek haar. Ek het maar net die krag oor ek die Here gevra die geduld het. Mevrou die belangrikste is jy moet geduld het met sulke kinders...
Sometimes back then, hey, then she e..e.. say maybe she cannot do something… The children teased her and it hurt me always. When they say maybe she can't write or she can't remember, things like that, you see ma'am, it really hurt me. Then she could not even remember. And that the children always teased her, "oh, Filida, you cannot even read." She is like that, she could not even finish school, poor child. Then she comes home and then I tell her not to worry and I teach her. I only have the strength because I asked the Lord for patience. Ma'am, the most important thing is to have patience with children like that.

Lastly, mothers denied their children access to undesired occupations as a way of discipline. Zelda disapproved of the game of chance (gambling) her son engaged in, because it often resulted in physical fights and/or stabbings. Although she grudgingly tolerated her son and his friends playing a make-believe version of the game with small stones, as soon as they began using real money, she destroyed their equipment by squashing their tin.

Kyk die dobbel speel [ongemaklike lag]... *en ek hou nie van die gespelery nie. Dis gevaarlik hulle baklei onder mekaar. Selfs die groot manne ook. Dis beter so as*

> *hulle met die klippe speel. Dis mos nie geld nie. As hy dit speel, ek wil dit nie hê nie. Maar om hom nou, partykeer my ma soek dit ok nie... Ek sê hulle moet nie speel nie ek het al die blikke plat getrap.*
>
> **Look there - make believe gambling** [uncomfortable laugh] **... I don't like that kind of play. It is dangerous, they fight each other. Even the adult men. It is better when they play with stones. That is not money. If he plays that, I don't want it. But around him, sometimes my mother also doesn't want it. I say they must not play. I have already stood on the tins to squash it.**

The second theme with its nested categories of *creating access, maximising access* and *limiting access*, described the way that mothers ***Vary access to engagement*** in order to facilitate their children's engagement in occupations of leisure and productivity as well as for their social engagement.

4.4. Conclusion

Mothers in this study facilitated the occupational engagement of their children with FASD by *doing together and grading their involvement* in their doing together, by *being flexible in their expectations* of their child, and lastly by *involving others* in the support for their children. This theme of ***Doing together*** underpinned the findings of the study. The second theme of ***Varying access to engagement*** described how mothers either assist in creating, maximising or limiting access.

The following chapter will discuss these findings in the context of the literature on FASD and the theoretical lens of the CMOP-E that informed the study.

Chapter 5: Discussion

5.1. Introduction

Chapter four described the important role mothers play in facilitating the occupational engagement of children with FASD as illustrated by the two themes ***Doing together*** and ***Varying access to occupational engagement***. This chapter will draw on the framework of the Canadian Model of Occupational Performance and Engagement (Polatajko et al. 2007) to explain the findings generated in the study. This framework is situated in client-centred practice and thus aligns with the study's intent to gain mother's perspectives of how they facilitate the occupational engagement of their children. The CMOP-E focuses on the dynamic interaction between the person and the environment through occupation. In this study, the variables that mothers experienced as hindering them in promoting occupational engagement of persons with FASD, were primarily rooted within the person – in other words, the challenges associated with FASD. On the other hand, the factors mothers identified as resources enabling their facilitation of their children's occupational engagement were embedded within their environment. Co-occupation (Price & Stephenson 2009) emerged as the key unlocking mothers' ability to facilitate interaction between the person with FASD and the environment. This chapter will discuss the interplay between the person, environment and occupation by highlighting the obstacles and resources as well as co-occupation which emerged as the key that mothers use to unlock their children's occupational engagement.

5.2. Factors limiting Occupational Engagement

The phenotype of a person with FASD has been well described in literature (Kalberg & Buckley 2007; Franklin et al. 2008; Kodituwakku 2009; Densmore 2013; Nash 2012; Mattson et al. 2013). However, understanding participants' perspective on challenges such as impulsiveness, distractibility, poor memory and hyperactivity enlighten the hindrances they experienced when facilitating the occupational engagement of their children with FASD. These strains are mainly embedded in the person as framed by the CMOP-E in a triangle of feeling (affect), thinking (cognition) and doing (physical), situated around a spiritual core.

The first hindrance within the *affective component* of the person that participants described, was impulsive behaviour. Impulsiveness is well recognized amongst people with FASD with traits such as blurting out inappropriate comments, acting before thinking, intruding in others' personal space, and difficulty in waiting their turn (Kalberg & Buckley 2007). In this research, Sylvie reported that André was quick to fight with his fists when teased and Maryna described Ali's quick temper when not getting her own way. Lya found it unacceptable that Rico threw down the rake he was using in the yard when she reprimanded him. Inability to wait for a turn was another aspect of impulsive behaviour recognized by Sylvie and Magret as they described their children's insistence to always win the games played with family or friends. Sylvie elaborated by describing the subsequent withdrawal of André's friends when he became too demanding. Thus, she recognised his impulsiveness as hampering his social engagement. Literature (Laugerson et al. 2007; Kalberg & Buckley 2007) confirmed Sylvie's observation, describing the challenges people with FASD experience with the rules of engagement that influence the establishment and maintenance of social relationships. Parents raising children with FASD in Alberta, Canada, raised similar concerns regarding externalizing behaviour (Sanders & Buck 2010).

Depression and mood swings are other affective elements within the person which mothers described as obstructing their facilitation of the occupational engagement of their children. Sophie, for example, described the long hours her daughter sleeps and her mood swings which relate to depression. Depression is associated with FASD (Olson et al. 2007; Franklin et al. 2008). Olson et al. (2007) found depression especially prevalent amongst people of lower income groups who experienced additional risk factors. The risk factors in this research included social violence, malnutrition and poor living conditions. Externalizing behaviour such as physical fights might be more obvious to recognize than internalized problems such as depression (Olson et al. 2007). However, the impact of depression on occupational engagement cannot be underestimated and the long hours Sophie observed her daughter sitting in the sun like a 'granny' may be related to her depression.

Obstructions to the way mothers facilitated occupational engagement were also nested in the *cognitive* realm of the person, such as distractibility and poor recall of verbal instruction. Zelda found it difficult to retain her son's attention while helping him with his homework. She tried to accommodate his short attention span by allowing breaks while doing homework. An attention break is one way to counteract distractibility, but literature describes a variety of strategies. Kalberg & Buckley (2007) recommended the use of routine and task structure as well as limitating visual and auditory distraction. When structuring a task, they (Kalberg & Buckley 2007) recommend underlining, highlighting or colour coding related issues to emphasize important facts and improve the clarity of tasks. In addition, they recommend the use of visual instructions such as placing an arrow to guide the child through the process of the task, numbering the sequence, or offering written instruction which may take the form of icons rather than written words. A predictable routine like setting aside a specific time of day for homework may also help a child with FASD to focus attention (Kalberg & Buckley 2007).

Maryna found poor recall of verbal instruction hampering when facilitating her child's engagement in the occupation of buying daily rations such as bread and milk for her family. She accommodated this by allowing her daughter a second chance to return for the item she had forgotten. It worked well when considering their close proximity to the shop, although a visual aid (Kalberg & Buckley 2007), in the form of a list with either written words or icons could also assist verbal memory.

