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Developing appropriate Fetal Alcohol Spectrum Disorder  
(FASD) prevention initiatives within a rural community  
in South Africa

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Dissertation submitted in fulfillment of the requirements  
for the degree:

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## ABSTRACT

This study focused on women who consumed alcohol during pregnancy. The study population was situated in the West Coast/Winelands, a rural area in the Western Cape Province of South Africa. The study was done in a community which is classified as one of the many previously disadvantaged groups in South Africa. This study was done as part of a larger three-year project on Fetal Alcohol Syndrome Prevention in the Western Cape and Gauteng Provinces of South Africa. The phenomenon of drinking during pregnancy was used as a case example of health compromising occupations in the South African context. Prenatal alcohol exposure may result in brain damage that affects behaviors of those affected. The beliefs, norms, values and perceptions of mothers regarding alcohol consumption are also an important aspect in maintaining healthy pregnancies. Participants shared their beliefs, values and perceptions towards alcohol consumption and contributed to an enhanced understanding of the impact of culture on the phenomenon of alcohol abuse during pregnancy.

**Aim:** To explore how participants' beliefs, norms, values and perceptions regarding alcohol consumption could be incorporated into Fetal Alcohol Spectrum Disorder prevention approaches.

**Methodology:** Critical ethnography was used with observation and interviews as the main methods for collecting data. Participants participated in individual interviews and group interviews. One participant expressed her views by doing a role play.

Participant-groups consisted of: (1) women of child bearing age; (2) life partners/ close family members or friends; (3) service providers. Participants were recruited via referral from clinic staff and snowballing. A total of 14 mothers, one father and 10 service providers participated in the study. A minimum of two interviews (individual or group) were held with each participant. Data was analyzed inductively. Historic political, economic and social conditions were analyzed and described.

**Findings:** Two themes were identified namely: 'Being drunk is the norm' and 'Ek is 'n drinker en klaar! (I am a drinker and that's it!)'. Theme One represents the context and Theme Two the identity of participants within the context. Within this study fetal alcohol spectrum disorders seemed to be a symptom of an array of underlying social, economic and political problems. Contextual conditions appeared to be one of the key factors that shaped individual and communal identities. Alcohol abuse as a normalized practice in the study community is expressed in the occupational identities assumed by mothers. Alcohol abuse is discussed as imposed occupation in motherhood. Alcohol abuse

amongst mothers was found to be an inherent occupation around which many other practices are organized. Current alcohol practices were linked to historical conditions that reinforced alcohol abuse in the study context. Prenatal alcohol exposure and the acute lack of support from family, community and health services contributed to the high incidence of Fetal Alcohol Spectrum Disorders in this community. The absence of opportunities for personal and communal development seemed to have created a trap from which residents can only escape if they leave the community.

**Conclusion:** Alcohol abuse is viewed as an imposed occupation on the study community. Historical factors influenced the current beliefs, norms, and perceptions regarding alcohol use practices in the context. A decolonizing, self-empowerment approach is suggested for collaborating with indigenous groups in identifying and initiating processes that will stop alcohol abuse as imposed occupation in this community.

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## **DISCLAIMER**

I hereby declare that this thesis is my original work and has not been submitted before to any other institution for assessment purposes.

Further, I have acknowledged all sources used and cited these in the bibliography.

Researcher (Lizahn Gracia Cloete)

Supervisor 1: Prof. Leslie London

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## DEDICATION

### UNTO JAHWEH, MY ONE AND ONLY SOURCE OF HOPE

"...although the future may unfold in indelible strokes, it doesn't mean that we have to read the same line over and over."

(Picoult, 2006:397)

"...we never know anyone as well as we think we do - least of all ourselves...we shouldn't rush to judgment until we've walked a mile in someone else's shoes. I can't tell you I would do what [mothers in this study] did in [their] situation...but I can't tell you I wouldn't, either." (Phrases in brackets were added by author)

(Picoult, 2006:396)

## ACKNOWLEDGEMENTS

William, my husband, William, my son and Milua, my daughter – thank you for all the support.

My Mom, Dad and all my brothers and sisters - thanks for being there all the way. You will always have the ability to inspire me to unimaginable heights.

The research community – you allowed me into your lives, thank you. You asked for concrete outcomes. This piece of work is the first step towards bringing about change and addressing some of the challenges you expressed. May this be the beginning of a process of self-empowerment, self-determination and radical transformation. A special thanks to all the participants and their families.

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## **PREFACE**

### **A. Prior research that led to this doctoral study on Fetal Alcohol Spectrum Disorder**

As a qualified occupational therapist my interest in understanding the phenomenon of maternal alcohol consumption during pregnancy in a rural context was sparked by the lack of any clear protocol in the health services for working with mothers who consumed alcohol during pregnancy<sup>1</sup>. During the monthly outreach clinics of the hospital where I worked on a part-time basis, I designed home programmes that focused on how mothers and primary caregivers could stimulate occupational engagement<sup>2</sup> and development of their children with development delay in the areas of self-care, play and schooling. Some of the mothers who lived on farms had problems with alcohol dependency and admitted to alcohol consumption during pregnancy. Home programmes were therefore developed to stimulate normal development in order to help children reach their developmental milestones at an appropriate age. During individual sessions with mothers and caregivers it became clear that they also needed input on caring for their own health and development as adults. The health promotion principles contained in the Ottawa Charter (World Health Organization, 1986) were helpful in identifying focus areas for this project that focused on mothers and children. Occupational therapy interventions were therefore combined with health promotion efforts.

In order to address the problem of alcohol abuse and binge drinking<sup>3</sup> during pregnancy appropriately, better insight into the lives of the women involved was required. These efforts culminated my research towards a Master of Science in Occupational Therapy (MSc (OT)) qualification. The goal of the Masters research was to explore the occupations of women who live and work on farms (Cloete, 2005). Farm worker communities are,

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<sup>1</sup>Fetal alcohol Syndrome has been identified as an important public health problem in certain regions and among specific population groups in South Africa. This is particularly the case for pregnant women in poorer communities in the Western Cape.

<sup>2</sup> Means to involve oneself or become occupied, to participate in occupation (Canadian Association of Occupational Therapists (1997-2002).

<sup>3</sup> Binge drinking, (defined as occasional bouts of heavy drinking), is considered the worst pattern of drinking for one's health. The cardio-protective effect of alcohol is determined by the volume and pattern of drinking. The effects of alcohol misuse are exacerbated by poor nutritional status and may lead to infectious diseases in the short-term and degenerative diseases in the longer- term.

amongst others, known as marginalized groups in South Africa. It was thus important to consider historical political factors<sup>4</sup> such as racial oppression and marginalization of indigenous groups as well as socio-economic factors<sup>5</sup> such as poverty and the lack of skills and education amongst indigenous groups. It was also critical to explore whether, and how, historical and current political and socio-economic factors impacted on current occupational engagement of women who grew up and continue to live in marginalized communities. The aim of the MSc (OT) research was thus to investigate what the occupational repertoire of participants consisted of. The physical, social and political spaces in which these occupations took place were also explored.

Results showed the following:

- Although the occupational repertoire of participants consisted of the usual occupations, such as activities of daily living (self-maintenance and caring for families), work (productivity) and relaxation (socialization), the environment in which these occupations took place played a significant role in why and how these occupations were executed.
- The lack of constructive free time activities was pervasive. With poor access to social spaces on farms and in the nearby town and lack of resources and infrastructure to support healthy engagement in activities that contribute to health and well-being, participants resorted to drinking alcohol at home or at social gatherings as a way of socializing and passing time.
- Living and work conditions were harsh and coupled with physical and emotional hardship.
- Participants lived in hope for a better life despite the various challenges they were facing.

One of the conclusions that was drawn from this MSc(OT) study was that, although participants made a living in a restrictive environment, they still had the hope to become more than what the environment and their circumstances predicted. This study provided a foundation upon which PHD research could build in exploring how appropriate Fetal

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<sup>4</sup> The main political factor was that of separate development. Although race-hatred evolved from around the 1700's on the African continent, Apartheid was only legalised in in 1948. Segregation of different races was enforced and the power and dominance of Whites (of substantially European descent) over other races was cemented.

<sup>5</sup> Institutionalization of racial discrimination maintained White power by denying Black South Africans political freedom, social freedom as well as economic freedom.

Alcohol Spectrum Disorders (FASDs)<sup>6</sup> prevention initiatives could be developed from within South African communities. Ideally this should be done in partnership with community members.

I was initially unaware of the bearing my own experience of maternal alcohol assumption in my extended family had on the way I approached the research context. It was only when I embarked on this doctoral research that I recognized the contribution of personal encounters. The following story illustrates how prenatal alcohol consumption and the associated disabilities affected my nuclear and extended family. A number of people may recall similar encounters with family, friends or acquaintances and while one has to admit that these encounters are far too common, people often distance themselves from those who are affected by alcohol consumption during pregnancy. This story also shows how unexplained physical, neurological and/or behavioral difficulties in children may be the result of unidentified prenatal alcohol exposure. This may lead to many children being ostracized in the environments of school, play and family. Children who are not identified early in life may experience difficulties in areas of education, empowerment, livelihood creation, health and socializing as adults. Impaired judgment, emotional immaturity and decision making skills in adulthood may impede the ability of alcohol affected adults and prevent them from raising their own children as healthy and responsible citizens.

### **B. Personal exposure to the impact of Fetal Alcohol Spectrum Disorders: Positioning the researcher in relation to Fetal Alcohol Spectrum Disorder**

The following story will reveal my personal encounter with the impact of FASD. Steve<sup>7</sup>, my cousin, is six years younger than me. His father and my mother were brother and sister. When Steve was five years old his father passed away unexpectedly. According to my mother, Steve's mother was an alcoholic since before she married my uncle. Because

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<sup>6</sup> Fetal alcohol spectrum disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. Children who are diagnosed with Fetal Alcohol Syndrome (FAS) have to present with three defining features (outlined on p22 – footnote number 10). These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis but rather a description of a spectrum of the consequences of prenatal alcohol exposure.

<sup>7</sup> Pseudonym

nobody asked her, she never admitted to abusing alcohol during her seven pregnancies (five daughters and two sons). After my uncle's death five of the children came to live with us; I was about 12 years old at the time. Three of my seven siblings were still living at home and the other four were studying at university. All five of my cousins, who now lived with us, were enrolled at the schools we attended at the time. They became part of our family structure and even shared our daily chores in and around the house.

Over a period of three months my parents received frequent complaints from the school about two of my cousins who had had difficulty concentrating or sitting still in class. I would overhear my parents' conversations on how to deal with incidents when property disappeared from their teachers' desks or how to deal with anger outbursts and fighting at school. Soon this kind of trouble shooting and problem solving conversation dominated family time. Constant sibling rivalry characterized our home with regular physical fights among cousins, brothers and sisters. My cousins went through a difficult time adjusting to the new life in a new family, having "lost" both parents. My parents reminded us to accommodate them as far as possible and expected us to assist them with their homework.

Although we knew at the time that my aunt had abused alcohol for as long as we had known her and possibly before, it was only later in my career as an occupational therapist that I made the link between her drinking habits and possible damage caused by prenatal alcohol exposure of her children. It was only then that I realized how difficult this situation of adjustment must have been for everyone involved.

During their stay with us my parents were called for numerous visits to the school and consultations with teachers. After a series of intense family meetings (that became increasingly hostile towards the end of their stay, because we felt that my cousins took all the attention and time my parents were supposed to spend with us), and occasional runaway attempts from two of my cousins, my parents decided to seek alternative homes for the two who expressed their unhappiness with staying with us. Other family members were approached and my cousins were given a choice of where to move next. While the rest of the extended family was keen to step in they did not know what they were letting themselves in for. As sibling rivalry became physical and rather aggressive at this point,

the tension within our household became unbearable and we counted the days and hours until their departure.

After twenty years without any contact, Steve, the younger sibling who had major learning difficulties during his primary education years, came back to re-unite with my family. At the time of his visit he was engaged to the mother of their nine-month old baby. Steve was now an adult. He never completed school and had not been able to find a job after leaving school. He told my mother how he roamed the neighborhood where he lived for the preceding years and begged for a place to stay. At the time of his visit he was living with his fiancé in a two-roomed house. His fiancé held a part-time job as a cashier at a supermarket. Steve stayed at home to care for their child. My new insight into the debilitating impact of alcohol exposure on the brain and how this can affect the social interactions of affected individuals made me appreciate the opportunity to see and connect with my cousin again. Steve was managing to negotiate his life with the disabling effects<sup>8</sup> of prenatal alcohol consumption thus far. It made me wonder how many other individuals were battling with undiagnosed prenatal alcohol exposure.

The needs of children who are affected by FASDs and who are undiagnosed might go unnoticed. Very little is known about the needs of mothers who might have been prenatally exposed to alcohol and who are abusing alcohol during pregnancy in South Africa. What is known is that descriptions of these mothers in literature on FASDs point to ethnic, race and class features as opposed to the limitations that prevent them from fulfilling their roles as daughters, sisters and mothers. The disabilities associated with FASD can have a lifelong impact and may inflict emotional and financial burdens on the individual, families and society (Warren, Hewitt and Thomas, 2011).

The reduction of the prevalence of FASDs is currently a health priority in South Africa. To this end research is needed to determine the needs of affected children and their mothers. One of the ways of achieving the goal of healthy pregnancies is to determine

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<sup>8</sup> FASD is characterized with lifelong learning and neurobehavioral deficits. The Central Nervous System is the most critical system adversely affected by prenatal alcohol exposure. Particularly vulnerable regions to prenatal alcohol exposure include the frontal cortex, caudate, hippocampal formation, corpus callosum, and components of the cerebellum, including the anterior cerebellar vermis. Changes in bundles of nerve fibers (i.e., white matter tracts) in the brains of humans at any age are known to be adversely affected by prenatal alcohol exposure and may relate to alterations in information processing.

how alcohol affected children and their mothers can be supported adequately. This doctoral study will challenge the reader to take a different perspective on the research participants, by viewing them against the background of disadvantage by historical and political factors. The participants in this study share a history where prenatal alcohol exposure possibly caused invisible and un-diagnosed disabilities of varying degrees. It is against this backdrop that some participants were struggling with alcohol dependency (as a typical feature of this rural, 'Black'<sup>9</sup> community). Before I conclude this section I would like to discuss some issues pertaining to ethnicity as it relates to the participants.

### C. Ethnicity of participants

The accounts that will be presented in this work are constructions that will draw from a combination of the experiences of Black research participants as well as my experience as a Black person. In combination with researched literature the accounts produced were constructed upon the presuppositions and tacit knowledge of socio-historical circumstances of the research participants and me. By using this approach I deliberately suggest that the knowledge produced in this text is not universally applicable. I attempted as far as possible to describe the reality of participants within the social context as well as to elaborate on the meaning of occurrences and observations.

The reference to my own ethnicity and the ethnicity of participants has an important significance in the study. There is a common misconception that FASDs is associated with 'colored' communities (Chudley, Conry, Cook, Loock, Rosales & LeBlanc, 2005). As stated by Erasmus (2001) 'Colored' was an ethnic identity that was forced upon descendants from slave maidens and European colonialists and in later years the Dutch. The 'creation' of this group was not a natural anthropological phenomenon, but rather a process of political engineering and part of a process of statutory race classification in South Africa (Goldin, 1987) that created decades of exclusion, oppression and rootlessness (Caliguire, 1996). Fischer (2007) argued that even if this group was not

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<sup>9</sup> In the early 1700's Khoen and Xhosa labourers (indigenous nation) were first brought into the Western Cape territory as captives. Other indigene Africans were brought to the territory first as slaves and later as indentured labourers from 1679 to the 1880s. These were the forebears of groups currently categorized as 'Colored' and 'African' communities. Freed slaves known as Free Blacks married with white settlers in the early period of settlement and many more entered into mixed relationships in later years. Up to the mid 1700's approximately one fifth of European settlers were in formal or informal mixed relationships including with slaves, Free Blacks and indigenes.

deliberately created, the apartheid government perpetuated negative images of this category of people to advance the policy of divide and rule.

For over a century the colored identity was fostered and manipulated to socially engineer a political alliance with the then White ruling parties (Goldin, 1987). Goldin (1987) also suggested that colored identity is not about lineage, but rather about politics. This explains the predominant focus on politics in scholarly debate on the subject of 'colored identity' in the period of National Party rule (Simons, 1976; Venter, 1974; Vosloo, 1970). This political manipulation contributed to the lack of a sense of place in the world as the identity and cultural consciousness of large groups of people from indigenous groups as well as people from mixed ancestry were distorted.

Indigenous cultures were obliterated during a process of name changes from indigenous names to Western (English and Dutch/Afrikaans) names. In this way heritage and past histories were replaced by a term (Colored) that encompassed a combination of shame, no belonging and a sense of impurity of breed (or mixed breed). Using the term 'Colored' thus serves as a point of reference for understanding how South African history shaped the social identities of participants. Although there may be links between the concepts of culture and ethnicity it is, however, important to note that this study took an occupational perspective to culture and did not focus on the ethnicity of participants. Questions about ethnicity were thus irrelevant. My stance of the ethnicity of participants is based on a definition by Erasmus (2001) who, according to the Black Consciousness Movement defines Black people<sup>10</sup> as a group of South African citizens who have been subjected to political, economic and social discrimination by law or tradition (Assata Shakur Forums, 2004). For the sake of consistency, I will hence refer to participants and the community of study as Black people.

The work that will be presented in this doctoral manuscript is a culmination of experiences and expertise (from both participants and researcher). It draws on historical as well as contemporary information to uncover the most appropriate way of developing intervention processes from within marginalized communities. In the summary presented

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<sup>10</sup> Black is a term that has historically been used to describe people who are not white. This included coloureds and Indians. Terms such as 'non-whites', 'non-Europeans', 'natives', 'Bantu' and 'plurals' were also used to refer to the black majority (Fischer, 2007).

below, the reader is guided in gaining a better understanding of the research process and the recommendations made.

#### **D. Summary of the research report**

**Chapter One** (Introductory chapter) provides an overall description of FASD as one of the main challenges to health and development in South Africa. Alcohol abuse as the legacy of the *Dop System* is discussed in relation to the beliefs, norms and practices of the study community. Historical institutionalization of excessive alcohol consumption is traced back to its roots and links are made with current alcohol consumption practices in this rural community.

**Chapter Two** discusses the current approach to health promotion and prevention of FASD. Alternative FASD prevention approaches that incorporate indigenous knowledge and participation are explored. The impact of alcohol on the development of the fetus as well as on the normal development of the central nervous system is discussed in relation to contextual factors. The literature covered in Chapter Two highlights how the application of the medical model as a framework for health promotion and prevention of diseases such as FASDs perpetuates the effects of political and economic marginalization of the study population.

In **Chapter Three** the methodology and how it was applied with this specific group of participants will be discussed. Chapter Three presents Critical Theory as the paradigm for the research (Guba and Lincoln, 1994). Specific principles for interacting with research participants and the research contexts are presented. A process for entering into a community and facilitating self-empowerment and transformation in current occupational engagement is proposed.

The findings of the research are presented in **Chapter Four**. Two themes emerged namely: 'Being drunk is the norm' and 'I am a drinker, that's it!' **Chapter Five** explains how theme two (identity) is imbedded in theme one (context). International examples of the consequences of colonization are used to make an argument for alcohol abuse as an imposed occupation in this community and in the lives of pregnant mothers. **Chapter Six**

offers recommendations for occupational therapy practice with FASDs as recognized disability. Implications for an alternative and radical approach to Occupational Therapy within FASD prevention in the South African context are also discussed. The paper concludes with implications for Occupational Therapy practice as well as recommendations for FASD prevention.

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## CHAPTER ONE

### 1.1 Introduction

This chapter provides an overall description of FASD as a disability<sup>11</sup>, but also as one of the main challenges to health and development in South Africa. The chapter also offers a different perspective from which the occupation of alcohol consumption in the lives of women of childbearing age could be viewed. FASD, as a consequence of alcohol consumption during pregnancy, is discussed from a woman's health determinant perspective. The current occupational therapy contribution in FASD is discussed. The development of excessive alcohol use is tracked from the period of colonization as it became an established occupation within a rural community in South Africa. The identity of mothers, alcohol abuse as occupation and the culture in the context of the local community are foregrounded as the three focal points<sup>12</sup> of this research (See Figure 2). The contextual background provides the experiential, conceptual and environmental contexts for the study.

In addition to the medical model of FASD prevention, this study explored an occupational justice perspective<sup>13</sup> that provides a political dimension to FASD prevention. Such an approach would explore alcohol consumption during pregnancy as a phenomenon that results from a combination of factors namely (a) the factors in the immediate home environment and (b) the influences of macro factors. The immediate home environment includes the content inside the participant's home environment, convenience within the home, comfort, cues for expected behavior and communication (Rowles, 2009). The macro factors include the influences of culture, economy and policies and political priorities (Scaffa, Reitz and Pizzi, 2010), on what activities participants engage in, how they engage in the activities and where they participate in activities. Figure 1 show how

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<sup>11</sup> Recognizing FASD as a disability and developing and maintaining appropriate and adequate supports to the extent that individuals with FASD can be fully integrated into cultural, economic, social and economic development is in line with inclusive development. Although this document does not discuss the advantages and disadvantage of this action, it is crucial to explore these before, during and after this process.

<sup>12</sup> After baseline data was gathered, the three areas of context, occupational identity and occupational engagement were highlighted as main themes within the conversations with participants. Focussing on these three aspects assisted with gaining an enhanced understanding of what participants viewed as important.

<sup>13</sup> Occupational justice is a term that emphasizes rights, responsibilities, and liberties that enable the individual to experience health and quality of life through engagement in occupations (Townsend & Whiteford, 2005)

underlying occupational determinants (related to an occupational justice approach) may have an influence on the health and well-being of mothers who live in communities where alcohol abuse is common. Lysack (2009) supported this approach by suggesting that social determinants are seen as main role players in the health and well-being of individuals. Viewed from a political perspective the phenomenon of FASD is explained as a disability that results from women's engagement in an occupation that is situated within a historical and cultural context. FASD is illustrated as a lifelong disability (Winokur, 2010). While FASD is caused by maternal engagement in alcohol consumption during pregnancy, this condition cannot be outgrown as affected children transition into adolescence and adulthood. Investigating alcohol use before, during and after pregnancy as an occupation in motherhood is thus a crucial step in preventing FASD as a disability. Individual factors (age, parity, alcohol status and educational status) are placed in the background and the following concepts are foregrounded (Appendix 8.16 demonstrates one step in the development towards a framework that focuses on the three aspects below:

- The beliefs, norms and values regarding alcohol consumption as an occupation in the study context.
- Occupational identities of mothers (as determined by exposure to certain conditions and activities that were situated within specific contexts from early childhood into adulthood).
- Contextual factors (such as easy access to alcohol and limited access to appropriate health care and employment opportunities, history of marginalization).

## **1.2 Phenomenon of Interest: FASD**

Alcohol, as a risk factor for disease, has both positive and negative aspects. As a depressant drug, small amounts of alcohol can make one feel relaxed and provide a feeling of well-being. Amongst the general population moderate alcohol consumption does not harm most people, whereas regular heavy drinking does cause health problems over time (Whelan and Gijsbers, 2000). However, in pregnancy, alcohol has been identified as a teratogen (harmful substance to fetal development), which means that alcohol consumption during pregnancy increases the risk of fetal growth disturbances and may damage the growth and development of an embryo or fetus (Streissguth and

O'Malley, 2000; Michaelis and Michaelis, 1994; Coles, 1994; Miller, 1993; Clarren, Astley and Bowden, 1988; West, Hodges & Black 1981; Chernoff, 1977; Tze and Lee, 1975). Clinical research done during the sixties and seventies in both France and the United States of America (Clarren and Smith, 1978; Hanson, Jones and Smith 1976; Jones, Smith, Ulleland & Streissguth 1973; Jones and Smith, 1973; Ulleland, 1972; Lemoine, Harousseau, Borteyru and Menuet, 1968; Lamache, 1967) provided evidence that alcohol exposure in-utero resulted in a constellation of dysmorphic features.

FASDs are caused by the effects of maternal alcohol consumption during pregnancy (Centres for Disease Control and Prevention, 2003; Wattendorf & Muenke, 2005). A study done in France and the United States showed that FASDs occur in approximately one percent of all live births (Sampson, Streissguth, Bookstein, Little, et al., 1997). Floyd, Sobell, Velasquez, Ingersoll et al. (2007) estimated a prevalence of 0, 2- 2, 0 in the United States. The severity of the effect of prenatal alcohol consumption on the developing embryo is determined by a combination of biological (including genetic background), familial, social and psychological factors (Gomberg, 1993), timing, pattern and level of exposure, and the nutritional status of the mother (Guerra, Bazinet and Riley, 2009; Floyd et al., 2007; Mengal, Searight and Cook, 2006; Warren and Li, 2005). Economic factors also play a role (Abel, 1995; Viljoen, Croxford, Gossage, Kodituwakku, et al., 2002; Kvigne, Leonardson, Borzella, Brock, et al., 2003). Vedder (2005) posited that FASD is a result of a combination of individual action (maternal alcohol consumption) and social factors (like poor family structures or poverty). She further stated that maternal factors such as being older than 30 years, history of binge drinking and low socio-economic status are likely to increase the risk of FASD. The dysmorphic features of alcohol exposure in-utero include craniofacial, central nervous system, skeletal, cardiac and urogenital abnormalities along with prenatal and post natal growth deficiencies.

It was in the early seventies that Fetal alcohol syndrome was coined as a medical condition (Ulleland, 1972; Jones, et.al. 1973; Jones and Smith, 1973). While alcohol consumption during pregnancy is the immediate cause of the above mentioned abnormalities, it is important to consider other personal and contextual factors such as (a) whether the mother was prenatally exposed to alcohol (which may compromise decision making and judgment abilities); (b) easy accessibility to alcohol as a result of

the number of alcohol outlets; (c) the availability and accessibility of support in the family; and (d) the antenatal and postnatal health services that are on offer. It is also important to note that not all women who drink alcohol during pregnancy will have a child with FASD. Aday (2001) described how certain groups of people can be categorized as vulnerable and at risk for poor physical, psychological and social health. She argued that the mental health and well-being of low socio-economic status groups (like the participants of this study) tend to be more adversely affected by stressful or negative events than a group of people with higher socio-economic status. The Black Report (Black, 1980) initially suggested that the major determinants of health were socio-economic conditions, geographical location and gender. Other additional contributing factors that serve as predictors of populations at risk of ill health and prenatal alcohol exposure include social capital (family structure, marital status, social networks) and human capital (schools, jobs, income, housing) (Scaffa, et al., 2010). Mundel and Chapman (2010) argued that indigenous groups, such as the study community, do not only suffer from diseases and social problems, but also from a depression of spirit as a result of damage that was done by colonization to their cultures, language, identities and self-respect. Childbearing is one of the health concerns for vulnerable groups in the United States of America such as African Americans, Hispanics and Asians (Ibid). Within the context of this study such vulnerable groups in South Africa are referred to as marginalized groups. Individuals who belong to these groups are more likely to be in poor health as a result of poor access to financial, social and political resources. Kelkar (2005) stated that the majority of women globally are still economically and politically marginalized.

A general assumption among health professionals and health promoters might be: 'If women knew about the adverse effects of maternal alcohol consumption during pregnancy, they would surely avoid alcohol during pregnancy'. However, the reality is that even if people knew and understood the implications of this practice there is a possibility that certain factors might perpetuate maternal alcohol consumption during pregnancy. Amongst a list of factors, other than the drinking patterns of the mother during pregnancy, the nutritional status of the mother and the baby and the emotional well-being of the mother are obvious risk factors that may result in abnormalities formed in the fetus (May, Gossage, Kalberg, Robinson, et al., 2009; May, Gossage, Marais, Hendricks, et al., 2008; Mulia, Schmidt, Bond, Jacobs, et al., 2008; May, Gossage,

Brooke, Snell, et al., 2005; Viljoen, Gossage, Brooke, Adnams et al., 2005). Additional reasons why mothers continue to drink despite their pregnancy may include:

1. Women may consume alcohol before they know they are pregnant.
2. Women may not know how harmful prenatal exposure to alcohol can be (especially in communities where literacy is a problem).
3. Women may consume alcohol because it is a social norm or expectation.
4. Women may drink alcohol because it helps them to cope with difficult life issues, such as stress, poverty or violence.
5. Alcohol use may have developed to the point of dependency (James, 2005).

Participants from studies that focus on FASD tend to originate from poor socio-economic backgrounds. Contextual factors, such as poverty, which may result in the shortage or absence of good nutrition, that impact on the mothers who consume alcohol during pregnancy, will invariably impact on the children once they are born. The effects of poor nutrition during childhood, for example, will not only affect these children as they grow into adulthood, but may be exacerbated by alcohol consumption in adulthood.

Alcohol exposure prior to conception may alter the genetic expression of the parental genetic material. Epigenetic changes<sup>14</sup> can be passed down to offspring (Kobor and Weinberg, 2011). Without the necessary support adults who have been affected in the fetal stages of development may present with difficulties in their work and social areas of life. There is the likelihood that, if they do not escape the contextual influences, these adults may be prone to excessive alcohol use themselves and in turn may produce alcohol affected children again (Astley, Bailey, Talbot & Clarren, 2000). FASD is often an invisible physical disability and those affected may find it difficult to understand the consequences of their behavior (Malbin, 2004).

Due to differences in the body mass index from one individual to the next, alcohol affects the developing fetus in different ways. It is only after birth and as the child gains movement and skills in the early developmental stages that the effects on functional capabilities in children can be observed. Amongst children who have been prenatally

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<sup>14</sup> Epigenetic changes refer to the stable but potentially reversible alterations in a cell's genetic information that result in changes in gene expression but do not involve changes in the underlying DNA sequence. These changes may mediate some of the detrimental effects of prenatal alcohol exposure and contribute to the deficits and abnormalities associated with fetal alcohol spectrum disorders.

exposed to alcohol the children who are most affected are the ones diagnosed with fetal alcohol syndrome (FAS)<sup>15</sup>. The syndrome presents with the following traits:

- Minor facial anomalies (all three FAS features should be present (i.e. palpebral fissure lengths two or more SD's below the mean; philtrum smoothness =Rank 4 or 5 on Lip-Philtrum guide; and upper lip thinness-Rank 4 or 5 on Lip-Philtrum guide;
- Pre-and post natal growth retardation with height and weight at or below the 10th percentile;
- Functional or structural central nervous system abnormalities (Wattendorf & Muenke, 2005). There should be evidence of significant structural, neurological or functional central nervous system damage (Astley, 2004: 347);
- Researchers differ on the fourth condition of confirmation of maternal alcohol consumption. Stratton, Howe and Battaglia (1996) suggested that FAS can be diagnosed without confirmation of prenatal maternal drinking. Conversely, Astley and Clarren (2000) require confirmation of drinking as compulsory for FAS diagnosis<sup>16</sup>. May, Brooke, Gossage, Croxford, et al. (2000) stated that a detailed maternal history is desirable as a way of exploring the nature of gestational drinking and as well as the social circumstances that might have contributed.

Fetal Alcohol Syndrome (FAS), the most severe condition of FASDs, is known as one of the leading causes of preventable mental and physical disability amongst infants

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<sup>15</sup> The diagnosis of FAS is applied to a child who has growth retardation with central nervous system anomalies and characteristic facial dysmorphology (Viljoen et al., 2005). The following three primary defining features should be present: (1) Documentation of characteristic facial abnormalities (smooth philtrum, thin vermilion border, and short palpebral fissures); (2) Documentation of prenatal and postnatal growth deficits; and (3) documentation of central nervous system (CNS) abnormalities (i.e., structural, neurological, or behavioral, or a combination thereof).

<sup>16</sup> FAS is one of five diagnostic categories recommended by the Institute of Medicine (IOM) in a 1996 report (Stratton, Howe and Battaglia, 1996). These categories include the following:

- a. FAS with a history of maternal alcohol exposure;
- b. FAS without a history of maternal alcohol exposure;
- c. Partial FAS with a history of maternal alcohol exposure, which includes people with signs and symptoms attributable to significant prenatal alcohol exposure who need medical, social services, and other attention but who would not receive a diagnosis of FAS with confirmed maternal alcohol exposure;
- d. ARBD, which refers to people with alcohol-related physical anomalies only; and
- e. ARND, which refers to people who manifest neurodevelopmental, cognitive, or behavioral abnormalities attributable to prenatal alcohol exposure.

worldwide (Centers for Disease Control and Prevention (CDC), 2003). In the United States alcohol is recognized as the leading preventable cause of birth effects and developmental disorders (Bailey and Sokol, 2008). Reduction in FAS prevalence would therefore mean a reduction in national disability figures. Unlike other congenital diseases FAS is a completely preventable condition. The effects of FAS are easily identified after age three to four. However, if left unattended these deficits may result in dysfunctional behavioral, cognitive, and emotional deficits (Russel, Czarnecki, Cowan, McPherson, 1991; Connor, Sampson, Bookstein, Barr, et al., 2000; Crocker, Vaurio, Riley & Mattson, 2009; Green, Mihic, Nikkel, Stade, et al., 2009) and dysfunctional social patterns (Malbin, 2004). The physical traits become less recognizable as children mature into adulthood. However, the soft signs remain. Adults who were affected by prenatal alcohol consumption may struggle to adapt in social and work environments (Balsa, Homer and French, 2009; Loser, Bierstedt and Blum, 1999). These challenges are often caused by cognitive impairments such as impaired judgment that might prevent them from fully engaging in health enhancing and development opportunities in their living and work environments. In the absence of an early diagnosis<sup>17</sup> of FASD and without a stable home environment individuals affected by prenatal alcohol exposure will be prone to a list of challenges such as disrupted school experiences, trouble with the law, confinement (in prison or psychiatric/alcohol dependence rehabilitation settings), inappropriate sexual behavior and alcohol/drug addiction (Streissguth, Bookstein, Barr, Sampson, et al., 2004).