A third cognitive aspect participants highlighted, as impeding the occupational engagement of their children, was learning difficulty (Kalberg & Buckley 2007). Participants described their children as slow learners at school, while quick to learn practical occupations such as baking bread, cooking a meal or when engaging in occupations of leisure such as singing or dancing (including learning the words of a song, or the moves of a dance). This paradox is in line with research on the occupation of mothering a child with disability (Larson 1998), as mothers try to keep a positive perspective of their children in spite of their challenges. However, exploring the successful learning which takes place during playful co-occupations like singing, dancing and board games or domestic occupations such as baking, may facilitate learning for school. It should be noted that participants of school aged children in the study all expressed a desire for their children to complete school. Kalberg & Buckley (2007) described school as daunting, and often a negative experience for children with FASD, emphasizing the need to offer intervention for learning challenges associated with FASD.

Hyperactivity is associated with FASD (Sanders & Buck 2010; Kalberg and Buckley 2007) and mothers in this research study described their children as busy. Some participants viewed the hyperactivity in a positive light and described their children as tireless when helping them in the home, while others described their children as constantly busy and active. Describing hyperactivity as tireless helps mothers take a positive view of the challenges associated with FASD which they recognise in their children (Larson 1998). However, children's busy and overly active behaviour did interfere when mothers helped them with homework for school. Abele-Webster et al. (2012) found that children with FASD were slower in habituating to stimulation. Their research found that when children with FASD register stimulation (sound or movement) they may become over aroused and seek more stimulation. These children may benefit from less auditory input, by using techniques to limit noise, wearing headphones or earplugs, and limiting verbal instructions (Abele-Webster et al. 2012). Participants in this study all lived in fairly noisy environments, where it would be challenging to eliminate noise. Under these circumstances, headphones or earplugs may prove effective in limiting auditory stimulation.

Physical challenges associated with FASD include low muscle tone, poor balance and clumsiness (Kalberg et al. 2006; Jirikowic et al. 2008 & Franklin et al., 2008). The occupations that participants and their children from this study engaged in, included plenty of physical activity, like playing with a ball, washing clothes by hand, and kneading bread. This physical exercise seems an effective way to combat the physical challenges of FASD as suggested by Kalberg et al. (2006). In addition, occupations of productivity in and around the house such as washing, cleaning, cooking and baking were frequently described by participants when they spoke about the ways in which they facilitated their children's occupational engagement. These occupations confirm the relative strength on the domestic subscales that Jirikowic et al. (2008) identified, as children in their research also helped to maintain the home.

According to the CMOP-E, the spiritual core of the person reflects one's central beliefs and values (Polatajko et al. 2007) and influences one's decision making (Culshaw 2015). Participants in this study influenced their children's decision making and occupational choice (Galvaan 2010) through the various occupations they shared with their children. Joe's free choice to join her mother in the occupation of washing their clothes demonstrates this influence. They enjoyed the shared occupation of doing the laundry, which motivated Joe to join her mother in this occupation, even when she had a choice not to. In addition, children tend to copy the occupations their mothers engage in, like when Joe carried her make-believe baby on her back while playing, in the same way her mother carries her baby sister while cooking or cleaning. Another example of mothers' influence on children's occupational choice is the way they model occupational engagement. Vikki never formally taught her daughter to sew, although Princess often observed her mother sewing. She has access to her mother's equipment and choses to engage in this occupation even when her mother is absent.

However, in spite of mothers' influences on children's decision making and occupational choice, the children remain individuals with unique interests and abilities shaped through unique family support structures. In this study, their individuality was illustrated by their engagement in various, unique occupations of leisure. Such examples included Princess' sewing, Filida's lead singing and Nathan's fantasy game of preaching and his sense of humour as he teased his mother, André's competitive spirit always wanting to win and Joe's helpful nature. Silva (2018) also recognised this individuality of children diagnosed with FASD, and recommended careful observation in order to identify their learning needs and prepare teaching plans. Incorporating their unique individuality in teaching plans or interventions may promote learning for children with FASD who experience significant learning challenges. Mothers in this study were experts in their children's unique characters and interests and their role should not be underestimated in setting goals or designing intervention. In line with this reasoning, Palay & O'Connor (2009) recommends individualized intervention rather than embarking on a "one size fits all" approach.

The variables that mothers identified as limiting their ability to promote children's occupational engagement are mainly found in the person. However, stigma emerged as a limiting factor that is best described as a social environment factor within the CMOP-E. FASD is preventable and working in this field one has to be sensitive to the possible stigma attached to the mother and the child (Corrigan et al. 2017). Sylvie and Marie raised the stigma of limited intelligence ('dom'), but Maryna's concern was more direct as the stigma associated with FASD when she expressed her hope to protect her foster daughter from knowing her diagnosis of FASD. Intervention programmes have to be sensitive to this stigma.

In conclusion, mothers described factors hindering them as they facilitated the occupational engagement of their children with FASD, primarily embedded in the person as framed by the CMOP-E. The obstacles they described were challenges associated with FASD and included impulsiveness, depression, distractibility, poor recall of verbal information, learning difficulty and hyperactivity. Mothers were accommodating these obstacles to some extent as the children engaged in occupations with them. In addition, mothers influenced their children's decisions and occupational choice (Galvaan 2010) by modelling occupations and engaging in occupations with their children, although their children's individuality could not be denied. The one environmental factor described as limiting by some of the mothers was the stigma associated with a diagnosis of FASD. The chapter will continue to explore the environmental components of the CMOP-E by discussing the factors, mothers described as enabling their facilitation of occupational engagement.

5.3. Resources enhancing Occupational Engagement

The variables, or resources, mothers described as enabling them to promote the occupational engagement of their children were embedded in what the CMOP-E refers to as environmental factors. This section will describe the enabling nature of the physical-, institutional-, cultural-, and social environments framed in the CMOP-E, from the perspectives of the study participants.

Mothers' ability to manipulate their *physical environment* appeared pivotal to facilitate occupational engagement. Sylvie explained the way that she arranged her kitchen enabled her son's engagement in preparing tea, coffee and sandwiches. Magret felt disempowered as she had no control over keeping the streets safe for her daughter, but was able to create access to a safe environment in her home. She was able to keep influences from unwanted elements away and she managed to enclose the yard in order to protect her daughter from passing cars. Mothers also created access to a safe school environment by walking children to and from school. Limited resources such as motorized transport was in some cases a physical-environmental factor that enabled occupational engagement, although such a lack may be an inconvenience when time and energy is limited in a busy life. For example, engaging children with FASD in the co-occupation of walking to and from school and washing clothes by hand, in the absence of a washing machine, involved physical activity that could be taxing on time and energy, but in this study seemed beneficial to the child.

On an *institutional* level, mothers described the church and schools as supportive. The church played an important role in the way that Marie facilitated Filida's engagement in the occupations of lead singing and teaching Sunday school. Zelda and Vikki both regarded the church as prominent in the way they facilitated their children's social engagement.

In addition, mothers mentioned the support from schools, with particular attention paid to the extra classes Sylvie's son received and the teacher support received by Zelda's son. Doreen identified the occupational therapist at a non-profit organization as a resource in the institutional environment, enabling her facilitation of Clavina's occupational engagement.

A contentious aspect in the institutional environment is the high level of unemployment described in chapter one (80% in De Aar) leading to poverty as 70% of inhabitants in De Aar live below the poverty line (Stassen 2012). Yet, the flipside of unemployment is that mothers are at home with their children and able to engage in a variety of co-occupations with their children. However, the time unemployed mothers have may not be sufficient to facilitate occupational engagement of children with FASD. Literature recommends that time is best utilized within a well-established routine (Nash 2012; Palay & O'Connor 2009; Jirikowic et al. 2008) to support the executive functioning challenges like poor planning that is associated with FASD. Participants in this study who succeeded in establishing a routine (Magret, Vikki, Sylvie and Maryna) seemed more successful in facilitating occupational engagement than those who lacked routine (Doreen and Lya).