Although occupational therapists have not been focusing on FASD as a disability, they are involved in developing interventions with individuals who live with mental or physical impairments as a result of prenatal alcohol exposure.

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<sup>17</sup> The diagnosis of FAS is most easily made between 4 and 14 years of age, when the diagnostic signs are most evident. Attempts to identify FAS in the newborn period have been problematic [Little, Snell, Rosenfeld, Gilstrap, et al., 1990]. Many of the dysmorphic signs of FAS (e.g., short palpebral fissures, thin upper lip, absent /indistinct philtrum) may become less distinct or disappear in late adolescence and adult life [Streissguth, Aase, Clarren, Randels, et al., 1991; Spohr and Steinhausen, 1996].

### **1.2.1 Current occupational therapy interventions for impairments caused by prenatal alcohol exposure**

Within settings where clients present with mental or physical impairments that could be linked to neurological defects caused by prenatal alcohol exposure, occupational therapy could intervene at an individual level with a rehabilitative approach. Activities within this approach would address functional limitations that resulted from the damage to the central nervous system. Functional limitations in children may hinder participation in meaningful activities that facilitate normal development into adulthood. Educational and learning interventions for the improvement of functional adaptation in everyday activities for children with FASD may include language and literacy programs such as Cognitive Control Therapy (Riley, Mattson, Jacobson, Coles, et al., 2003), language and literacy training (Stromland, Mattson, Adnams, Outti-Ramö, et al., 2005; and fire safety and street safety (Coles, Strickland, Padgett & Bellmoff, 2007).

Behavioral interventions may include focusing on attention, non-verbal reasoning ability and executive functions through the provision of Attention Process Training with games and academic support (Vernescu, 2007). Social skills and social communication interventions may focus on problem behaviours and management of child behaviour by the primary caregiver.

Outside of the rehabilitation framework occupational therapy intervention with affected adults could be expanded to include:

- Raising awareness of FASD as a disability;
- Facilitating active participation in occupations of meaning;
- Advocating for accommodation of limited mental and social capacities;
- Incorporating FASD prevention initiatives into health promotion programs at different levels of health care provision (Dotson, Henderson and Magraw, 2003; First Nations and Inuit Health, 2007; May 1995):
- Utilization of a less medical (yet more political approach) may suggest the development and establishment of supportive health, cultural, economic and political environments as an integral part of FASD prevention.

The occupational therapy profession with its focus on occupation has many skills to contribute to the prevention of FASD. Occupational therapists can become involved at individual, community and population levels. Occupational therapy's contribution lies in their expertise in analyzing occupations of work and productivity, play and leisure and self-care as well as the factors which may impact on participation in meaningful occupations that enhance health and well-being. Occupational therapists have skills to ascertain the interest of individuals in different occupations in relation to the context and its accompanying limitations. In collaboration with the individual the occupational therapist can identify occupations that may assist with the pursuit of a healthier and more satisfying lifestyle. A different or broader variety of culturally meaningful and appropriate occupations could be explored that may have a positive impact on individuals, communities and populations. As mentioned above, occupational therapists can become involved in advocating for structural and systemic changes and redress for people who have been previously marginalized. The focus on structural and systemic changes resonates well with two of the occupation-based models for health-promotion in occupational therapy in the public domain, namely community development,<sup>18</sup> and social justice<sup>19</sup> (Wilcock, 1998a).

One of the common ways of raising awareness of FASD in South Africa is via written messages and pictures on posters and t-shirts. While such materials may seem clear to the designers of the message they often do not convey the right message(s) or may fail to convey the message(s) in a way that will motivate the target group to either use contraceptives more effectively while drinking alcohol (Rendall-Mkosi, Morojele, Zama, London, et al., 2007) or to stop drinking alcohol completely during pregnancy. Another controversial yet neglected issue amongst women who consume alcohol remains effective contraception. In this instance, occupational therapists have a contribution to make to client-centered health promotion and education with pregnant women. Graham, Logan and Harrison (2006) suggested that knowledge transfer (knowledge translation) occurs when research results that were produced in an academic setting are exchanged, synthesized and applied in the practice setting. Facts and figures therefore have to be

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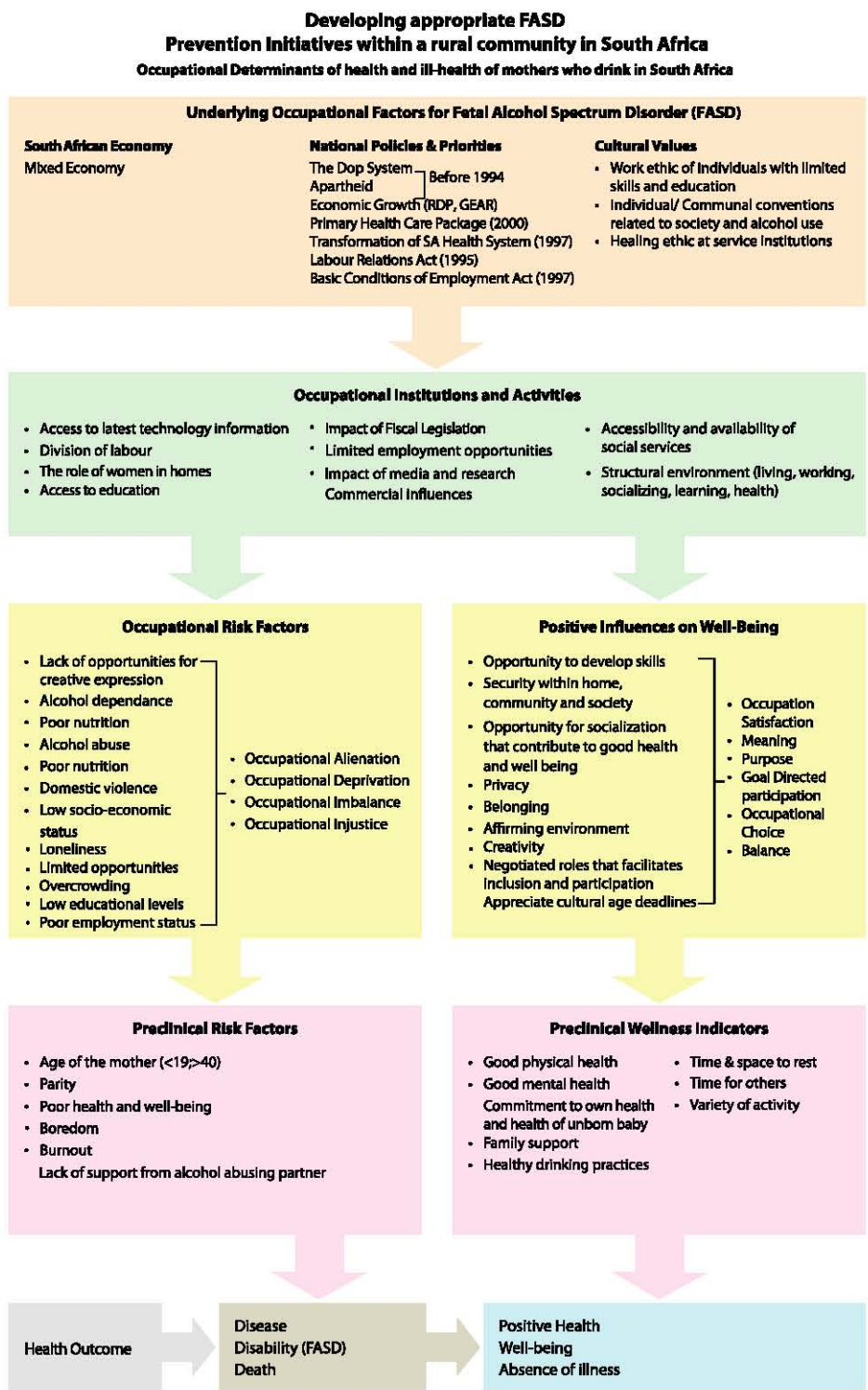
<sup>18</sup> The Community development model focuses on self-sustaining occupational infrastructures that support community life. Activities are also aimed at improving community members' experience of health and well-being (Wilcock, 1998a:229).

<sup>19</sup> Social justice addresses occupational inequities and injustices that prevail due to political and economic hegemony (Wilcock and Townsend, 2000).

related to pregnant women in the way that they find meaningful (Choi, 2005). As in any other knowledge translation process (Shaw, Bondy and Dodman, 2009; Morrow, 2005) awareness of the dangers of maternal alcohol consumption during pregnancy has to be supplemented with a process that allows women to understand and integrate information into their lives. The support that pregnant women receive within the South African health system is a point of much debate. Based on a review of the literature Figure 1 below was developed to depict how risk factors and indicators for health and well-being could determine health outcomes for South African women of child bearing age who are being affected by alcohol.

University of Cape Town

**Figure 1: Occupational Determinants of health and ill-health of mothers who abuse alcohol in South Africa**



Adapted from Wilcock, (1998a)

Within the development of FASD prevention interventions the underlying economic, political and cultural determinants should therefore be considered. Groups of people have different experiences of their world and these experiences are shaped by many social, political, economic, historical and other factors (Townsend, 1999). These factors may hinder knowledge translation in the area of FASD prevention. Health education officers or health professionals involved in the design and development of FASD prevention methods are often unfamiliar with the contexts, the unique experiences, the capabilities and needs of target groups for whom such methods are being developed. The danger thus exists that the target population might not relate to the content or emphasis of the message or the language used (Doak, Doak and Root, 1996). However, if people find the approach and methods of prevention initiatives relevant and appropriate in addressing their needs, they are able to contribute to and participate in the development of such initiatives.

### **1.2.2 Justification for this study**

FASDs have been recognized as an epidemic in the Western Cape (Viljoen et al., 2002; May 1995). A Comprehensive Fetal Alcohol Syndrome Prevention Program (CFASPP) was established in the Western Cape and Gauteng Provinces (Rendall-Mkosi et al., 2007) in the form of a three-year project that commenced in September 2005 to develop a model for the prevention of FASD and alcohol related birth defects that can be applied in different areas of South Africa. It comprised three phases, namely Formative, Intervention and Evaluation.

The Formative phase, which ended in July 2006, aimed at understanding the current patterns, norms, and consequences of alcohol consumption amongst women of childbearing age, as well as available alcohol related services. In the intervention phase the main objective was to develop and implement a detailed intervention and management program based on the findings of the first phase. At this stage a community intervention that focused on the prevention of FASD was non-existent. This doctoral study thus emanated from the bigger project with the intention of contributing to and following up on the findings of this project by developing a model that offered appropriate strategies to the implementation of a FASD prevention at community level.

### **1.2.3 The importance of inquiry into the development of appropriate FASD prevention approaches in Occupational Therapy**

Iwama (2003) defined occupational science as the study of humans as occupational beings, focusing on how human beings achieve personal meaning through occupation. All humans are occupational beings (Gray, 1998; Yerxa, Clark, Frank, Jackson, et al., 1989). In occupational science, occupations refer to the daily activities that have personal and/or cultural meaning (Yerxa, Clark, Frank, Jackson, et al., 1990, Clark, Parham, Carlson, Frank, et al., 1991). Occupation can also be defined as the various everyday activities people do as individuals, in families and within communities to occupy time and bring meaning and purpose to life. Occupations include “things people need to, want to and are expected to do” (Asaba, Blanche, Jonsson, Laliberte Rudman, et al., 2007: 1). Wilcock (1993) suggested that ‘culturally sanctioned occupations’ enable the organization of time and resources and assist economic self-sufficiency, social relationships and personal growth. When exploring the main construct of occupational therapy (occupation) occupational therapists have to caution against defining occupation along “culturally narrow lanes” with contextual meanings that were derived from Western ideologies (Iwama, 2003:584).

In keeping with this caveat this study explored alcohol abuse in pregnancy as a practice that should be acknowledged as an occupation in the study context. Alcohol abuse is associated with spaces for social interaction and it has become an activity that some women of childbearing age engage in on a daily basis. Although it is not a healthy occupation it has personal and cultural meaning to individuals and to the community at large. Excessive alcohol use in the general community and amongst mothers has become an activity around which individuals, families and the community organize time and resources. It also became an activity that marks the social matrix of this community. Alcohol abuse during pregnancy is one of many occupations that are compromising the health of individuals in South Africa. Occupational therapists can view alcohol abuse during pregnancy as a case example of health compromising occupations in the South African context. As such, this study could be helpful in providing insights into approaches or methodologies for exploring other health compromising occupations.

### 1.2.4 Owned vs. Imposed identities

Christiansen (1999: 549) stated that our “identities are closely tied to what we do and our interpretations of those actions in the context of our relationships with others”. This statement implies a close relationship between an individual, his/her identity, the environment, context and the activities in which the person participates (occupation) within the environment. Occupational therapists operate from the premise that all individuals have the ability to exert an influence on their environment and those individuals purposefully select occupations in which they could engage that will give expression to who they are. Iwama (2003) cautioned against the applicability of such assumptions to populations with Eastern ontological foundations as this may not hold true for them. The same caution should be held when the applicability of these assumptions are evaluated in an African context. Assumptions that are informed by the ontological foundations of the occupational therapy profession should thus be interrogated where marginalized populations are concerned. It is therefore crucial to become aware of the definitions and assumptions from which one operates, in order to distinguish personal assumptions from actual root causes of a problem. Being distinctly aware of my professional foundations I continuously had to interrogate my own assumptions as well as the questions I needed to ask in order to answer the research question. I set out with the following questions in mind:

1. How should alcohol consumption as imposed occupation within the culture in the study context be understood in this community?
2. What identities are being held by women who live in the study community?
3. How does the context impact on alcohol use practices in the study context?

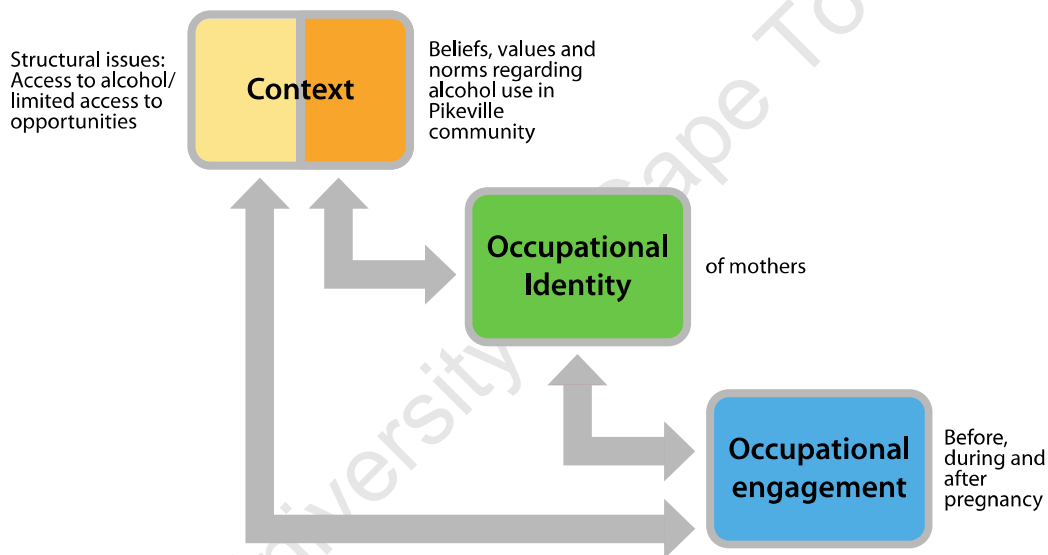
The three focal points would therefore be used to explore:

1. Cultural practices in the context in which mothers who consume alcohol during pregnancy grew up and continue to live.
2. Identities held by mothers in home and community contexts.
3. Occupations in which mothers engaged before, during and after pregnancy.

Unruh, Versnel and Kerr (2002:12) suggested that “an occupational identity is like a fabric of choices that conveys something about who a person is at particular points in his or her life.” Occupational identity is thus dynamic and has a capacity to change over

time. As mothers consume alcohol during pregnancy, they may assume a particular identity that is closely related to their alcohol practices. If certain practices are normalized and imposed on individuals it may shape or contribute to the occupational identity of those individuals. However, if exposed to new occupations, these mothers may develop new identities. The way in which alcohol consuming, pregnant mothers will interpret health information at a certain point and time will then also be influenced by their identity construction processes. Figure 2 demonstrates the framework used to position the constructs of context, occupational identity and occupational engagement within this study.

**Figure 2: Focal points for research on FASD prevention in Occupational Therapy**



The statements made by Christiansen (1999) and Unruh, Versnel and Kerr (2000) have not been proven applicable in situations of alcohol dependency or in environments where people’s ability to actively choose is compromised by socio-economic and political factors that are beyond their control. Based on the evidence provided in the historical account of groups of people, such as the study community, a different perspective might be needed that allows for a view that occupational identities of the residents may have been imposed instead of chosen. This is often the case with social groups, also referred to as vulnerable populations, who experience “limited resources and consequent high relative risk for morbidity and premature mortality” (Flaskerud and Winslow, 1998: 69). Wilcock

(1998) refers to these groups as marginalized groups. When working with vulnerable/marginalized populations such as these, caution needs to be taken with assumptions regarding occupational identity, its impact on occupations and occupational choice. New assumptions may need to be made explicit, such as: Imposed occupations may give rise to imposed identities and vice versa. An alternative view of contextual factors that press for the engagement in certain occupations, as opposed to an individual choosing to participate in the same, then becomes viable.

Cloete (2005) suggests that despite their alcohol practices, mothers who are at risk of exposing their babies to alcohol prenatally also have aspirations for other aspects of their lives. However, the contexts in which they live facilitate easy access to alcohol and lack support for healthy lifestyles. Emerging research on occupational justice (Townsend, 1993), occupational transformation (Townsend, 1997) and occupational deprivation (Molineux and Whiteford, 1999; Whiteford, 1997) contribute interesting insights to theory on occupational identity. Yet a considerable amount of research is still needed to verify theoretical concepts on occupational identity in developing contexts like South Africa. However, in exploring the occupational identity of a group of people from the study community, with particular reference to women who are at risk of bearing alcohol affected babies, this study illustrated the link between the context, occupational identity and occupational engagement.

The notion of doing, being and becoming is challenged in terms of exploring how imposed belief systems and perceptions of their world impacted on the being and the doing of women who live in the study context, thus preventing women from becoming people they never knew they could become. The mother who engages in alcohol abuse and who views herself as a drinker will continue to see herself as a drinker for as long as she engages in this practice. She may also continue to abuse alcohol for as long as she perceives herself as a drinker. This cycle could keep her from becoming another person until she is exposed to an alternative occupation and different contextual influences that can inform her beliefs about who she is, what she is able to achieve, what she is able to engage in and who she could become. Only then can she become a person that she never knew she could become. The stance taken in this research is that the effectiveness of any awareness, prevention or developmental campaign lies in its ability to convey information that will facilitate the reconceptualization of individual and social

identities. It is at this point at which the target group would be able to internalize the information and incorporate it into their daily living. In this way new beliefs can be created and new practices could be taken up.

### **1.3 Researcher's Assumptions about study participants.**

Based on the literature on FASD one is tempted to make negative assumptions about the inherent capabilities of people who are affected by alcohol. Some of these assumptions may include that:

- People affected by alcohol do not care for their own health and for the health of their unborn babies,
- People affected by alcohol are not fit parents and/or lack parental abilities,
- People affected by alcohol are helpless and hopeless drunkards,
- People affected by alcohol are lazy and in this situation because of their own doing.
- People affected by alcohol choose this occupation for themselves – in ways one would perceive it as a personal choice.

The abovementioned include some of the assumptions I held before embarking on the research for my MSc (OT) degree that focused on a group of mothers who consumed alcohol during pregnancy. As I became more familiar with the factors underlying this public health problem, I realized my own ignorance regarding the impact of social, economic and political history on people's health and development. Goldin (1987) suggested that it is useful to fully understand any practice by exploring its historical roots. This will aid the possibility of recognizing how to move away from these and transform society.

I approached my doctoral research with an expectation to get to know the participants and their context better. I reminded myself constantly to connect with participants as human beings and more importantly as mothers first. This in itself was the foundation for building trusting relationships.

### **1.3.1 Tracking the emergence of problematic alcohol consumption as Imposed Occupation**

Although FASD have been reported in different racial groups (Bingol, Schuster, Fuchs, Iosub, et al., 1987), cases of FASD have predominantly been described among Native and Indian Americans (Mulligan, Robin Osier, Sambuughin, et al., 2003), and Aboriginal populations in Australia (Goh, 2006) as well as in indigenous populations of the Northern Cape and Western Cape Provinces of South Africa (Viljoen et al., 2002; May 1995; Rendall-Mkosi et al., 2007). Alarming, the figures of a study done in Black schools in the Western Cape and Northern Cape Provinces of South Africa revealed the highest prevalence in the world (McKinstry, 2005). Besides the tendency to associate FASD with indigenous groups it should be noted that the high prevalence of FASD among the indigenous populations of South Africa is not a coincidence. The occurrence of this problem has been linked to the history of farm workers of the Western Cape. Scully (1992) stated that farm workers employed by the Dutch and subsequently English colonialists used to get paid for their labor with tobacco, bread and wine. It is commonly known that alcohol is addictive and farm workers received large amounts of low quality wine (higher ethanol concentration) as payment. This was called the Dop system. The Dop system was widely practiced on wine farms as well as deciduous fruit farms in the Western Cape and operated by partly remunerating farm workers with daily allocation of alcohol (London, Nell, Thompson & Meyers, 1998; London, 1999a; London 1999b; Crome & Glass, 2000). While the Dop system was initiated on wine farms, it had later become an institutionalized practice in agriculture as a form of worker control. Even after the Dop system had become illegal in 1961 (Department of Trade and Industry, 1963) this system of remunerating and controlling of farm workers was still reported by farm workers in 1993 (London, Saunders, Te Water Naude, et al., 1998). Alcohol abuse, as an inherited legacy of the Dop system resulted in a disproportionately high rate of alcohol abuse amongst farm workers in the Western Cape (London et al., 1998; May et al., 2000). While the 1928 Liquor Act managed to curtail the Dop system, it did not abolish it. However, its effects on the lives of many farm workers are still evident (London, 2000) and its legacy is deemed one of many imposed practices of colonization. These actions were precursors to the systematic breakdown and ultimate destruction of people's dignity, their relationships with family and neighbours and their overall culture. Problematic alcohol use and alcohol dependence became part of the culture of the

present generation of farm workers (De Kock, 2002; London, 1999a). In combination with excessive drinking and binge drinking poor living and work conditions inevitably result in poorer health status for those affected. Even in the absence of the Dop system, farm workers and their families are enmeshed in a cycle of poverty and dependence (London, 1999b). Ross (2010) suggested that alcohol abuse is a historical problem in South African farming communities as well as in informal settlements (which offered housing for many Black people in urban areas where the provision of housing was historically limited or not allowed). This tendency was established during the period of 1950-1955 when an artificial segregation was made between 'Colored' and Black people. This segregation was stringently enforced by offering "Coloreds" preferential treatment by excluding Blacks from the job market and offering 'Coloreds' preferential access to jobs in the Western Cape Province. What seemed to be an advantage at the time was part of a systematic plan to isolate and manipulate this group of people for political reasons. For the next fifty or more years "Coloreds" would become the political pawns manipulated for the political gains of the White ruling party.

With the advent of the democratic government in 1994 farming communities as well as other marginalized groups of indigene Africans became more mobile. Some families were evicted from farms and others moved in search of a better future in nearby towns (such as the study community). Alcohol consumption was already a defining feature of everyday life for some and this practice continued wherever families settled. For people who lived on farms for many years alcohol abuse offered a routine to the day. Drinking did not only offer a routine, but it also became an occupation around which many other activities were organized in the lives and culture of generations of farm workers and their families. Drinking also allowed for the emergence of a particular type of sociality – that of drinking friendships and the excessive use of alcohol and binge drinking as a norm in this community (Ross, 2010). Scully (1992) posited that the Dop system provided a unique cultural space for farm workers which farm owners could not share. Besides the structural condition of poverty, social and political exclusion, excessive alcohol use resulted in chaos for most of the time. Sztompka (2000) stated that for social change to be potentially traumatizing the following four characteristics must be present in conjunction:

1. The change should be marked by a particular temporal quality – it is sudden and rapid.
2. It has particular substance and scope – it is radical, deep, comprehensive and touches the core of individual and collective psyche.
3. It has particular origins – it is perceived as imposed, exogenous, coming from the outside, as something to which those who are affected have not contributed, or if they did, then only unwittingly (people ‘suffer’ traumas, traumas ‘occur to people’, people ‘encounter’ traumas).
4. It is encountered with a particular mental frame – it is perceived as unexpected, unpredicted, surprising, shocking and repulsive.

Measured against the criteria outlined by Sztompka, the conditions created by the culmination of events discussed above, meet all four of the criteria. The discord caused by excessive alcohol use included interpersonal violence (domestic violence and rape) and the unpredictability of family and friendship relations. Alcohol abuse also stripped people of dignity and purpose (Ross, 2010). Communities that are ridden with problematic alcohol use might generally be supportive of each other in times of need, threat or danger from people outside of the community, but alcohol dependency creates fluctuating states of being chaotic and being supportive (Ross, 2010). Engagement in an occupation that results in such upheaval can therefore never be viewed as an occupation of choice, but one that was imposed on a group of people who were forced to live in conditions that robbed them of basic rights and dignity. In the same way, the modeling of excessive alcohol use by grandparents and parents to children was not by choice. The reinforcement of alcohol abuse as occupation amongst farm workers at different levels (political, cultural and socio-economic) ensured the maintenance and transmission of excessive drinking over the past two hundred years. With a macro process, such as the normalization of alcohol in the study community, the effects of issues such as broken families and peer pressure during adolescence were magnified. What would be experienced as an expected influence of peer pressure during adolescence in a community with better social and economic status becomes an effect that is exponentially transformed into cultural pressure to drink excessively in all stages of life. In a community in which excessive alcohol use is the very thread on which social relations are built the cultural matrix is too vulnerable to absorb and maintain any

developmental process that might be deemed normal for individuals who are influenced by and who are influencing cultural systems and practice in this community.

### **1.3.2 Shifting from a historical to an emergent perspective of understanding risk for Fetal Alcohol Syndrome**

Fetal alcohol syndrome was first recognized and documented as a distinct birth defect in the late 18th century (Jones and Smith, 1973). Ever since then researchers have investigated the maternal characteristics, risk factors and protective factors for determining the specific etiology of FASD as well as prevention possibilities (Viljoen, et al., 2002). Studies that reported on the common characteristics of mothers who bear children affected by alcohol listed the following characteristics: women who are older, multigravidas, not currently married, and who smoked cigarettes or used other drugs (Sokol, Miller & Reed, 1980); advanced maternal age, high parity, low socio-economic status, African-American race, severe drinking patterns (Abel & Hannigan, 1995; Abel & Sokol, 1986; Darrow, Russel, Cooper, Mudar, et al., 1992; Day, Zuo, Richardson, Goldschmidt, et al., 1999; Ernhart, Sokol, Martier, Moron, et al., 1987; Jacobson, Jacobson & Sokol, 1996; Sokol, Ager, Martier, Debanne, et al., 1986; Sokol et al., 1980). A number of studies also showed evidence on the determinant factors as well as the prevalence in different parts of the country (May, et al., 2005; Urban, Chersich, Fourie, Chetty, et al., 2008). Day, Robles, Richardson Taylor, et al., (1991) identified older women of low socio-economic status were likely not only to produce children with FASD, but also children with growth and developmental delay and neurobehavioral defects. A more in-depth discussion on the most recent studies, methodology and findings on FASD will be undertaken in the next chapter.

Previous studies on FASD were successful in identifying the causal factors that mostly related to the pregnant mother's contribution to this condition. A survey carried out by Rendall-Mkosi et al. (2007) in the Westcoast/Winelands revealed similar risk factors for an alcohol exposed pregnancy as were found by a study done by Croxford & Viljoen (1999). The primary risk factors that were commonly included were low educational levels of mothers, poor employment status, heavy alcohol consumption and high levels of problematic substance consumption (tobacco and alcohol). In addition, male partner alcohol use characteristics were associated with being at risk of an alcohol-exposed

pregnancy. Also, having given birth to a previous child with FASD has been identified as a risk factor for FAS (Astley et al., 2000). More distal factors included the women's degree of access to alcoholic beverages and to recreational facilities (Rendall-Mkosi, 2007). These identified causal factors point to a combination of individual, interpersonal and group factors in different spheres (physical, sociological and economic).

While this information is important for understanding the interplay of factors on the micro level (the place in which occupations are being engaged in and the space that is being created or occupied), there is a paucity of information on the macro influences on the overall occupational engagement and drinking practices of women who live in the study community. Macro influences that may impact on what women do on a daily basis include the type of economy, national policies and priority (e.g. policy on health services or job creation) and cultural values. Scaffa et.al (2010) built onto Wilcock's (1998a) occupational perspective of health and suggested three macro influences that determine the occupational institutions and activities in any context namely:

1. the type of economy;
2. international and national policies and priorities; and
3. cultural values.

#### ***1.3.2.1 Type of economy and FASD***

Economy is one of the pronounced macro factors that impacts on people's development. The economy will have a direct influence on how citizens are able to meet their own basic physical, emotional and social needs. Access to financial, material and social resources may help or hinder people's health and their ability to participate and contribute to development.

Walker, Cooney & Riggs (1999) found that socio-economic status had an effect on the health behaviors of pregnant mothers. Their study showed that lower family income resulted in poorer health behaviors during the first trimester of pregnancy. In a comparison of the offspring of alcoholic mothers from a lower versus upper middle class it was found that the offspring of the upper middle class alcoholic mothers were less affected; they only presented with attention deficit disorder, poor educational achievement and perpetuation of alcoholism. The offspring of alcoholic mothers from the low socio-economic class had a high prevalence of FAS and alcohol effects (Bingol et al.,

1987). Although it is possible that the better nutritional status of the upper middle class group of mothers played a crucial role in reducing the risk for developing FAS in the Bingol study, Abel (1998) and Abel (1995) also provide evidence that low socio-economic status markedly increases the risk for FAS and is a leading variable associated with FAS births. It may therefore be necessary to do more research on social environments and their impact on the occurrence of FASDs.

### *1.3.2.2 International and national policies and priorities*

Historical South African legislation had a profound impact on current occupational engagement and development. National policies in the 16th century were mainly segregationist. In 1713 the supremacy of Europeans was legalized due to a decline in Khoi-San numbers as a result of a smallpox epidemic. Decreasing numbers of indigenous nations groups partly facilitated imperial domination and political control of the smaller groups of indigenous people. Towards the end of the 1700's the number of slaves in the Cape was higher than that of European colonists. The British colonial era started in 1795 and this marked the beginning of the era of industrialization. Between the 16<sup>th</sup> century and the 18<sup>th</sup> century South Africa shifted from a colonialist system to a capital economic system. The legacy of a capitalist system, which was marked by the exploitation of the labour of imported slaves and other indigenous groups, is still evident in the pronounced images of poverty and displacement of large pockets of the South African population.

Land dispossession predated apartheid and in 1940 a number of civilians were moved away from centers of economic development and into informal settlements in peri-urban areas. These camps had no infrastructure and no access to basic health and education services. During 1943 previous slaves and Khoi-San servants were grouped together as a separate nation called 'Coloreds'. Indigenous groups were manipulated and forced into accepting colonial protection in return for reserved land and freedom of self-governance. Following the victory of the National Party in 1948 the Group Areas Act was passed and enforced. This model of segregation was based on separate development, the conquest and/or dispossession of land, taxation and pass laws. In 1950 'Coloreds' were removed from the voter's role. Segregated residential areas were initiated and groups of people were forcibly removed into areas further away from central economic development. There was a buildup of national political uprising against the Apartheid government that was

crushed after the Sharpeville massacre in 1960. After the Sharpeville massacre activities of political resistance decreased and only re-emerged in the late 1970's. In 1983 all citizens who were not classified as "white" had limited or no participation in Parliament (Du Pre, 1994). The consequences of the enactment of segregationist law upon specific groups of people advantaged some groups and disadvantaged others. The disadvantaged groups were excluded from engagement in decision making structures and were thus politically disenfranchised.