None of the study participants made any reference to their low socio-economic status during the interviews, but their context and poverty, the small town they live in, and mothers' own historical background of occupational engagement, determine the occupational choice of participants as well as their children (Galvaan 2014). However, within these limitations, the participants in this study were able to facilitate engagement in meaningful occupations for their children. Most of the occupations that emerged from this study demonstrated a relative strength in domestic skills. This relative strength is in line with a study by

Jirikowic et al. (2008b) in a different context in Canada affirming that the participants in this study are facilitating engagement in appropriate occupations irrespective of their context.

The *cultural environment* contributes another resource for mothers to facilitate occupational engagement for their children. Participants in the study all stayed with extended family which in most cases included the maternal grandmother. The norm seems to be for adult children such as Marie and Sophie's daughters to live in the family home even after becoming parents themselves. Communal living with an extended family in this collective society (Lim & Iwama 2006 in Duncan 2006) supports the challenges associated with FASD. This is seen as Marie continued to assist Filida to raise her baby. She continued to supervise the family planning for Filida, which she may forget to take as a result of executive planning challenges associated with FASD. In this collective society (Lim & Iwama 2006 in Duncan 2006), neighbours move in and out of each other's homes as Marie and Magret described, to allow children opportunity to transfer domestic skills they have learnt at home to a different context when helping a neighbour. The collective society lastly permits mothers to engage others in facilitating occupational engagement, as illustrated by the category of *involving others to support the child* in the theme ***Doing together***. Participants in the study involved mainly maternal grandmothers and siblings (especially those without FASD) in the home to assist them in facilitating the occupational engagement of their children with FASD, although neighbours, friends and extended family living close by, paternal grandmothers, aunts, cousins and fellow members of their churches also played a role. Although resources within the Departments of Health, Education and Social Development are limited in this district as discussed in chapter one, participants included professionals, such as teachers, doctors, social work practitioners and staff from a non-profit organization, when they *involved others to support their child*.

The *social environment* uncovers probably the most important resource to facilitate occupational engagement, namely a stable, caregiving home (Streissguth et al. 2004 & Ryan & Ferguson 2006). Participants in this study who were able to offer such stability to their children were happy with the occupations their children engaged in. Some participants managed to stop or limit their alcohol intake. However, for those biological mothers who were unable to abstain, their maternal grandmother played an important role in providing stability within the home. The mothers who continued to drink, were also the mothers who were unhappy with the occupations their children engaged in – such as sniffing glue and playing games of chance (gambling). These findings confirm the importance of a stable, caregiving home as emphasized by Streissguth et al. (2004).

In conclusion, the enabling factors embedded in the physical, institutional, cultural and social environment support stable, caring homes. Here, the family and specifically mothers are emerging as primary agents of change (Olson et al. 2009) to facilitate occupational engagement for their children with FASD. The following section will describe co-occupation as the key to facilitate children's occupational engagement.

5.4. The Key: Doing together

For the mothers in this study, facilitating the occupational engagement of their children was embedded in co-occupation (Price & Stephenson 2009). Co-occupation requires active engagement from both mother and child while sharing intention & closeness (Pickens & Pizur-Bernekow, 2009). This research offered many examples, such as Magret and Joe preparing a meal or cleaning together, or Vikki and Princess playing ball with friends or singing as they clean together. As Marie illustrated, this co-occupation could evolve into the child's solitary engagement in an occupation. She had taught her daughter Filida to bake bread by baking with her, yet at the time of the interview, Filida was often baking bread on her own even without the presence of her mother. On the other hand, the co-occupation between mother and child may extend into adulthood, again illustrated by Marie and Filida as they care for Filida's baby together. Thus, it is both the child's solitary engagement which may develop over time in some occupations, as well as the co-occupation between the mother and child that are pivotal to developing the child with FASD to their full potential.

Co-occupation is described as orchestrating a dance between mother and child and includes planning, organizing, balancing, anticipating, interpreting, forecasting, perspective shifting, and meaning making (Bourke-Taylor et al. 2010; Larson 1998; Larson 2000; Pierce 2009). Vikki illustrated this orchestration as she planned her time off work, organized chores to complete while her children were at school, and kept others such as cleaning for the family to do together. As Vikki and her daughters clean and sing together the task becomes meaningful to both parties. Marie similarly orchestrates the dance of co-occupation with her daughter as she interprets malicious words from others and shifts the perspective from Filida's poor reading to her melodious voice as lead singer, bestowing meaning as she affirms her daughter.

Participants in this study expanded the orchestration of the dance of co-occupation to include flexible expectations, gradual withdrawal from the co-occupation, including others in co-occupation, creating, maximizing and limiting access as described earlier.

The flexible expectations that mothers in this research used when orchestrating the dance of co-occupation, echoes findings by Sanders & Buck (2010) in Alberta, Canada, who found parents' adjustment of expectations an important strategy to cope as they raise a child with FASD. In addition, Sanders & Buck (2010) emphasized under-reaction to behavioural challenges which Sophie illustrated in the way that she manages her daughter's mood swings. Maryna similarly under-reacted to her daughter's poor memory when returning from the shop with only some of the items she was asked to buy.

Mothers orchestrated the dance of co-occupation by grading their support in occupational engagement. In some occupations they gradually withdrew from the co-occupation, while maintaining the co-occupation in others. This can be seen as mothers engaged in supervising the daily intake of medicine, which may be influenced by executive functioning challenges associated with FASD. The grading of co-occupation can be summarized in the following steps: firstly, allowing children to observe as mothers do, secondly, by guiding the child verbally to do, thirdly, by watching as the child does, and then allowing the child solitary engagement in the occupation while the mother engages in another occupation close by, and finally, by facilitating solitary occupational engagement at home without the mother's presence or in a different context, such as at a grandmother's or aunt's home.

Creating access to friends, equipment or material (toys and sewing), safe space and time adds to the way that mothers orchestrate co-occupation. Limiting access to undesirable occupations was the last strategy that mothers described in their orchestration of the dance of co-occupation. By limiting access, they protected their children in the same way that parents in Alberta, Canada created a bubble of protection for their children with FASD (Sanders & Buck 2010).

The value of co-occupation lies not only in the mother's ability to engage the child in an occupation but also in what the child gains from doing together - like learning rules of social engagement. In this research, co-occupation emerged as the key to unlock the occupational engagement for children with FASD. Mothers orchestrated the co-occupation with flexible expectations, grading their own involvement, including others in co-occupation, as well as creating, maximizing and limiting access.

5.5. Conclusion

Chapter four described mothers' essential role in facilitating occupational engagement of their children with FASD though co-occupation. This chapter proceeded to discuss the findings in the light of the CMOP-E as a framework. The discussion revealed that the factors limiting mothers' facilitation of occupational engagement were mainly embedded in the person. In contrast, mothers described resources that enhanced their ability to promote the occupational engagement of their children, as being embedded in the environment. Uncovering these resources and deterrents holds promise for future intervention. Co-occupation emerged as a key construct to frame the way mothers facilitate the occupational engagement of their children on the spectrum of fetal alcohol disorder. Mothers maintained co-occupation well into adulthood for some occupations, such as that of caring for a baby or taking medication, while other occupations such as baking or cleaning evolved into solitary engagement by the child. Mothers were able to make this distinction by observing their children through prolonged engagement in co-occupation.