As a result of oppressive national policies all indigenous populations suffered historical trauma (Fischer, 2007; James, 2010). Sztompka (2000) uses the notion of cultural trauma to refer to the effects of traumatic conditions pre-empted by major social changes. He defines cultural trauma as a shock to the cultural tissue of a society. In addition, the institutionalization of alcohol and tobacco as remuneration among indigene groups caused an endemic lack of personal coping strategies. This is evident in the problematic alcohol use that was already integrated as part of the culture of the then predominant Black work force even after the Dop System was declared illegal in 1961. Alcohol abuse was established among employers and the public as a 'natural' tendency of farm workers (London, 1999a).

### ***1.3.2.3 Cultural values***

Culture underlies occupational choice and is therefore of central interest for occupational therapy practitioners (McGruder, 1998). Culture is defined as "the learned, shared experiences that enable people to interact with each other and with their environment" (Kefting & Krefting, 1991). McGruder (1998) outlined the following six attributes of culture:

1. Culture is real and while it is intangible it is a powerful force that has the ability to shape the forms and meanings of changes in social status in the group
2. Culture is learned and not inherited as may be believed by many
3. Culture manifests in social interactions and takes place within a specific context. Culture is thus shared in human society
4. Culture is dynamic and has the ability to change slowly over time

5. Culture drives and shapes human values
6. Culture is invisible and we are often blind to our own cultures. It takes repeated experiences with entering other cultural spaces, coupled with introspection, to make our own cultural assumptions visible to us

Iwama (2003) argued that occupational therapy as a profession is culture bound and mainly based on Western culture. South African occupational therapists therefore have to constantly appraise the relevance and applicability of occupational therapy constructs, especially with regards to the diverse range of cultures that exist in the country. Iwama further posited that the lack of critical reflection on the core tenets of the occupational therapy profession may be “partially due to the fact that the profession shares so many of its core values with the Western social context that emerged, developed and nurtured it to its current prominence” (Iwama, 2003:582). When contributing to FASD prevention occupational therapists should therefore be aware of their own cultural values as opposed to the cultural values of women who consume alcohol during pregnancy and the underlying cultural values of the profession.

McGruder (1998) suggested that although culture, race and ethnicity are different concepts they may overlap, interact or intersect with each other. An example of this is how historical experiences of oppression or privilege that was based on racial, ethnic or other group membership shape culture within a group. Sztompka (1993:451) suggested that the process of an individual becoming a social being occurs in the inherited cultural environment, the socially shared pool of ready-made templates for socializing, interpreting, framing and narrating the ongoing social praxis. There is thus a close link between historical, political and socio-economic conditions and current cultural expressions. Appreciating this link between historical and present factors is crucial and occupational therapists should remind themselves of the ontological constructs of the profession.

The concept ‘occupation’ is an unusual and often misunderstood term among marginalized groups within South African society. Women who consume alcohol during pregnancy have their own set of beliefs and values towards practices that relate to their own health and the health of their unborn babies. These values and beliefs of individual women should thus be viewed in relation to the values and beliefs held by family

members, friends and the wider community in which these women live, work and socialize. The close link between occupation and culture (whether occupation or culture was imposed on a group or not) begs for further exploration among marginalized populations for the simple reason that marginalized groups first need to unpack what they classify as occupations within their own contexts. The same applies to concepts like occupational choice, occupational potential and occupational agency. Within traumatized groups women who abuse alcohol during pregnancy may do so as an expression of oppression rather than as an expression of a choice made for engaging in binge drinking. Alcohol abuse and binge drinking as occupation in motherhood should thus not be seen as a practice that is naturally inherent to the culture of mothers who abuse alcohol during pregnancy. It should rather be viewed from a perspective that considers the impact of historical socio-political factors (Frank, Kitching, Joe, Harvey, et al., 2008). A pertinent awareness of one's own culture as a practitioner is therefore of utmost importance if occupational therapy practitioners want to avoid the profession being experienced as oppressive to people who have different worldviews (McGruder, 1998). For this reason we should examine what is worth knowing and doing in the profession and just how socially inclusive and culturally relevant our ideas really are.

Mundel and Chapman (2010) highlighted the need for changing social and economic conditions as a way of improving the health of indigenous populations. The argument is made that these either give rise to occupational risk factors or may provide opportunities that have positive influence on well-being. While this study focused on one of the three macro influences, namely cultural values, it should be noted that the cultural values of a group of people could not be isolated from the other two macro factors. The Findings chapter will illustrate the dynamic interplay between these three factors.

### *1.3.3 Phenomenon discussed within West Coast/Winelands – Cape Town, South Africa*

The study took place in Pikeville<sup>20</sup>. Pikeville is a small settlement situated in a rural town in the West Coast/Winelands district, Western Cape Province, South Africa. This is one of the areas in which FASD and accompanying risk factors were identified as a major health problem within surrounding farming and central town communities. This part of the West Coast/Winelands district is known for wheat and grain farming. There are also a number of table and wine grape farms in the area as well as citrus and other fruit. The mobility between farms and the urban area is high and health services are being provided to surrounding farming and smaller town communities via established clinic services or mobile health clinics that travel to a central point where these services can be accessed. The Western Cape Province of South Africa has a population size of 1140000 people. Pikeville is situated in a town with a population size of 9271 residents. 78% of the 9271 residents live in Pikeville. The residents of Pikeville mainly travel by foot or make use of lift opportunities (also referred to as “hiking”). Farm owners also provide transport for farm workers to and from farms and the business center of town. Some farm owners also provide transport for clinic visits in town.

The majority of the people from the study population are unskilled workers who do either seasonal work on surrounding farms or they assume employment within the town as domestic or general workers. Some of the participants who grew up in Pikeville worked as teachers, nurses or political activists during the time of the research. South Africa has a population of 40,2 million people (Statistics South Africa, 2008). In 2005 a total of 7.8million individuals were unemployed. The unemployment figure increased in 2010 from 19,4% to 23.3% (Bhorat, 2008). In 2011 the total number of South Africans who received social grants<sup>21</sup> was estimated at 14,810,957. This number is increasing as 15.3 million registered for social grants in 2012 (Mail and Guardian, 15 Feb 2012).

Since 1995 there was an increase in farm worker families and families that moved to Pikeville and who qualified for housing that was made available as part of the

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<sup>20</sup> Pseudonym

<sup>21</sup> Social grant” as defined in section 1 of the Act; as Child Support Grant, Care includes the Dependency Grant, Foster Child Grant, Disability Grant, Older Persons Grant, War veteran’s Grant and Grant-in- Aid

Reconstruction and Development Program<sup>22</sup> (RDP). While the greater town in which Pikeville is situated was established in 1836, Pikeville developed as a result of the Group Areas Act in 1957. Although the Group Areas Act was repealed in 1991 this settlement expanded as families moved from nearby farms into town. Mobility of families between town and surrounding farms increased as families would live and work on farms during harvesting seasons and move back to town during quieter seasons. As in the past some workers were transported to and from farms on a daily basis (personal communication with farm owner, 2008). The occupation of excessive alcohol use amongst farm workers in this area was already established in the early 1960's. Excessive drinking practices could therefore be transferred from farm worker families to families who moved between the farms and Pikeville town. When the unique historical context of alcohol consumption in South Africa, whereby access to alcohol by the Black majority was prohibited or restricted during the apartheid era, is considered in combination with subsequent market influences from commercial beer and cheap wine sales, one cannot help but wonder how this impacted on transforming indigenous traditions of home brewing of alcohol beverages into proliferation of homebrews and the widespread small-scale outlets for alcoholic beverages called shebeens<sup>23</sup> (A Ojo, Louwagje, Morojele, Rendall-Mkosi, et al., 2010). The excessive drinking of alcohol may have become an act of resistance. Easy access to cheap alcohol from shebeens in an area may have exacerbated excessive drinking patterns in Pikeville.

#### **1.4 Research question**

What are the values, beliefs, norms and perceptions of a rural community and how could knowledge about this be incorporated into the development of effective FASD prevention approaches?

#### **1.5 Aim and Objectives**

The aim of this study was therefore:

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<sup>22</sup> Reconstruction and Development Programme (RDP) is an integrated, coherent socio-economic policy framework. It seeks to mobilise all our people and our country's resources toward the final eradication of the results of apartheid and the building of a democratic, non-racial and non-sexist future. It represents a vision for the fundamental transformation of South Africa. The central goal for reconstruction and development was to create a strong, dynamic and balanced economy by eliminating poverty, addressing structural and economic imbalances. This process was aimed at empowering the historically oppressed (White Paper on the Reconstruction and Development Programme, 1994)

<sup>23</sup> An unlicensed or illegally operated drinking establishment (2012 Miriam-Webster, Inc. online dictionary)

To explore the existing beliefs and values of participants that could be incorporated into FASD prevention approaches.

The following objectives were identified:

1. To explore the beliefs, norms, values, perceptions and practices of participants with regard to general alcohol consumption and alcohol consumption during pregnancy.
2. To explore the links between general beliefs, norms, values of drinking women and the identities that were shaped and held by mothers.
3. To understand and explain how beliefs, values and norms about maternal alcohol consumption could be incorporated into the development of appropriate FASD prevention initiatives in communities like Pikeville.
4. To develop an appropriate approach to FASD prevention in Pikeville.

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## CHAPTER TWO

### LITERATURE REVIEW AND THEORETICAL LANDSCAPE

#### 2.1 Introduction

This literature review will give an overview of the burden of FASD internationally as well as locally. Existing prevention initiatives that target individual behavior change as a way of FASD prevention will be explored. Suggestions are made for future FASD prevention approaches that focus on the impact of cultural systems on alcohol use practices. The chapter will highlight how the application of the medical model as a framework for health promotion and prevention of diseases such as FASD had been effective in FASD prevention. However, there is a need for considering alternative models for educating on the impact of the social and cultural environments on the drinking practices of mothers and promoting the health of mothers by changing the environments in which they live. This study made a specific contribution to Occupational Therapy and Occupational Science by promoting transformation through occupation in marginalized populations such as South Africa. Alternative approaches to the traditional medical model of disability were thus deliberately explored as a way of highlighting and exposing tacit power relations that prevent traditional FASD prevention approaches to reach their fullest potential in promoting cultural-, economic-, social- and political- health and - well-being. Hence, as a way of re-conceptualizing FASD in the South African context, assumptions about the occupational human were used to situate this study within the following four fields:

1. **Occupational therapy** - which provided a framework for the study of alcohol abuse as an occupation in motherhood.
2. **Occupational science** - the construct of narrative, or story making within occupational science was used to illuminate the issues related to maternal alcohol consumption. Taking an emic (insider's) perspective of alcohol abuse provided information on cultural values in Pikeville. One important commonality between occupational science and occupational therapy is the relationship between the concepts of occupation, health and culture.

3. **Liberation psychology theory** – the link between individual identity, social identity and the occupational engagement of mothers was explored as a way of facilitating social transformation and subsequent transformation in occupational engagement.
4. **Education for liberation** – the six adult education principles by Friere (1972) were used to facilitate the research process. Dialogue was an efficient method that allowed the researcher and participants to name issues relevant to prenatal alcohol consumption.

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## 2.2 Alcohol consumption globally and in South Africa

In 2002, 17% of disability-adjusted life-years (DALYS) and 7.1% of deaths in South Africa were attributable to alcohol (Schneider, Norman, Parry, Bradshaw, et al., 2007). Alcohol abuse is listed as one of the three leading public health risk indicators in South Africa (Bradshaw et.al. 2007).

The amount of alcohol consumed per drinking person in South Africa is about 20litres of absolute alcohol consumed per person per year and rates are the highest in the world for a country (Schneider et al., 2007). In the South African Demographic and Health survey done in 1998, the alcohol consumption levels for males and females older than 15 years were estimated at 45% and 17%, respectively (Parry, Plüddemann & Steyn, 2005). The levels of problem drinking among South African women are high with 25 percent of female drinkers exceeding the recommended levels for responsible drinking (Department of Health, 2003). According to a survey done by the Department of Health, four percent of female drinkers drank at hazardous or harmful levels (Department of Health, 2004).

The African sub-Saharan region has 29 million women of reproductive age of which 20 percent have an unmet need for family planning service (The Science of Improving lives, 2012). In a cross-sectional retrospective survey the prevalence rate for unplanned pregnancy<sup>24</sup> in South Africa was estimated at 59,7% (Bafana, 2010). The survey was conducted among 1018 women who lived in Potchefstroom, South Africa. Bafana investigated the factors that influenced contraceptive use among women of childbearing age. The results showed that a total of 616 women discontinued using contraceptives during the course of their reproductive stage of life. Thirty five percent of the women who discontinued contraceptive use reported reasons such as side-effects, cost of getting to and from health facilities and poor access to health facilities. Although not presented as a recommendation in Bafana's (2010) study it is important to also explore the factors that impact drinking patterns of women during the reproductive stages of their lives.

There are no statistical figures available for the prevalence of FASD globally or nationally. For this reason the next section will therefore refer to FAS statistics in order to discuss

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<sup>24</sup> An unplanned pregnancy occurs when a woman or a couple use contraception or when a woman or couple do not desire to become pregnant but do not use contraception (Santelli, Rochat, Hatfield-Timajchy, Colley et al., 2003). In 2004 the unplanned pregnancy rate in the United States was estimated at 50% (Ventura, Abma & Mosher, 2008).

and compare South African statistics with international statistics of FAS. The FAS rate in South Africa is extremely high when compared to estimated FAS prevalence in the United States of America. Due to differences in the methodology used as well as varying subpopulations, the prevalence rate for the United States ranges between 0.5 per 1, 000 births (May and Gossage 2001; May et al., 2009) and 2.0 per 1, 000 live births (Floyd et al., 2007). The incidence of FAS in the Western Cape Province, South Africa has been reported as the highest in the population of a country anywhere in the world (McKinstry, 2005). The population of children in the Western Cape comprises 10% of the total population of children<sup>25</sup> who live in South Africa (Hall, 2010). This means that from a national population figure of 18 771 children in South Africa, 1 789 live in the Western Cape. The prevalence of FAS thus has to be seen in relation to the number of children who live in the province.

With a population of 4 524 335 people living in 1 173 304 (South African Census, 2001) households the figure of FASD may be an underestimation of this problem in the Western Cape. The different measures used by researchers when it comes to determining the incidence and prevalence of FASD calls for a critical interpretation of the prevalence of this condition. For example, Abel and Sokol (1987, 1991a) and Abel (1995) used the term incidence to describe new FAS cases (e. g. births) per annum as opposed to May and Gossage (2001) who referred to prevalence figures by describing the frequency of occurrence or presence of FAS, alcohol related birth defects (ARBD) and alcohol related neurological disorders (ARND). The high FAS rate in South Africa is in correlation with the highest levels of alcohol consumption per person (Schneider et al., 2007).

The incidence rate of FAS in South Africa has escalated over the past fifteen years. In 1997 the incidence rate was between 40.5 and 46.4/1000 in a study done in a Western Cape community with a population size of 36 359 people (35 364 urban dwellers and 986 people living in rural areas). Alcohol-related birth defects (ARBD) and alcohol-related neurological defects (ARND) were excluded from the study (May et al., 2000). Within this study an active case ascertainment, 2-tier methodology was used with grade one learners (n=992) from a community in the Western Cape province of South Africa. A case-control design was used. This study, which only focused on FAS diagnoses, reported

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<sup>25</sup> Children are defined as persons aged 0 - 17 years

a prevalence FAS of 46.6 per 1000 children of 6 years of age for FAS. FAS prevalence for children aged 5–9 years in the Western Cape Province was estimated at 40.5 to 46.4 per 1,000 (May et al., 2000), while a rate of 39.2 - 42.9 was estimated for 6-7 year old learners. An escalating prevalence of FAS was found by May et al., (2005) in a case-control study for which all participants were recruited by active case ascertainment; 64 out of 863 children screened were diagnosed with FAS. This prevalence is up to 148 times greater than FAS estimates in the United States. The highest reported prevalence rate of 68-89 per 1000 children was found in a case control study done in the Western Cape Province of South Africa (May, Gossage, Marais, Adnams, et al., 2007).

In a quantitative, cross-sectional research study done in the Western Cape Province, face-to-face interviews and a questionnaire were used to collect data from forty-four primary caregivers of children with FAS/Partial Fetal Alcohol Syndrome (PFAS)<sup>26</sup> (Crede, Sinanovic, Adnams, London et al., 2011). This study confirmed the significant burden that Fetal Alcohol Syndrome and PFAS place on the health care system, as well as the financial burden to society in caring for children aged 12 years and younger. Health care utilization for children with FAS and PFAS was approximately 3 times higher than that for a child without FAS/PFAS. The costs of such increased utilization are likely to contribute up to 5% of health care costs in the Western Province. The prevalence of FAS in the Northern Cape Province is even higher in some areas, and Gauteng was surprisingly high (about 2%). While the size of the FAS problem has been recognized in the Western Cape and Northern Cape Provinces, research suggest a high prevalence nationally.

The estimation of the lifetime cost of caring for a child with FASD presents a major challenge to public health authorities (Crede, et al., 2011; Lupton, Burd & Harwood, 2004). Except for the United States, no estimates of the lifetime costs of this condition could be found. The figures presented here should therefore be interpreted with caution, especially when comparisons are drawn. Although numerous FAS prevalence studies are available in South Africa, it is important to note that little reliable data is available on the prevalence of individuals who have been exposed prenatally to alcohol (this include

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<sup>26</sup> Partial Fetal Alcohol Syndrome (PFAS) refers to a lesser FASD in which a child presents with characteristic facial dysmorphic features but with fewer abnormalities in growth or central nervous system structure and function than a child with FAS (Hoyme, May, Kalberg, Kodituwakku, et al., 2005).

individuals with alcohol-related neurodevelopmental disorder (ARND<sup>27</sup>) and alcohol-related birth defects (ARBD<sup>28</sup>). The impacts, or disabilities caused by prenatal alcohol exposure as well as the required services and costs involved in caring for affected individuals are also unknown. For this reason only the costs for individuals with FAS will be presented. Acknowledging that other babies born with other FASD conditions make up a much larger group, accounting for as many as five times the number of FAS cases (Astley, Stachowiak, Clarren & Clausen, 2002), it is important to mention that the figures on FAS represent a fraction of the overall figure. The studies presented below focused on various items in estimating cost for different periods of lifetime costs as calculated between 1985 and 2002.

In 1980 Harwood and Napolitana (1985) used a prevalence rate of 1.9 per thousand live births and estimated the national annual cost estimate for FAS in the United States at \$596 000. The adjusted cost for 2002 was estimated at \$2 million for each individual with FAS. This estimate included medical treatment, services for affected children, special education and social service cost, adult vocational services and institutional care for intellectual impairment to the age of 65 years. Rice, Kelman, Miller & Dunnmeyer (1990) estimated annual costs in 1985 to be \$1.6 billion, using a prevalence rate of 1.9 per 1,000 live births. This cost included neonatal intensive care services and other treatment and care services up to age 21. It also included residential care for persons with mental retardation over age 21. At the same prevalence rate of 1.9 cases per 1,000 live births, Abel and Sokol (1991b) estimated the annual cost was \$250 million in 1987. Based on growth in population and increases in health care costs between 1985 and 1990 the total cost for 1990 was projected at \$2.1 billion (Rice et al., 1990). Harwood, Fountain & Livermore (1998) estimated the 1992 annual cost to be \$2.9 billion. Using a prevalence rate of 2.0 cases per 1,000 live births this study did not only include treatment and care services to the age of 21; it also calculated home and residential care services for moderate and severe cases of mental retardation to age 65. Special education services and lost productivity were also included. In 1995 the lifetime cost was estimated at \$1.5 million (Advisory Board of Alcoholism and Drug Abuse, 2001). The

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<sup>27</sup> Alcohol-related neurodevelopmental disorder (ARND) is used to describe individuals with confirmed prenatal alcohol exposure who exhibit CNS neurodevelopmental abnormalities and/or evidence of complex patterns of behavioral or cognitive abnormalities that cannot be explained by other genetic or environmental factors.

<sup>28</sup> Alcohol-related birth defects (ARBD): the term is used to describe "observed anatomic or functional outcome to the impact of alcohol on the offspring" (Sokol & Clarren 1989, p. 598). Refers more specifically to physical anomalies associated with prenatal alcohol exposure.

median of these adjusted annual cost estimates for FAS in the United States was \$3.6 billion.

In 1980 the total lifetime cost of FAS per person was estimated at an initial estimate of \$596,000 (Harwood & Napolitano, 1985). Including the cost of medical care services and lost productivity and accounting for inflation, the adjusted 2002 cost becomes \$2.0 million for each individual with FAS. Cumulative lifetime costs of \$2 million for one case of FAS were spread out over the person's lifetime. Based on a life expectancy of 60 years, Harwood and Napolitano estimated the lifetime cost per person with FAS at \$600,000. When updated based on the United States medical services price index, the adjusted 2002 total cost per individual was \$2.9 million. The National Institute on Alcohol Abuse and Alcoholism (NIAAA) estimated the cost of FAS alone between \$2.8 and \$9.7 billion per year (NIAAA, 2002). When the most recent prevalence rate of FAS in South Africa (May et al., 2007) is compared to the prevalence rate of 2 per thousand live births in the United States, the figure for the lifetime cost estimation is 34 times higher. Although maternal drinking during pregnancy seems to be the single most important variable to address it is useful to explore the concomitant factors that might offer a deepened understanding of how to approach the reduction of maternal drinking.

### **2.3 Drinking patterns of women of childbearing age**

One of the consequences of high alcohol consumption amongst women is maternal drinking during pregnancy (Ojo et al., 2010). Due to the potential harmful effects (including FASD) to the fetus<sup>29</sup>, alcohol consumption by women of childbearing age is of particular concern (Rendall-Mkosi et al., 2012, unpublished). Globally, the rates of women of childbearing age who drink have increased (Velazquez, Ingersoll, Sobell, Floyd, et al., 2010). In the United States the prevalence of alcohol use amongst women of childbearing age is estimated at between 55 and 60 percent (Tsai, Floyd, O'Connor & Velasquez, 2009; Rasmussen, Kully-Martens, Denys, Badry, et al., 2010). Amongst American women of childbearing age and who might become pregnant 12.4 percent reported binge drinking (consuming five or more drinks on one occasion) and 13.1

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<sup>29</sup> The hormonal systems of the mother and the fetus are intricately connected during pregnancy. Maternal alcohol consumption can cause direct and indirect adverse effects on fetal development (Gabriel, Hofmann, Glavas & Weinberg, 1998).

percent of women reported hazardous drinking (Rasmussen et al., 2009). Findings of a study done in the United States showed that 30 percent of pregnant women reported drinking at some time during their pregnancy (Ibid).

Branco and Kaskutas (2001:334) proposed that the “changes in drinking behavior depend on a woman’s susceptibility to having a child with birth defects, her understanding of the risks associated with drinking during pregnancy, the values she places on abstinence and the barriers or difficulties experienced to reduce alcohol intake.” The woman’s understanding of her risk of bearing an alcohol-exposed baby could therefore be a cue for cessation of alcohol use or binge drinking.

In a cross-sectional household survey done in Gauteng (urban site) and in the Western Cape (rural site), Ojo et al. (2010) found that the levels of drinking for women of productive age (18-44 years) in the Western Cape were 44% higher than women of the same age who lived in Gauteng. The results showed that current employment was inversely associated with high-risk drinking in Gauteng. Women who started using alcohol after the age of 18 years were less likely to have risky drinking patterns. Possessing five or more household amenities were inversely associated with high -risk drinking in the Western Cape. Women who were current smokers and those who experimented with cigarettes were more likely to have risky drinking patterns. Having a family member with alcohol problems was associated with high-risk drinkers whilst living in a household that never/seldom goes hungry was inversely associated with risky drinking at both sites.

The Centers for Disease Control and Prevention analyzed data from the Behavioral Risk Factor Surveillance System (1991-2005). Figures from 1999 showed that from the 553 506 women who were interviewed, 12.8% of pregnant women consumed alcohol in the month prior to the interview (Centers for Disease Control and Prevention [CDC] 2002). A total of 3.3 percent of pregnant women reported frequent drinking and 2.7 percent reported binge drinking (CDC 2002). Limitations of this telephonic survey included reporting bias and the exclusion of women who lived in institutions (Hankin, 2002).

In a prospective survey of alcohol ingestion in pregnant women from rural and urban areas in the Western Cape, a sample of 636 pregnant women from three underprivileged communities was recruited from 17 antenatal clinics (Croxford and Viljoen, 1999). High rates of alcohol and tobacco intake was reported as 29.6% of the sample reported

problematic drinkers with heavy drinkers engaging in binge drinking over weekends. Alcohol intake of participants was sufficient to place unborn children at risk. Some women are at higher risk for prenatally exposing their babies to alcohol than others.

### **2.3.1 The Pathophysiological effects of alcohol**

Although this work does not focus on the clinical aspects of FASD, it is important to grasp the pathological and physiological effects of alcohol on the mother and on the fetus. This section will shortly discuss the effects of prenatal alcohol consumption to the fetus and will refer you to research done on the effects of alcohol consumption to the drinking women. Gabriel et al., 1998 lists the following as adverse effects of alcohol consumption on the fetus during pregnancy:

- Impairment of the functioning of the hypothalamic-pituitary-adrenal axis. This may lead to irregular bodily responses to stress.
- Impairment in reproductive functions – this is controlled by the hypothalamic-pituitary-gonadal axis,
- Impaired metabolism controlled by the hypothalamic-pituitary-thyroid axis,
- A possible impaired hormonal functioning (i.e growth hormones and insulin)

For more information on the effects of alcohol on the neuroendocrine functioning of pregnant women refer to Mello, Mendelson & Teoh (1993). Emanuele, Weseman & Emanuele (2002) discuss the numerous negative consequences of mild to moderate alcohol use on female reproductive function. Dees, Srivastava, & Hiney, (2001) suggest that alcohol consumption during early adolescence may delay puberty and adversely affect the maturation of the reproductive system.

### **2.3.2 Risk factors for prenatal alcohol exposure**

In a study done by Morojele, London, Olorunju, Matjila et al., (2010) it was found that being at risk for an alcohol exposed pregnancy included the following predictors: current alcohol use, being of childbearing age but not being pregnant, being fertile and no effective use of contraceptives. Within this cross-sectional household survey a number of 1018 women between the ages of 18-44 years were recruited from one urban and one rural site. Structured interviews were used to collect data. The results showed that rural

women (8.5%) are more at risk of having an alcohol exposed pregnancy in comparison to women who live in urban areas (2.48%). Education, knowledge about FAS and parity were identified as three significant protective factors.

In a retrospective case-control study Viljoen et al., (2002) found the following factors associated with women who had given birth to an alcohol exposed baby. Firstly, low socio-economic circumstances with a weekly income of \$22 to \$30 per week (in 1997). Secondly, mothers of FAS children had 1.7 years less formal education than the control group. May et al. (2008) reported that educational attainment of the mothers of children with FASD forms a significant spectrum where the lowest mean education is 4.6 years among mothers of children with FAS. Within the South African education system this is equivalent to a grade four education.

Viljoen et al. (2002) found that other factors that are associated with risk for prenatal exposure mothers of FAS children who lived in an environment where heavy drinking was the norm (fathers of the FAS children, male partners, brothers, sisters and friends). Lastly FAS women more frequently reported not having a 'best friend' and if they did have friends these were heavy drinkers. Eighty one percent of the mothers of FAS children were drinkers at the time of the study as opposed to 45% of the controls.

### **2.3.3 Factors associated with alcohol abuse in pregnancy**

The factors associated with the continuation of alcohol abuse during pregnancy relate to environmental as well as personal factors. The environmental factors include poor socio-economic status, low education levels and having a child with FASD.

#### **2.3.3.1 Environmental factors**

Greunewald, Remer and Lipton (2002) state that understanding the drinking environment and mapping the area in which excessive alcohol use is predominant may produce information that will inform reorganization of social spaces and thus improvement of environments that will discourage widespread substance abuse. Understanding the drinking environment will also aid in evaluation of the alcohol environment and in analyzing the links between the geography of community, alcohol

related disorders and the problems caused by these disorders that might disable affected individuals.

Kogan, Alexander, Kotelchuck, Nagey et al., (1994) found that poorer women and women with low educational status are less likely to receive advice on alcohol cessation during pregnancy. Women may thus be unaware of the dangers of alcohol consumption during pregnancy. In a screening done among 3 797 Californian women, O'Connor & Whaley (2006) suggest that continuation of drinking was associated with socio-demographic factors. They found that 23.8% of the women used alcohol post-conception. Approximately 62% of women who continued drinking while pregnant, stopped after counseling and pregnancy recognition while 38% continued drinking. Drinking also continued after a health care provider advised 60 percent of the women in the sample to stop drinking.

In a prospective survey done in the rural and urban areas of the Western Cape Province, 636 pregnant women from poor socio-economic communities were interviewed. The majority of women were between 20-30 years of age. From a total of 636 women 42.8% admitted to ingesting varying amounts of alcohol during their pregnancies (Croxford & Viljoen, 1999). Twenty three point seven percent of women engaged in binge drinking. Results showed that 59.7% of women were aware that alcohol consumption during pregnancy could harm their baby. Since 35.6 % of the significant drinkers showed varying degrees of insight into the harmful effects of alcohol on the fetus, it became clear that awareness alone is not adequate in reducing or eradicating alcohol consumption during pregnancy. In contrast to the insight displayed by heavy drinkers only 22.8% of the mothers who reportedly did not drink and those who drank minimal amounts of alcohol, indicated insight into the teratogenic effects of alcohol. Mothers who reported no drinking or minimal drinking thus showed less insight into the teratogenic effects of alcohol.

In a rural comparative study in the Western Cape the mothers of 53 grade one learners with FAS were compared with 116 randomly selected mothers of grade one learners without FAS (May et al., 2005). Mothers who had children with FAS used to binge drink over weekends and 87% of the sample did not reduce drinking during pregnancy. Mothers who had children with FAS were also smaller in measures that indicate poor

nutrition and second generation fetal alcohol exposure (height, weight and head circumference, and body mass index). It was further reported that among a group of 75 mothers who already had children with FAS, 92% reported drinking during pregnancy. Fifty eight percent (58%) of these mothers preferred beer as alcohol beverages and 45% preferred wine (May et al., 2005). In a later case control study, 57 mothers of children who were suspected of having FAS were interviewed (May. et al., 2008). Sixty six percent (66%) of mothers reported drinking during the time of the study. While there was a substantial reduction in drinking levels of mothers since giving birth, 27% of mothers of FASD children still reported binge drinking.

#### *2.3.3.2 Personal factors related to continuation of alcohol abuse during pregnancy*

It has to be taken into account that there are still women who are not aware of the dangers of consuming alcohol during pregnancy. Other women might be unable or unwilling to reduce or stop their alcohol intake (Russel, 1991). Appropriate and culturally sensitive assessments might illuminate reasons why some women continue to drink during pregnancy (Plested, Jumper-Thurman, Edwards & Oetting, 1998). Women may also start using or abusing substances as a response to historical or current physical, sexual, psychological, emotional, cultural, social, intellectual and financial abuse. Women with a history of abuse are 15 times more likely to become dependent on alcohol than the general public (Logan, Walker, Cole & Leukefeld, 2002).

A provincial survey done by the Women Abuse Response Program, Canada, determined whether services met the needs of vulnerable women. The sample consisted of women who experienced physical abuse, but who also abused substances such as alcohol and drugs. Service providers who offered services to abused women were also interviewed. Four hundred and sixty service providers and policy leaders participated in the standardized cross-sectional study in which consultations and interviews were used to collect the data. Thirteen focus groups were conducted with a hundred women (n=100) who live across British Columbia. Findings from this study indicated that women abused substances for the following reasons: as a means of surviving, escaping and coping with abuse; self-medicating the impacts of abuse and suppressing nightmares and flashbacks. One of the findings made by Cory, Godard, Abi-Jaoude & Wallis (2010) was confirmed when the survey results showed that the partners of some of the participants

intimidated women into using drugs or alcohol to increase their dependence and control their behavior. Anderson, Kaner, Wutzke, Funk et al. (2004) found that it is more difficult for women who are dependent on alcohol to reduce or stop alcohol consumption and specialized treatment is often required. Literature suggests a link between alcohol consumption in pregnancy, abuse and later mental health difficulties in mothers (Streissguth & Randels, 1988; Spohr & Steinhausen, 1987). Other factors that may contribute to mental health problems in alcohol abusing women are the use of other substances, smoking, background socio-economic factors, maternal anxiety and depression and maternal nutrition (Sayal, 2007). O'Connor & Whaley (2006) confirmed that psychological factors may cause women to continue using alcohol during pregnancy. They found that sixty-two percent of women in their study had high TWEAK<sup>30</sup> scores (high risk for alcohol dependence). Sixty percent had a CES-D<sup>31</sup> score greater or equal to sixteen (CES-D >16) (within the clinical range of depression).