The final chapter will summarise the thesis and describe the strengths and limitations of the study. Chapter six will also suggest recommendations for practice, policy and future research and conclude the dissertation.

Chapter 6: Conclusion

6.1. Summary of the Study

This qualitative descriptive study (Sandelowski 2000, 2010) explored the ways in which mothers in the Pixley Ka Seme District in the Northern Cape facilitate the occupational engagement of their children with FASD. The research built on previous quantitative studies establishing the FASD prevalence in De Aar and in the Renosterberg area, as well as research to measure the impact of prevention.

Mothers of nine children with a confirmed diagnosis of FASD participated in the research. Their children's ages varied between three transitional life stages in FASD described by Olson et al. (2009). Five children were in early primary school, two children were teenagers transitioning from primary to high school and two were in their early twenties, making the transition into adulthood. Of the five primary school children, two lived in the Renosterberg region and were diagnosed with FASD while in grade 1, and three lived in De Aar and were diagnosed between 9 and 15 months of age. Encouraging participants' voices to reveal their perspectives was essential for data generation, therefore, photo-elicited and semi-structured interviews were implemented in order to gather data. Data was transcribed verbatim and once participants' perspectives were identified, meaning was constructed from these perspectives through inductive analysis. Interpretation of data was verified through member checking with the various participants.

The first theme that emerged from the research was ***Doing together,*** describing mothers' co-occupation with their children as a means to facilitate their occupational engagement. The theme of ***Doing together*** encompassed four categories namely *Doing with the child*, *Flexible expectations*, *Grading support* and *Involving others.* Collectively, they describe the ways that mothers facilitate children's engagement in occupations of productivity, leisure and self-care. Secondly, the theme of ***Varying access to engagement*** emerged with three categories of *Creating access*, *Maximising access* and *Limiting access.* This theme described the ways mothers manipulated their children's access in order to facilitate engagement in various occupations. These themes are powerful informants for future intervention with people with FASD.

6.2. Strengths and Limitations

This study is part of ongoing research on a dynamic, complex phenomenon (raising children with FASD in a rural district in the Karoo) that 'resists simple classification' (Sandelowski 2010: 77). Therefore, qualitative description was well suited as a study design.

6.2.1. Strengths

- The qualitative descriptive design allowed the researcher to learn from study participants. The study answered the research question revealing that the manner in which mothers facilitate the occupational engagement of their children with FASD, is embedded in co-occupation. Furthermore, the study uncovered that the limiting factors mothers experienced were mainly nested in the person as described by the CMOP-E, with the exception of stigma which is an environmental obstacle. Lastly, the study revealed the environmental resources that mothers described as enabling their facilitation of the engagement of their children in various occupations.
- Mothers of children with FASD are often stigmatised. The research gave this marginalised group of women a voice by describing the positive contributions they make towards their children.
- Photo-elicited interviews were an effective way to encourage the voice of participants. Some participants engaged the help of others to take photographs or brought photos taken in the past to discuss during the PEI, while others used their cell phones to take photos in preparation for the PEI. However, irrespective of the way participants obtained the photographs, it was a powerful tool to bring mothers' expertise, in raising their children with FASD, to the foreground. Unfortuantely, children could easily be identified in all the photos and in the light of the stigma mentioned earlier, the researcher had to refrain from publishing photos in the dissertation.
- Findings in this research hold promise for realistic, contextualised intervention for people with FASD.

6.2.2. Limitations

- Participants emerged as effective facilitators of the occupational engagement of their children in occupations of leisure and self-care, however, their facilitation of occupations of productivity reached only as far as domestic chores. The research revealed little of children's (especially the adult children in the study) engagement in occupations of productivity outside the home, such as income generation, in order to contribute not only to the family, but also to society. High levels of unemployment in the research site (described in chapter one), complicates this matter further.
- Two of the participants were drinking heavily at the time of the study. These were the same two participants who had little to say about the way they facilitated occupational engagement of their children. The scope of this research did not allow for the exploration of these mothers' own occupational engagement or the possibility of drinking as an imposed occupation (Cloete 2015). Participant observation may reveal more information about the culture of drinking in these participants immediate neighbourhood. A deeper study would be required to explore the factors limiting these participants' occupational repertoire (Cloete 2015) and the way that it impacts on their children's occupational choice (Galvaan 2015).
- FASD may become a generational phenomenon when women with FASD drink alcohol and produce children who are also on the spectrum of fetal alcohol disorder. In this study, one of the adult children

with FASD, had a young baby of her own. She participated in the FASD prevention programme during her pregnancy and abstained from alcohol. With the grandmother's help, her baby is developing well and playfully engaging with her mother, but one wonders about future engagement in occupations of productivity (such as schoolwork) as the child matures. The study did not reveal information regarding people with FASD's engagement in the occupation of mothering, beyond caring for a baby.

6.3. Recommendations for Research

Participants in this study hold a wealth of life experiences raising children with FASD that may be explored at a much deeper level through ethnography or phenomenology study designs (Elliot 2018). Such research may uncover a deeper understanding of the impact of poverty and historical, political factors on the occupational engagement of mothers and children and reveal more about the researcher-participant dynamic while bringing participants' experience of the research process to the foreground.

Educators in the Pixley Ka Seme District have raised concern about the numbers of children who drop out of school soon after the junior primary grades. Mothers in this study, added to this concern by expressing hope for their children to finish school. Literature supports this finding that learning challenges and subsequent poor progress at school is a challenge associated with children with FASD (Kalberg & Buckley 2007; Silva 2018). Further research is needed to explore whether the approach of doing together, that emerged from this study would enable learning for children with FASD if schools offered a more active and participatory curriculum.

Although this study focussed on mothers as participants, fathers were absent in most families (with the exception of two families). In the category *involving others to support the child,* none of the participants mentioned the role of fathers. Further research could offer insight into the reasons for fathers' absence as well as father's potential contribution to facilitate the occupational engagement of children with FASD.

6.4. Recommendations for Practice

The findings of this study underlined the important role mothers play to facilitate occupational engagement of children with FASD. In line with literature by Olson et al. (2009) on the family systems approach, practitioners cannot treat children with FASD in isolation. Not only should mothers be included, but treatment should also consider others involved in the child's support. In this research, mothers often involved grandmothers and siblings to support children with FASD. Intervention should include these extended family members. It should address areas of concern identified by the family, empower them to manage these challenges, as well as look after the wellbeing of the family as they support children with FASD.

Intervention cannot follow a recipe or 'one size fits all' approach (Palay & O'Connor 2009), because children with FASD are individuals, each with their own interest and abilities as discussed in the previous chapter. Thus, families must be empowered with knowledge and skills (Franklin et al. 2008) to manage the challenges associated with FASD on an ongoing basis and in a variety of contexts as the child matures. FASD is a lifelong disability. Hence, families of children with FASD need support for their children, throughout their lifespan (Patrenco & Alto 2005).

Practitioners have to be sensitive to *the stigma* attached to FASD (Corrigan 2017). For this reason, intervention offered in groups, must target a cohort that will encompass children with FASD, for example, pre-schoolers who are not thriving (gaining weight according to age) or school-going children with learning challenges. Group intervention should therefore include strategies to the benefit of children with any developmental delay and not exclusively to children with FASD.

Apart from addressing challenges associated with FASD, intervention should alert families to environmental variables acting as *bridges* to enable occupational engagement. Recognising bridges that might be taken for granted as resources will empower families to tap into other, as yet, undiscovered resources.

The collective society (Lim & Iwama 2006 in Duncan 2006) is a strength in the *cultural environment* that should not be underestimated. Children living in family homes well into their adulthood enables much needed supervision. The openness of people coming and going in each-others' homes allows mothers of children with FASD to include others in the *doing together* to their children's benefit. The importance of a stable caring home cannot be over-emphasised. Practitioners in the Pixley Ka Seme District should consider these resources when offering services to people with FASD.

6.5. Recommendations for Policy

The Education White Paper 6 (EWP6) recommends inclusive education to allow all learners, irrespective of their individual needs, access to education and training. Inclusive education, according to the EWP6, has three levels with the first at the local, neighbourhood/mainstream school where educators are trained to offer support to learners with minimal needs. Moderate educational support is offered at full-service schools equipped to support a variety of learning needs, while learners with intense educational needs are best catered for in special schools. Special schools, combined with DBST are the resource to support the full-service schools and the EWP6 calls for one full-service school per district.

The EWP6, further calls for learner participation in the curriculum. Findings in this research underlines the value of active learner participation, as it is through *doing together* that mothers enabled their children's occupational engagement. Extending this co-occupation between mother and child into experiential learning at school may enable children with FASD to learn academically. Within inclusive education (EWP6), full-service schools are in the best position to focus on experiential learning within the curriculum they offer. The curriculum at full-service schools should prioritise experiential learning with enough time to learn through active learner participation.

However, Pixley Ka Seme District is geographically a large district (chapter one) and a learner with FASD from the Renosterberg area would need a hostel, should they wish to attend a full-service school in the district capital, De Aar. The frequent changes involved in moving between a hostel and home, may not be in the best interest of learners with FASD. In addition, living in a hostel could undermine the important role mothers play as agents of change for their children. For this reason, learners requiring moderate educational support may need this support in the mainstream school. Schools with high prevalence of FASD, far from a full-service school, such as those in the Renosterberg area, require greater flexibility in their curriculum to allow for experiential learning.

Similarly, learners with FASD requiring intensive educational support may not be able to attend a special school as far as 300km away (chapter one). Parents may not wish for a young child with intellectual impairment to move that far away, or the special school may not have adequate hostel facilities. When schools with a high prevalence of FASD are allowed more time in the curriculum to offer experiential learning, these schools may be in a better position to accommodate learners with both moderate and intensive educational needs.

The Department of Basic Education's initiative for Focus Schools (Norms and standards for focus schools: www.Education.gov.za) hold much potential to offer experiential learning to children with FASD. Focus Schools offer education with a special focus on talents such as sport, performing or creative arts, aiming to develop specialized skills and competencies for high school learners (grades 8 -12). Subjects in focus fields are offered for grade 10-12 learners in engineering, technology (technical mathematics, technical science), agriculture, arts and culture (dramatic arts, dance studies, visual arts, sports and exercise science), services (hospitality and tourism), as well as computer science. With an educator to learner ratio ranging from 1:12 to 1:15, the emphasis is on practical skills and experiential learning. However, learners with FASD require experiential learning from a much younger age and would benefit from expanding the mandate of focus schools to include experiential learning in primary schools.

The Department of Health's policy to only offer treatment for children with developmental delays until the child enters school, leaves a gap with the limited resources within the Department of Education in the Pixley Ka Seme District. It is vital that the DBST in the Pixley Ka Seme District should develop to its full capacity in order to support learners' educational needs at mainstream school as well as one full-service school in Pixley Ka Seme. The DBST plays an even more important role in Pixley Ka Seme considering the distance (300km) from the nearest special school.

Literature on FASD builds a strong case for early diagnosis and intervention. In South Africa, the National Integrated Plan for Early Childhood Development (ECD) in South Africa 2005 – 2010 (UNICEF 2005) guides the provision of ECD services. Three government departments play a key role in ECD, namely Departments of Education, Health and Social Development, but they tend to work in silo's with little recognition of the needs of young children with disability (Storbeck & Moodley 2010). Although all three departments emphasise the importance of ECD, there is limited funding for and implementation of policy (Storbeck & Moodley 2010). Considering the high prevalence of FASD in Pixley Ka Seme, there is a need to move beyond policy into service delivery. The Department of Health is well situated to screen for early developmental delays through the

Road to Health Books, but the work load at the Primary Health Care clinics impacts this service. Too little time is afforded screening for developmental delays, which often go undetected. When developmental delays such as FASD are recognized, children are referred to specialists such as occupational therapists or speech and language therapists. Often these specialists underestimate the role that parents and family can play as primary agents of change for children with developmental delays, especially FASD. The Gauteng Provincial Government Disability Policy (Gauteng Provincial Government 2003) is the only provinces to promote self-reliance of people of disability, built on a view that recognises people with disabilities (including FASD) as contributing members of society. This view opens the opportunity to empower families as agents of change. However, in the Northern Cape, there is little commitment to empower families to play this role and no funding is as yet allocated to such a move. Of concern is the statement in the Education White Paper 5 that private ECD institutions are better funded to serve children under 4 years than government funded initiatives (Storbeck & Moodley 2010). The socio-economic challenges (described in chapter one) families of children with FASD face, underline the impracticality of parents financing ECD services for children with FASD. Having said that, when government does supply ECD services, the important role of mothers must not be underestimated. In conclusion, policy on ECD needs to address integration between the three key departments. Priority should be given to the implementation of ECD and greater consideration should be given to children with disability including children diagnosed with FASD. Attention should be given to empower families of these children, in order for them to become agents of change.

6.6. Conclusion

The research for this dissertation moved beyond a description of the deficits and risk factors associated with FASD. It explored the contributions that mothers are making in the lives of their children with FASD by simply *doing together*. The study gave a voice to this marginalized group of women, to express their spark of genius (Pixley Ka Seme 1906) as they facilitate the occupational engagement of their children.