Dawson, Das, Faden, Bhaskar, et al. (2001) listed factors that were unique to the drinking mother herself that may make it more difficult for her to stop drinking even if she has been advised by her care provider of the adverse consequences to her fetus. These factors included the woman's alcohol risk based on the psychological and behavioral consequences associated with her drinking behavior (Chang et al., 1999b; Russell et al., 1996). Comorbid psychiatric problems, such as depression, also have the potential to exacerbate the negative consequences of alcohol use during pregnancy. It is well established that depression is a significant contributing factor to high-risk drinking in women who are pregnant (Littleton, Breitkopf, & Berenson, 2007; Bowen & Muhajarine, 2006). Studies reveal that women who are experiencing symptoms of depression drink a higher number of drinks per drinking occasion (Flynn et al., 2003) and have more problems associated with alcohol use (Marcus et al., 2003), thus impeding the effectiveness of treatment attempts (Raskin & Miller, 1993). Maternal depression is thus

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<sup>30</sup> The TWEAK is a screening tool that is used to assess high risk drinking (Russell, 1994). This tool identifies potential problem drinking with items that inquire about consequences, behaviors, and perceptions frequently associated with alcohol abuse. The TWEAK has been determined to be the optimal screening tool for pregnant women and high levels of sensitivity/specificity can be obtained across different ethnic groups

<sup>31</sup> The CES-D is a self-report measure containing 20 items designed to assess recent depressive symptoms. The scale is used widely as a screening instrument to detect depression in nonclinical and clinical populations. The measure has high internal consistency, reliability, and validity and has been used extensively in studies of depression in women from low-income minority populations (Chung et al., 2001).

an important variable to consider when counseling women about alcohol cessation during pregnancy (O'Connor and Whaley, 2006).

#### **2.4 FASD prevention approaches that focus on changing health behaviors of women.**

Awareness raising around FAS/D should start with conscientizing not only those at risk, but the general public on the different environments involved in the fight against FAS (First Nations and Inuit Health, 2007). A valid question that should be asked is whether awareness raising should start with the mother's body (and the womb), first, as a protected space in which the fetus needs to develop (Ibid). An advantage of this approach as a starting point is that the immediate environments in which the mother has to function can then be analyzed and evaluated as well. This concretization of immediate environments might contribute to an overall awareness of the responsibility of the mother firstly towards her own body and secondly towards the unborn child. It may even spark increased awareness of the family environments and broader environment within the community and foster ownership and problem solving abilities that will counter maternal alcohol consumption. These are the values that are imbedded in existing FASD prevention efforts that focus on behavioral change of mothers who drink during pregnancy.

The existing theoretical foundations from which health promotion and prevention efforts can be drawn are vast in number and include health education and prevention (Kountz, 2009), social marketing in health, and early intervention approaches (FAS Community Resource Centre, 2007). While increased knowledge and awareness of FASD do not necessarily lead to changes in behavior, it is unlikely that prevention initiatives will be successful without such knowledge or awareness (Dufour and Williams, 1994). According to Hoffmann (2010) health information should be developed at a level of grade five or six in the Australian education system to ensure that people with varying educational levels are able to understand. Reading ability and comprehension as two of the subcomponents of health literacy are two main challenges in the FASD prevention process with mothers who are at risk of having children with FASD or those mothers who already have children with FASD. Careful consideration should therefore be given to the development of successful FASD prevention efforts that emphasize abstinence from

alcohol during pregnancy; or effective contraception while drinking alcohol or both (Rendall-Mkosi, 2007), in a way that mothers can clearly understand and integrate into their lives.

The National Institute for Alcoholism and Alcohol Abuse (NIAAA) proposed the NIAAA model to FASD prevention. This model of FASD prevention is a comprehensive strategy at different levels (individual, community and society) of intervention. This approach includes the tracking of women who are classified into different groups according to their drinking practices. Universal prevention strategies include public service announcements and beverage warning labels with the aim to increase the public's knowledge about FAS. Indicated prevention approaches target high-risk women, for example women who have previously abused alcohol or who already have a FAS child. Selective prevention approaches target women of childbearing age who drink alcohol.

#### **2.4.1 Effectiveness of Universal Prevention strategies**

Universal prevention programs (Stratton, Howe and Battaglia,1996) target the broader society, regardless of risk, and involve people of all ages, both genders and from different walks of life. Universal prevention strategies strive to reduce alcohol exposed pregnancies (AEP's) or FASDs and, although there is insufficient evidence of the effectiveness of this approach, these kind of strategies have demonstrated increased awareness and knowledge about the topic of alcohol use and pregnancy. When defined more broadly, universal prevention approaches target the general public with their focus on limiting alcohol consumption through alcohol policies and environmental changes. These broad-based strategies are important in changing social and cultural norms, by raising awareness about the dangers of alcohol and indirectly decreasing excessive alcohol use among the general population as well as amongst women of childbearing age.

Hankin, et al. (1996) conducted a comparative study on the impact of the Federal Alcoholic Beverage Warning Label on American multiparae (women with at least one previous live birth) and nulliparae (women with no previous live births).The label, that was implemented in 1989, urged women not to drink during pregnancy due to possible damage by alcohol to the fetus. A total of 17 456 inner city black gravidas at one

antenatal clinic were screened between September 1986 and September 1993. About seven months after implementation of the warning label nulliparae (n = 7,349) reported a significant decline in drinking (t = 2.00, p < .04). In contrast, multiparae (n = 10,107) showed no change in reported drinking (t = 1.23) after implementation of the label. This study showed that it is important to target multiparae who are heavy drinkers for intensive prevention efforts.

#### **2.4.2 Effectiveness of Indicated Prevention approaches**

Indicated prevention approaches target high-risk women (e.g., women who have previously abused alcohol or have had a child with FAS or other alcohol-related effects) and typically offer repeated counseling over several years. Branco and Kaskutas (2001) conducted research on pregnant and postpartum women (n=11) to determine how at-risk women regarded warnings about alcohol consumption during pregnancy and what their emotional reactions to these were. The goal of their study (which entailed two focus groups in which Native American and African American women from Los Angeles, California participated) was to uncover relevant aspects of these women's beliefs and opinions regarding alcohol use during pregnancy. The findings showed that changes in a woman's drinking behavior depended on four aspects namely: a woman's susceptibility to having a child with birth defects; her understanding of her risk associated with alcohol consumption during pregnancy; the value she places on abstinence; and the difficulties experienced to reduce alcohol intake.

Loudenburg and Leonardson (2003) based their study on the Health Belief Model and provided evidence for successfully addressing alcohol intake during pregnancy. A multi domain approach was used among women of higher socio-economic status. During their interventions Loudenburg and Leonardson (2003) provided evidence for the reduction of alcohol intake and other harmful substances of high-risk women of childbearing age. The approach used included intensive case management and home visits to a group of at risk women who were in the process of completing substance abuse treatment. The two areas in which success was achieved were abstinence and reduction of usage. Firstly, it resulted in maintaining abstinence for women who did not use substances. Secondly, it reduced the usage for those women abusing substances.

### 2.4.3 Effectiveness of Selective Intervention approaches

These approaches target women of reproductive age who drink alcohol. Such approaches may involve screening of women for alcohol consumption and counseling those women who do drink. As opposed to counseling, motivational interviewing as an approach is particularly preferred by researchers as one of the main strategies for the reduction in FAS prevalence and the prevention of alcohol exposed pregnancies. Motivational interviewing is a client-centered directive method for enhancing intrinsic motivation to change by exploring and resolving ambivalence (Fischer, 2007). Rollnick, Miller & Butler (2008) suggest that motivational interviewing is a collaborative process that guides a person to elicit and strengthen motivation for change. Motivational interviewing builds on humanistic theories about people's capabilities for exercising free choice and changing through a process of self-actualization (Miller and Rollnick, 1991). Individuals who receive motivational interviewing would get feedback on personal risk, responsibility for personal control, advice to change and strategies to help individuals to reduce or stop drinking.

In the United States of America Floyd, et al. (2007) conducted a randomized control trial of a brief motivational intervention to reduce risk of alcohol exposed pregnancy in pre-conceptual women. The study focused on both risk drinking and ineffective contraception. A total of 839 women between the ages of 18 and 44 were recruited. Participants were randomized to receive information plus a brief motivational interview. Results showed that across the 9 month follow-up period 69% of the intervention women were at reduced risk of an alcohol exposed pregnancy. The intervention group was also twice less likely of being at risk for an alcohol exposed pregnancy than the control group. Forty seven percent of women had both reduced their drinking and were using contraceptives at nine months. Brief motivational interventions were therefore shown to reduce the risk of an alcohol exposed pregnancy. Furthermore, women indicated that they found the caring, compassionate and encouraging attitude of therapists during the intervention phase an important factor for a successful outcome.

Kaysen, Lee, Labrie & Tollison (2009) examined the variability of readiness to change and drinking behavior and whether motivational interviewing increases readiness to change in an intervention group compared with controls. Two hundred and eighty five

first year female college students participated in the intervention study. After a six month follow-up 36% reported no alcohol use, 64% reported at least one drink in the previous month. The data of one hundred eighty two women who consumed alcohol at least once a month was analyzed for readiness to change and drinking behavior. Participants reported drinking on 58% of the 10 weeks of intervention. The average number of drinks that individuals planned to drink was 2.98 per drinking occasion. The average level of readiness across the 11 weeks was .97. Consumption and drinking intentions were relatively greater on weeks with midrange readiness to change. Participants in the intervention group reported significantly higher readiness to change scores than the control group. The intervention was associated with readiness to change. In a randomized control trial done in Piketberg it was found that poor women can also benefit from motivational interviewing as much as middle or upper class women (Rendall-Mkosi, 2010 - personal communication).

The effectiveness of universal, indicated and selective prevention efforts was of particular significance to this study on developing appropriate FASD prevention initiatives amongst women of childbearing age. Although the proposed process for FASD prevention in this study could be incorporated into universal prevention strategies, it links more closely with the indicated and selective prevention strategies. While efforts to improve mothers' responsibility towards their own health and the health of their babies are important, FASD prevention efforts that explore the impact of the social and cultural environment on the drinking practices of women are equally valuable.

## **2.5 FASD prevention approaches that focus on beliefs, attitudes and values**

### **2.5.1 Beliefs, attitudes and values of mothers who abuse alcohol during pregnancy**

The reduction of alcohol consumption and/or abstinence during pregnancy in a community where excessive alcohol use has been normalized over generations, calls for intervention on individual, family and community levels. Prevention strategies should be supplemented and strengthened by building multi-sectoral partnerships as a way of reinforcing efforts (Wilson and Martel, 2003).

Narrowcasting, as a technique of exploring beliefs, values and attitudes, is a “marketing strategy that uses highly focused messages for specific priority populations using media that reaches only a specific group” (Glik et al., 2001: 222). In contrast to broadcast media, narrow cast media research identifies specific beliefs, values and attitudes of a particular group of people. Messages are then formulated to reflect these values (Chae and Flores, 1998; Smith-Shomade, 2004). Despite the dearth of research about narrowcasting in health promotion, this technique is frequently used in commercial marketing, political campaigns and social marketing (Chae and Flores, 1998, Dretzin, Goodman and Soenens, 2004; Evans, 2001; Reitman, 1986; Smith-Shomade, 2004). Narrowcasting campaigns are based on social marketing principles of extensive audience, market and formative research conducted within specific segments of the population that will be targeted (Andreasen and Kotler, 2003; Grier and Bryant, 2005).

Glik, Prelip, Myerson and Eilers (2008) compared two narrowcasting campaigns amongst women of childbearing age in two disadvantaged Southern Californian communities. The study campaigns aimed at preventing FASDs by counteracting the mixed messages women receive about the dangers of alcohol. Focus group interviews were conducted to uncover cultural and psychosocial correlates of drinking behaviors and concerns linking to pregnancy. Messages were developed in collaboration with community leaders who were representative of health coalitions, interest groups and the target population (women between the ages of 18-35 years). Participants were asked to assess the suitability of the messages for specific communities. Pretesting of materials demonstrated that the audience preferred messages that highlighted social norms that showed what idealized women should do if they were pregnant or if they suspected they were pregnant. Findings showed that modeling of socially acceptable behavior, thus the social value of a ‘good’ parent was more appealing than fear-based messages that depicted a sick child as a result of drinking practices of mothers. Community members also selected role models outside of the community. These role models looked like the participants, but were better looking in terms of health and social status. Campaign slogans echoed assertiveness and empowerment and the tone of messages was serious. Developed materials were placed where women of childbearing age often go (e.g. convenience stores, Laundromats, businesses, stores and restaurants). A clinic based survey showed that 54.2% of the audience from the second community reported

exposure. Women who had graduated from high school were more likely to see messages advertised on posters ( $\chi^2 = 6.823$ ,  $p = .009$ ) and t-shirts ( $\chi^2 = 4.589$ ,  $p = .032$ ). The fact that the modeling of socially accepted behavior was more appealing than fear-based messages confirmed an approach that focuses on the positive attributes of the target group rather than on the results of alcohol abuse during pregnancy. It also showed that mothers will respond positively to a social norm that promotes healthy mothers and healthy children.

A national survey done by the Environics Research Group in Canada examined the following: knowledge and beliefs about alcohol use during pregnancy, awareness of FASD, recall of information and advertising about the impact of alcohol, preferred information sources and the effectiveness of information initiatives, support for initiatives to provide information about the risks of alcohol use, and the expected behaviors of women and partners of women during pregnancy (Environics Research Group, 2006). It was found that 52% of males and 60% of females believed that cutting down on drinking alcohol during pregnancy would result in having a healthy baby. The report also showed that 68% of males and 79% of females stated that any alcohol consumption during pregnancy can cause harm to the developing baby. From the sample 87% of males stated that they would encourage their female partner to stop drinking during pregnancy and only 43% said that they would stop drinking themselves. This finding is significant in the sense that drinking patterns of women's partners play an important role in the alcohol consumption of women.

Aja, Umahi and Allen-Alebiosu (2011) explored culturally oriented strategies for raising awareness about women's health issues in a community where oral tradition is predominant. An activity-orientated workgroup discussion methodology was used to engage 30 female participants from 15 churches in southeast Nigeria. The participants, who were 26 years and older and from different educational levels and occupations, participated in a 16 hour small group workshop that was conducted in an adult-learning format. Participants developed products that ranged from a dialogue on adolescent health, a drama on violence against women, a song on nutrition and women's health, a story on the use of medicines by women, a quiz on cervical cancer and a poster on family planning. Three of the fifteen churches organized a workshop on increasing awareness on women's health issues within three months of the workshop. This study showed that

the incorporation of women's' health issues into the programs of existing community organizations can raise awareness of women, families and communities.

### **2.5.2 Attitudes of service providers**

Negative attitudes and beliefs of service providers could be a major problem when women who consume alcohol may need medical assistance. The World Health Organization conducted a randomized control trial that involved 304 general practitioners across four countries. The study investigated the impact that training and support had on the attitudes of general practitioners to do screening and brief interventions as part of their routine consultation practices. The result showed that providing training and support to general practitioners increased the rates of screening and brief intervention of those practitioners who were already committed to working with drinkers. However, it worsened the attitude of practitioners who felt insecure with working with patients with problem drinking.

Mothers might be reluctant to seek assistance from health professionals in fear of the risk of child removal by social services (Cory and Dechief, 2007). In a before-after study in the West Coast Winelands, Mwanza- Kambafilwe, Rendall-Mkosi, Jacobs, Nel and London (2011) found an association between capacity building for service providers of women at risk of alcohol-exposed pregnancies and increased knowledge, confidence gain and changed practice. The effectiveness of service provider training was determined from exit interviews of patients before and after training with staff. With regards to reproductive and sexual health English and Ford (2004) suggest that the privacy of adolescents should be protected and health information and medical records should be confidential even if adolescents are younger than 18 years. Ford and English (2002) suggest that some minors prefer health care that ensures that confidentiality is maintained.

### **2.6 Education for Liberation as framework for FASD prevention**

Freire's pedagogy of the oppressed (also referred to as adult education theory) proposes that education should be used to liberate oppressed or marginalized groups by conscientizing them on oppressive social, economic and political factors. This process will involve members from marginalized communities participating alongside health

professionals in identifying relevant needs as well as contributing suggestions for solutions to identified needs. In the long run this process should lead to the equalization of power relations of marginalized groups and should result in radical transformation in the contexts in which marginalized groups live and radical transformation in the occupational engagement of marginalized individuals and groups. When applied to the FASD scenario radical transformation would result in mothers being aware of the negative impact of alcohol during pregnancy, taking initiative and action to reduce drinking, abstaining from alcohol or seeking professional help, and seeking and exploring occupations that contribute to health and well-being in an attempt to reduce FASD prevalence. Since adult education theory has not been explored as theoretical foundation in the prevention of FASD or in the prevention of any other public health issue, its application to FASD prevention may open possibilities for developing more appropriate prevention strategies.