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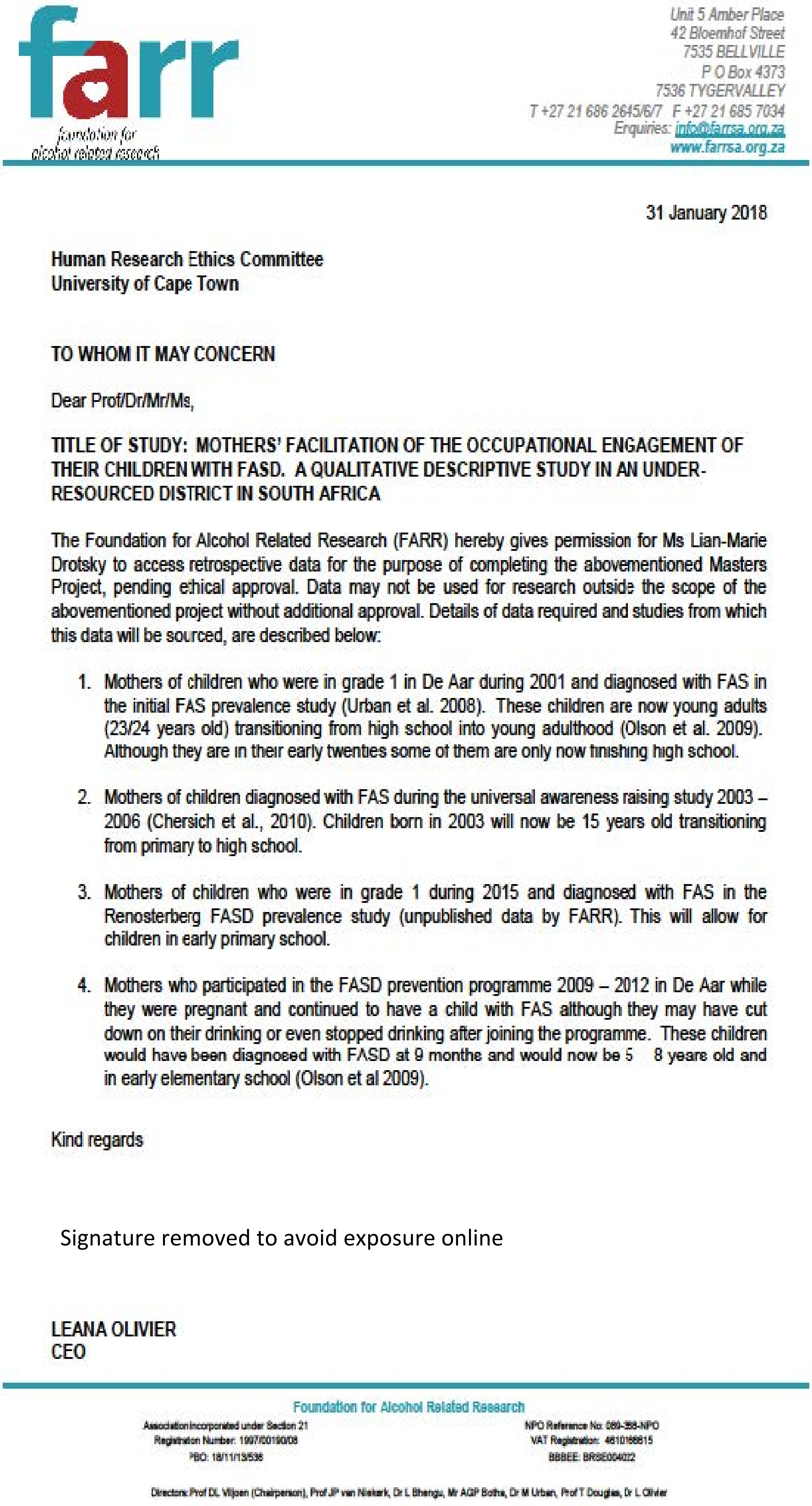
Addendum A: Letter of Approval



foundation for alcohol related research

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31 January 2018

Human Research Ethics Committee
University of Cape Town

TO WHOM IT MAY CONCERN

Dear Prof/Dr/Mr/Ms,

TITLE OF STUDY: MOTHERS' FACILITATION OF THE OCCUPATIONAL ENGAGEMENT OF THEIR CHILDREN WITH FASD. A QUALITATIVE DESCRIPTIVE STUDY IN AN UNDER-RESOURCED DISTRICT IN SOUTH AFRICA

The Foundation for Alcohol Related Research (FARR) hereby gives permission for Ms Lian-Marie Drotsky to access retrospective data for the purpose of completing the abovementioned Masters Project, pending ethical approval. Data may not be used for research outside the scope of the abovementioned project without additional approval. Details of data required and studies from which this data will be sourced, are described below:

1. Mothers of children who were in grade 1 in De Aar during 2001 and diagnosed with FAS in the initial FAS prevalence study (Urban et al. 2008). These children are now young adults (23/24 years old) transitioning from high school into young adulthood (Olson et al. 2009). Although they are in their early twenties some of them are only now finishing high school.

2. Mothers of children diagnosed with FAS during the universal awareness raising study 2003 – 2006 (Chersich et al., 2010). Children born in 2003 will now be 15 years old transitioning from primary to high school.

3. Mothers of children who were in grade 1 during 2015 and diagnosed with FAS in the Renosterberg FASD prevalence study (unpublished data by FARR). This will allow for children in early primary school.

4. Mothers who participated in the FASD prevention programme 2009 – 2012 in De Aar while they were pregnant and continued to have a child with FAS although they may have cut down on their drinking or even stopped drinking after joining the programme. These children would have been diagnosed with FASD at 9 months and would now be 5 – 8 years old and in early elementary school (Olson et al 2009).

Kind regards

Signature removed to avoid exposure online

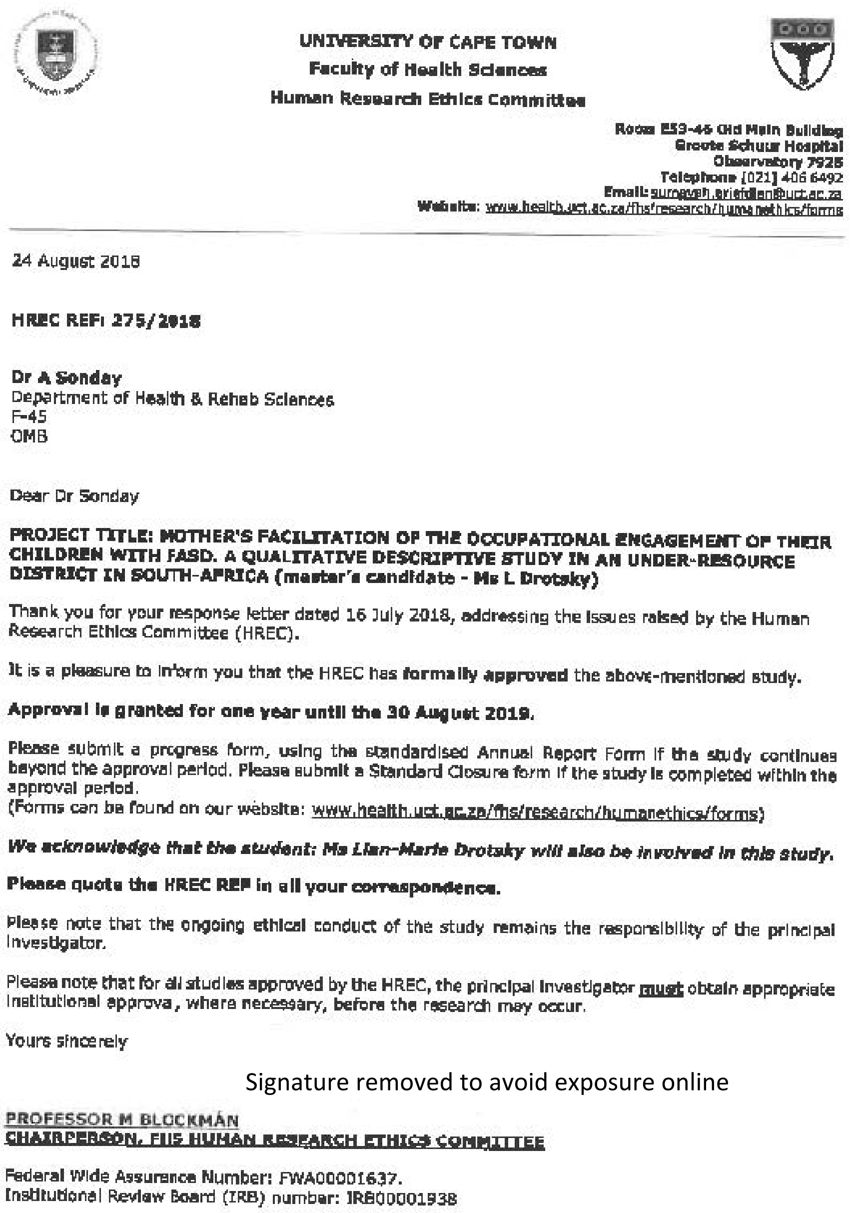
LEANA OLIVIER
CEO

Foundation for Alcohol Related Research

Association Incorporated under Section 21
Registration Number: 1997/00190/08
PBO: 18/11/13/538

NPO Reference No: 089-358-NPO
VAT Registration: 4810188815
BBBEE: BRSE004022

Addendum B: Ethical Approval



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: sumayah.ariefdien@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

24 August 2018

HREC REF: 275/2018

Dr A Sonday
Department of Health & Rehab Sciences
F-45
OMB

Dear Dr Sonday

PROJECT TITLE: MOTHER'S FACILITATION OF THE OCCUPATIONAL ENGAGEMENT OF THEIR CHILDREN WITH FASD. A QUALITATIVE DESCRIPTIVE STUDY IN AN UNDER-RESOURCE DISTRICT IN SOUTH-AFRICA (master's candidate - Ms L Drotsky)

Thank you for your response letter dated 16 July 2018, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 August 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: Ms Lian-Marie Drotsky will also be involved in this study.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator must obtain appropriate institutional approva, where necessary, before the research may occur.

Yours sincerely

Signature removed to avoid exposure online

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

Addendum C: Information Letter

Dear Participant

Thank you for keeping in touch with FARR since your child attended the diagnostic clinic. At the clinic your child ___________________ was diagnosed with Fetal Alcohol Syndrome and FARR would like to find out how you and your child is coping.

Lian-Marie Drotsky, an occupational therapist wants to interview mothers of children with FASD for a study towards a Master's Degree at the University of Cape Town.

The purpose of this study is to learn as much as possible about the things your child does and how you help your child to actively participate in those things. All the information gathered will be confidential. This means that not you or your child's name will be used and that your identities will be protected when the information is used. When refering to you or your child in the research, a psydonym will be used.

You would need to do the following

1. Take cell phone pictures of your child in an activity he / she typically does around the house. The picture will help the researhcer to understand what you describe during the interview.
2. Meet with the researcher for 1 ½ to 2 hours at the FARR / Joan Wertheim Centre (Pink House) to tell her about your child. This meeting will be at a time that is convenient for you.
3. Meet with her again (1 to 2 weeks later) for about half an hour at the FARR / Joan Wertheim Centre to clarify the information you discussed if necessary.
4. Meet with her and the other participants, about 6 months later for feedback about the findings and training on FASD if you are interested. This session will be a joint session with other members of the community who may be interested in the topic and will last from 09:00 – 12:00.

You may benefit from participating in the study as a small incentive in the form of a hamper to the value of R100 for your child will commpensate for your time participating in each interview.

I understand that your child may experience learning or behavioural challenges as a reseullt of FAS and it may be uncomfortable or even stressful to discuss this. Your child may also be stigmatised if a diagnoses of Fetal Alcohol Spectrum Disorder is not kept confidential. I undertake to treat you and your child with respect and information will be confidential.

Please note that I undertake to refer you or your child to the relevant medical and / or educational staff if we discuss any issue that you require further help with. For the well being of your child issues that requires reporting under the Child Protection Act will be discussed with you and with your knowledge be reported.

Everything you tell the researcher will be added to the data gathered for the study. No names or any information that may identify you will be written in the report or issued to the media. When the information for the study is published it will be done with pseudonyms and there will be no link to you or your child.

Your participation in this study is entirely voluntry and you can refuse to participate or may withdraw at any time without giving any reason.

If you agree to participate in the study, please sign the attached Consent form

Your sincerely

Signature removed to avoid exposure online

Lian-Marie Drotsky

For further questions contact: Lian-Marie Drotsky Email: Ld@farrsa.org.za; Postal Address P.O. Box 495, De Aar, 7000, Mobile 0827161410; Tel – office 053 631 7063; Fax 530 631 1922
For ethical considerations contact: Marc Blockman (Chairperson of the HREC) Email:marc.blockman@uct.ac.za; Postal Address: Division of Clinical Pharmacology; K45-48, OMB University of Cape Town/Groote Schuur Hospital. Observatory, 7925; Mobile: +27 83 458 5510; Tel- Office: +27 21 4066496; Fax: +27 21 4481989

Addendum D: Informed Consent

Mother's Informed Consent to participate in the study:

Mothers' facilitation of the occupational engagement of their children with FASD

I hereby confirm that I have been informed by ___________________________ of the nature, conduct, benefits and risks of participating in the study. I have also received, read and understand the attached written information.

I, ____, hereby agree to participate in research by Lian-Marie Drotsky.

I read the information sheet and agree to participate in an interview on an agreed day and time. I am aware that I have the right to refuse to participate and can withdraw any time I feel I need to.

Please tick:

___ 👍 I agree to take a picture of my child for the study and participate in an interview.

____ 👎 I do not want to be iterviewed or take a picture of my child.

____ 👍 I agree that the interview with the researcher may be recorded

____ 👎 I do not want the interview to be recorded

Signed at (*place*) .... on (*date*) .... 2018.

....

Signature of participant Signature of witness

Complete in the event of an illeterate mother:

The above consent was discussed with _____________________________________ by

____, permission to continue with the study was obtained verbally.

Signed at (*place*) .... on (*date*) .... 2018.

....

Signature of participant Signature of witness

Addendum E: Informed Consent of Adult Child

I ____ am aware that my mother is participating in a research study by occupational therapist Lian-Marie Drotsky. I am aware that my mother will tell the researcher about some of the acivities I participate in daily. I agree that my mother can take a picture of me while doing an activity to use during the interview.

Please tick:

___ 👍 I agree to being phographed and that the picture will be discussed during an interview.

____ 👎 I do not want a picture to be taken of me

Signed at (*place*) .... on (*date*) .... 2018.

....

Signature of participant

....

Signature of witness

Complete in the event of an illeterate child:

The above consent was discussed with ____________________________________ by

____, permission to continue with the study was obtained verbally.

Signed at (*place*) .... on (*date*) .... 2018.

....

Signature of investigator

....

Signature of witness

Addendum F: Child Assent and Information

The way mothers help children to do things.

RESEARCHER: **Lian-Marie Drotsky**

ADDRESS: FARR / Joan Wertheim Centre, 6 Wentwort Street, Sunrise, De Aar

CONTACT NUMBER: 053 631 1922 / 082 7161410

***What is RESEARCH*?**

Research is something we do to find new knowledge about the way things and people work. We use research projects or studies to help us find out more about the challenges people live with. Research also helps us to find better ways of helping, or treating children who live with challenges.

The researcher wants to learn from mothers as much as she can about the things mothers see their children do and how mothers help their children to do these things. She will ask your mother to take pictures of you while you are busy around the house. Then she will ask your mother to tell her about the things you like to do and things that you find difficult to do.

Mothers of children who participated in research conducted by FARR in Pixley Ka Seme District before are invited to participate in this study.

Lian-Marie Drotsky is an occupational therapist and a student at the University of Cape Town and wants to learn from you and your mother because she is studying for a Master's Degree.

What will happen?

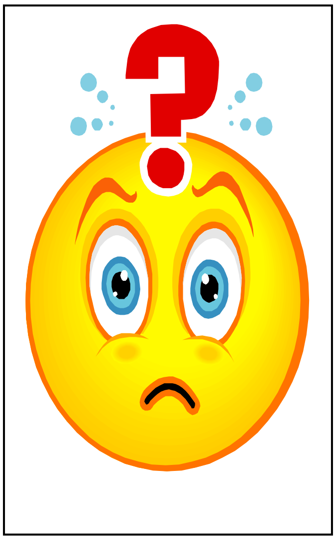
Your mother will take pictures of you as you play alone or with friends or learn around the house. Then she will meet with the researcher at the Pink House (FARR/Joan Wertheim Centre) and they will talk about the pictures and other things you like to do as well as things that your mother thinks are difficult for you to do.

Can anything bad happen to me?

Some people may think badly of you if the things your mother tell the researcher is told to other people. The researcher will therefore not show any pictures that show your face (or anything else people may recognise you with) to others and she will make sure that when she uses the information your mother tells her, your name will not be used. She will give you a secret name when she talks or writes about you.

Can anything good happen to me?

When your mother talks to the researcher, she will receive some food or things you will need for school to bring home to you.



Who can I talk to about the study? If you have any questions you can talk to the FARR Community Worker or to the researcher (at the Pink House or phone 053 631 1922). You can also contact the University: Marc Blockman (Chairperson of the HREC) Email: marc.blockman@uct.ac.za; Postal Address: Division of Clinical Pharmacology; K45-48, OMB University of Cape Town/Groote Schuur Hospital. Observatory, 7925; Mobile: +27 83 458 5510; Tel- Office: +27 21 4066496; Fax: +27 21 4481989

What if I do not want to do this?

Even if your mother agrees to participate and you do not want to be part of the study, you are allowed to say NO and you do not have to explain to anyone why you say no. You can also stop being in the study at any time without getting in trouble.

Do you understand this research study and are you willing to take part in it?

☐ YES ☐ NO

Has the researcher answered all your questions?

☐ YES ☐ NO

Do you understand that you can pull out of the study at any time?

☐ YES ☐ NO

______________________________ ________________________

Signature of Child Date

Addendum G: Guidelines for Interviews

Demographics

Study Number: ____

Age of Participant: ____

Address: ____

Age of child: ____________________ Gender: ________

1. Please describe a day in your home:

   Prompt: Structure and routine at home.

2. Tell me about what your child does on a daily basis:

   Prompt: Who does he/she spend their time with? (Friends)
   How does he/she spend their free time?
   How is this child different to others?
   Does your child do things that frustrates you or that you find challenging?
   What do you like /enjoy about your child?

3. Can we look at the pictures you took of your child engaging in the different occupations?

   Prompt: What is your child doing?

   Tell me more about your child's engagement in this occupation.

   How frequently does your child engage in this occupation?

   Where does he engage in this occupation?

   With who does he engage in this occupation?

   How did you facilitate your child's occupation as depicted here?

   Prompt: Tell me more about how you create opportunities for your child to engage in this occupation?

   Are there challenges to creating opportunities for the child to engage in this occupation?

   Did you require help from others to facilitate your child's engagement in this occupation?

4. Tell me what it is like to raise your child with FAS?
    a. Prompt: Did you experience challenges with your child's play, development, making friends or learning?

5. How did you help / enable (facilitate) your child's play, development, making friends or learning?
    a. Prompt: What enabled you to do this?

6. What do you think would help you with your child at home?
   Prompt: Is there anything you would like to do better in the way you manage your child?

7. Think of a moment when you felt: "Wow, my child is really into this."
   Prompt: Describe the events preceding the moment
   Describe the moment. How did you know it was successful?
   What happened next?

8. Think of a moment you felt: "Yes! My child is making progress."
   Prompt: Describe the events preceding the moment
   Describe the moment. How did you know it was successful?
   What happened next?

9. Think of a challenging event with your child
   Prompt: What preceded the event?
   Describe the challenging event?
   What happened next?
   How did you respond to this event?
   Looking back, is there anything you would have done differently?

Addendum H: English Poster

Doing together to support your child with FASD

Read a book together

Singing together

Praying together

Drawing together

Sharing a meal

Making a bed together

Playful bath time

Cooking together

Carry shopping together

Doing dishes together

Hanging washing together

Gardening together

Sweeping & talking

Stacking blocks

Playing ball together

Card & board games

Cheer a playing child on

Skipping together

Addendum I: Afrikaans Poster

Ondersteun jou kind met FASA deur saam te doen

Lees saam 'n boek

Saam sing

Bid saam

Teken saam

Deel 'n maaltyd

Maak saam die bed op

Badtyd is speeltyd

Kook saam

Dra pakkies saam

Was saam skottelgoed

Hang saam wasgoed op

Versorg plante saam

Saam vee & gesels

Stapel blokkies

Speel saam bal

Kaart- of bordspeletjies

Moedig 'n spelende kind aan

Spring saam tou

Addendum J: Participants

Name: Mother & Child	Mother / Participant					Child			Housing			Previous contact with FARR / Researcher
	Relationship to Child	Marital status	Employment	Monthly Income	Age	Age	Highest grade past	Current life stage (re school / work)	Type of house	Number of residents	Where	
Magret & Joe	Biological mother	Singled	Part time employment	Child support grant (R1,680) & part time employment	39	9	Grade 2	Grade 3	Brick house	2 adults & 4 children	De Aar	Focused FASD prevention; Early childhood stimulation
Doreen & Clavina	Foster mother	Cohabitating	Unemployed	Child support grant (R1,680)	46	8	Grade 2	Grade 3	Brick house	2 adults & 4 children	De Aar	Focused FASD prevention; Early childhood stimulation
Marie & Filida	Biological mother	Widow	Retired	Child support grant (R1,680)	59	23	Grade 4	Unemployed, Mother House keeper	Brick house	4 adults & 4 children	De Aar	FASD prevalence study 2001; Focused FASD prevention
Sylvie & André	Foster mother	Single	Unemployed	Foster care grant (R1,000) & Foster fathers wages	36		Grade 2	Garde 3	Brick house	3 adults &, 5 children	Renosterberg	Renosterberg FASD Prevalence study 2015
Sophie & Anna	Biological mother	Single	Retired	Family support	56	23	Grade 4	Unemployed; House keeper	1 Room structure made of corrugated iron	3 adults	De Aar	Prevalence study 2001
Zelda & Nathan	Biological mother	Single	Unemployed	Child support grant (R1,260)	29	8	Grade 2	Grade 3	Wendy house	1 adult & 3 children	De Aar	Focused FASD prevention
Vikki & Princess	Biological mother	Single	Employed	Employment	37	11	Grade 3	Grade 4	Brick house	2 adults, 4 children	Renosterberg	Renosterberg FASD Prevalence study 2015
Lya & Rico	Biological mother	Married	Unemployed	Child support grant (R840) & Father's wages	46	12	Grade 3	Dropped out of school	Brick house	2 adults (including the father) & 2 children	De Aar	Universal Awareness Raising study 2003-2006
Maryna & Ali	Foster mother	Married	Full time mother	Father's wages & Foster care grant (R2,000)	38	14	Grade 6	Grade 7	Brick house	2 adults (including the father) & 4 children	De Aar	Universal Awareness Raising study 2003 - 2006