The Paulo Freire methodology (Cole, 2009) is a useful, but an underutilized philosophy in health education and the promotion of healthy lifestyles. Within the current FASD prevention and health education intervention programmes, health educators and service providers need to acknowledge both the facilitative as well as the limiting nature of such efforts. An advantage of the Freire methodology is that cultural, social and political aspects of people's lives are considered and a critical awareness of underlying determinants of social realities are explored by those who are affected. Freire (1972) posits that critical conscientization facilitates a process whereby individuals name the realities that perpetuate oppression and marginalization. The Freire methodology acknowledges that practices, values and norms are embedded in the social matrix of a society and are determined by how the individual and group's experience the environments in which they spend most of their time (Drabble, Poole, Magri, Tumwesigye, Li and Plant, 2011). The underlying determinants of FASD are therefore rooted in the social matrix. Appropriate education and awareness message for South Africa should thus speak to this reality of individuals and groups and convey social realities as well as speak to the realities as experienced by the individual. The following questions framed the research process and were carefully considered throughout:

- What are the critical issues related to FASD that we should be raising awareness about?
- What is the cultural context in which we are hoping to prevent FASD?

- What are the cultural appropriate sources and methods of preventing FASD within the context?
- What processes are needed to facilitate translation of knowledge and bring about change in what people do, where they do things and how they do things?

## 2.7 Conclusion

While the literature shows that a combination of individual and contextual factors (maternal age, binge drinking, poor mental status, spirituality, socio-economic status, educational levels, nutritional status and social class) are determinants in alcohol abuse during pregnancy, the challenge lies in understanding exactly how historical and current cultural, economic and political factors impact on the micro environments in which women live who are at high risk of bearing children with FASD. It is imperative to consider the impact of the interplay between factors in the macro environment and the constructs of the micro environment on the development and formation of individual and social identities. The cultural values, practices and beliefs that emerge from a group of people with a history of displacement, generational trauma (Busey and Bula Wise, 2007) and continuing marginalization should be brought under the spotlight in order to begin to draw the links between health (or ill-health), well-being (or existence), occupational engagement and overall development (or stagnation). Once this understanding has been established ways of minimizing or eliminating the barriers posed by individual characteristics and environmental factors can be explored by involving the women concerned in designing programs that will enhance self-determination and developing a reflective ability and problem solving skills in life changing situations. The success with which health information is incorporated as an integral part of everyday practices of any group of people should be evident in such peoples' occupational choices and how these choices enhance their quality of life. This can only happen if health practitioners and more specifically occupational therapists initiate the process of increasing their knowledge and understanding of groups of people and populations and their contexts to the extent that participants are co-producing solutions to the challenges of engaging in health promoting occupations. Wilson and Martel (2003) add that this process takes time and needs to be supplemented and strengthened by building multi-sectoral

partnerships that can reinforce efforts on different levels and build capacity within the community.

Successful FASD prevention efforts will provide the target group with an opportunity to understand the health information provided. The target group should also be able to identify and define the nature of environmental supports needed for effective and continued health communication to younger generations in the community.

University of Cape Town

## CHAPTER THREE

### METHODOLOGY

#### 3.1 Introduction

This chapter will discuss the theoretical foundations and methodological approach used for the research study. Qualitative methodology is explained and its appropriateness for the research question explored. Critical theory will be explained and applications in the setting will be illustrated. Postcolonial theory used as a lens through which different aspects of the data were viewed, will be introduced. The chapter further discusses the method of data collection. Quotations will be used to demonstrate how I tailored the data collection process to this specific population. Principles of interaction between the participants and me are offered to provide insight into the participant–researcher relationship. The chapter concludes with short critique on critical methodology as a paradigm in research that leads to developmental processes.

#### 3.2 Qualitative method of choice:

Qualitative methodology was used to explore the obvious and tacit beliefs, norms, values and perceptions in relation to alcohol consumption practices in the general community as well as to maternal alcohol consumption. FASD prevention in Occupational Therapy and Occupational Science is a new area of research and not much is known about the cultural beliefs, norms and values of the study population. Qualitative methodology was therefore the most appropriate approach to explore the beliefs, norms, values and perception in relation to alcohol consumption practices in this marginalized community. A participatory approach was incorporated into the methodology of critical ethnography (See Appendix 8.20 for process and steps used for data collection).

A critical ethnographic design allowed me to provide a thick description of the research setting. Descriptions were theoretically grounded in Wilcock's (1998) work on the occupational perspective of health and Scaffa's proposed components of the macro

environment that may influence occupational engagement (the economy, policy and national priorities and culture) (Scaffa et al., 2010). Since the elements of the three components of the macro environment are interrelated and inter-dynamic, this study will highlight these elements in relation to the culture of participants as presented in the data. Yet another advantage of critical ethnography as an approach is that it provides accounts of some cultural processes as seen through the lenses (Wolcott, 1998; Fetterman, 1998) of participants (women of childbearing age, their partners/husbands and service providers in the community).

The nature of ethnography is such that the participants will never fully represent all the human elements involved in a cultural system in which different roles are displayed and interactions enacted. Rather, the knowledge produced from studying the sub cultural system concerned provides information on how a selected group of people within this context understand the concepts around alcohol consumption in general and more specifically, maternal alcohol consumption during pregnancy.

Some of the participants had a better understanding of the research process as an opportunity to share their opinions and to contribute to new developments in their community than others. These participants were able to make suggestions for possible FASD developments in the future. Other participants were completely caught up in their circumstances and focused their suggestions on initiatives that would address personal and familial circumstances. All the contributions were meaningful and added to the richness of the dataset. Finally, the use of an ethnographic approach provided a structure within which I could highlight power relations (Cannella and Lincoln, 2011) between study participants and service providers as well as power relations between myself and participants.

### **3.3 Paradigm: Critical Theory**

From the four competing paradigms in both qualitative inquiry and quantitative methods (Positivism, Post positivism, Critical theory and related ideological positions and Constructivism) (Guba and Lincoln, 1994) the theory and principles of Critical Theory (as described by Guba and Lincoln, 1994) as well as ontological and epistemological

foundations (later discussed) guided the research process. Table 1 below shows how Critical Theory answers the three fundamental questions in relation to research with women who consumed alcohol during pregnancy and FASD.

**Table 1: Critical Theory as applied to the research**

Fundamental questions related to the research	Critical Theory as applied to the research
<p><b>The ontological question:</b> What is the form and nature of reality? What is there that can be known about women and FASD?</p>	<p><b>Ontology:</b> The nature of women’s reality is greatly impacted by history. History has an impact on the current occupational engagement of women. Historical realism provides a lens through which occupational engagement of South African mothers who are at risk of having children with FASD or already have children with FASD is viewed. The reality of participants over the past 300 years was shaped by a congeries of macro factors (social, political, cultural, economic, and ethnic and gender factors). This impact of a combination of these factors resulted in women being marginalized and living in conditions that perpetuate occupations that harm their health and the health of their unborn babies. Research presented ‘reality’ as the women having to take responsibility for making healthy life choices. Their health condition is of their own doing – this is the reality created and established by dominant forces (health system, legal systems, labor practices). These macro</p>

	<p>factors are then reified into a series of structures that are 'real' for all practical purposes. These women and their family members remain in a stable and lowly paid workforce or maintain political subservience. This reality can be either virtual or historical and is inappropriately taken as 'natural' and immutable.</p>
<p><b>The epistemological question:</b> What is the relationship between the researcher and the participant and what can be known about FASD and interrelated concepts?</p>	<p><b>Epistemology:</b> Transactional and subjectivist: The researcher and the participants are assumed to be interactively linked. The values of the researcher (and participants) inevitably influence the inquiry. Findings are therefore value mediated. What can be known is inevitably intertwined with the interaction between the researcher and participants. What is produced by the research should be viewed within the context of the research setting and as a combined effort of researcher and participants.</p>
<p><b>The methodological question:</b> How can the researcher go about finding out whatever s/he believes can be known about FASD and related concepts?</p>	<p><b>Methodology:</b> Dialogic and dialectical: The transactional nature of inquiry requires a dialogue between the researcher and participants. Dialogue is dialectical in nature to transform ignorance and misapprehensions (accepting historically mediated structures as unchangeable). Dialogue facilitates more informed consciousness</p>

	<p>(seeing how the structures might be changed and understanding the actions required to effect change.</p> <p>The researcher acts as a “transformative intellectual” Giroux (1988:213) and demonstrates transformational leadership. (Burns , 1978), The researcher’s role is to uncover those forms of historical and subjugated knowledge that point to experiences of suffering, conflict and collective struggle. Understanding of historical elements is used to critique existing structures and bring hope to those affected by oppressive systems.</p>
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**3.3.1 Postcolonial Theory in FASD prevention**

Postcolonialism is a cultural, intellectual, political and literary movement of the twentieth and twenty-first centuries. This theory is characterized by the representation and analysis of the historical experiences and subjectivities of the victims, individuals and nations of colonial power. The Postcolonial movement is marked by its resistance to colonialism and it attempts to understand the historical and other conditions of its emergence. An understanding of the link between existing systems and structures were used to illuminate and address the lasting consequences of colonization (Ficher-Tine, 2011). Postcolonialism therefore aims to account for and combat the residual effects of colonialism on cultures. In addition to exploring processes, systems and structures that existed and operated in colonial times, the goal is to learn how to move beyond the space where historical and contemporary worlds meet towards a place of mutual respect.

Concepts in postcolonial theory include power, subjectivity, identity, ethnicity, race and nation. Within FASD prevention the concepts of power, subjectivity, identity, ethnicity and race are of particular relevance and these concepts will be discussed to demonstrate the impact of colonialism on the occupational engagement of community members of Pikeville. The collected data illustrate the link between oppressive systems and the development, establishment and functioning of these constructs in participants' lives. This study focused on the identities of women as women first and then as mothers. Identity as a core concept is described in terms of learned practices as part of an imposed culture<sup>32</sup>. Great care was taken to distinguish alcohol abuse (including binge drinking) as practice from issues of ethnicity.

Within this study a postcolonial theoretical perspective was used to understand how continuities from the past shape the present context of health and health care to women of childbearing age. (Browne, Smye & Varcoe, 2005:19). This approach is also used to analyze traditional approaches to health promotion and thus FASD prevention. When applied to health promotion, postcolonialism suggests that all efforts must be linked to processes that center on political, cultural, economic and social self-determination as well as positive individual and social identities. Within occupational therapy, this may include healthy occupational identities (Kielhofner et al., 2001). Decolonization is seen as a process that draws on pre-colonial knowledge and practices to address the legacy of colonialism. To this end adult education principles were incorporated into the design of the study as one of the approaches to begin to address the impact of colonialism in the area of FASD prevention.

### ***3.3.1.1 Re-conceptualizing FASD in the South African context***

#### **Assumptions about the Occupational human**

The fundamental values and beliefs that enable participation in meaningful occupation are linked to the person, the occupation, the environment, health, well-being, justice and client-centered practice (Townsend and Politajko, 2007).

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<sup>32</sup> Imposed culture: Practices, norms and values that are embedded in the social matrix of society. These practices, norms and values are products of hegemonic historical systems and structures and have a negative impact on personal and social health and development and have been adopted by marginalized groups as their own.

### *An alternative perspective to 'occupation' in Occupational Therapy*

Emerson (1995) suggested that all human beings are agentic and dynamically responding on and to their environment. An agentic identity manifests in self-stories of active agency and stands in direct contrast to a victimic identity which manifests in a self-story of how participants have lost the power to bring about change in their lives (Polkinghorne, 1996). Within occupational therapy people are viewed holistically and with the ability to interact with their surroundings and apply tools, technology, art and knowledge (Hooper and Wood, 2002) to create and derive meaning from interactions with other people and objects. Occupation is defined as the “the ordinary and familiar things” that people do every day (Hasselkus, 2002: 300). All these descriptions refer to a group of people who can actively choose when and how to interact with their environment. Occupations generally also refer to the activities that contribute to health and occupational well-being (Caron Santha & Doble, 2006; Doble et al., 2006). What term should then be used to describe the activities that are not necessary chosen, but imposed across generations and are the only ones available and that impact negatively on health and wellbeing?

The Occupational Spin-off model (Robeiro and Cook, 1999) is helpful in explaining how the individual will respond positively to an affirming environment by actively selecting occupations that will maintain and reinforce health and well-being. Occupational Spin-off presents the social environment as its foundation. The affirmation received by other members in the social environment enables engagement in occupation. Furthermore, the interaction between the environment and the occupation and the combined impact on the individuals may enhance the development of self-confidence, competence and subjective well-being.

According to the Occupational Spin-off model active occupational engagement will help individuals realize their goals (confirmation). Once individuals are confident it creates self-confidence (actualization) they will look forward to engaging in occupations that enhance competence and self-worth. Individuals will therefore seek occupations that confirm their value in the larger group (anticipation) of family and even society. As individuals anticipate more and other occupations that are meaningful and that will sustain the desired state of health, they move into a newly defined identity that will

continue to seek affirmation as they explore occupations with similar results. This continuous, cyclical process is known as Occupational-Spin-off. A similar model for how health compromising occupations are reinforced by marginalizing environments does not exist. The Occupational Spin-off model operates with individuals who interact with supportive environments that facilitate self-actualization and is therefore limited in its application to marginalized groups. Conversely, a model that will illustrate the impact of historical trauma and loss of ties with original, indigenous cultures on current occupational engagement is needed to conceptualize FASD.

### Liberation Psychology

This study is further informed by liberation psychology theory (Ratele, et al., 2004). Liberation psychology functions on the notion that change and transformation is possible if the requirements of critical analysis, self-definition, and self-determination of naming, labeling and badging such as ‘touch a woman, strike a rock<sup>33</sup> are present and utilized by those affected. In addition other aspects such as collective organizing, collective action and spatial re-formations –retrieval of stolen physical spaces (Rowles, 2009), opening of closures and transcending divides, are met as part of radical social transformation.

Different to the theoretical foundations of the Health Belief Model and the Occupational Spin-off model, the constructs of liberation psychology focus on reflection and redesigning self-identity as a precursor to accessing physical spaces that were previously denied and crossing boundaries that were previously set based on political ideology that shaped initial identities before self-reflection. Liberation psychology therefore suggests that marginalizing environments should be redefined in their meaning. Those individuals who were previously marginalized should retrieve places and spaces (Rowles, 2009) that were previously denied as a way of transforming society.

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<sup>33</sup> This slogan was derived from the title of the song that was composed by a group of women who mobilized 20 000 South African women to demonstrate against the oppressive pass laws instituted in 1956. Women resisted legislation that required them to produce the “pass” or reference book to confirm their identity and place of residence as a way of gaining access to certain parts of the country. This sent a loud message to the public that the women of South Africa would not be intimidated and silenced by unjust laws.

## Education for Liberation

Cole (2009) suggested that the analysis of reality and the implementation of actions to transform this reality are efficiently done with a method that consists of three steps:

- a) Seeing the situations as lived by participants.
- b) Analyzing the root causes (political, socio-economic and cultural).
- c) Acting to change the situation following the precepts of social justice.

This literacy method for working class, Brazilian adults was useful in raising the social consciousness of oppressed workers. The Freire methodology was based on the belief that when the people began to talk about their problems in the community and received the opportunity to plan some action about these problems, fatalistic attitudes were replaced by a sense of agency and the belief that it was possible to change their life situations. Selection of this theory as a vehicle for the development of agency of participants stems from the need to address issues of oppression and occupational marginalization as root causes. This does not mean that other techniques are not valuable or needed. Within occupational therapy this approach should therefore be utilized to precede and/or to supplement existing occupational therapy interventions that focus on the development of occupational potential within marginalized communities. An important precept of this methodology is that both educator and students have equal power in the knowledge production and knowledge exchange processes (Cole, 2009). Below is an outline of the alignment between pedagogic principles proposed by Freire and political principles of social justice:

**Table 2: Comparing political and pedagogic principles**

Political Principles	Pedagogic principles
The principle goal of popular education is to change the power relationships in our society.	The learner is the SUBJECT, not the object of the learning process.
The objective is to create mechanisms of collective power over all the structures of society.	The educator and the learners are equal participants in the learning process; all are the producers of knowledge.
The means of attaining this goal cannot be in contradiction with the final objective—to construct a really democratic society you cannot use authoritarian methods.	The learning process is developed by a continuous dialogue between the educator and the learners.
The projects, strategies and tactics used in the political process have to be produced collectively by the participants themselves.	The objective of the learning process is to liberate the participants from their external and internal oppression; to make them capable of changing their reality, their lives and the society they live in.

Freire (1972) suggested dialogue as a method for engaging with adults who live in developing contexts. Dialogue offers an opportunity for people to become aware of their selfhood and also to take a critical stance to the social situations in which they find themselves. Dialogue can initiate actions to transform individual reality and society. If people get the opportunity to name their world, they can begin to understand and transform their world. Dialogue sparks critical awareness of occupational injustice and fosters response to concrete social and political realities. Occupational therapists can use dialogue as a tool in practice to name and transform occupational engagement of

marginalized groups in South Africa. Freire (2002) defined dialogue as an encounter between two people who trust each other and who experience each other as equals. The way in which dialogue was used in this study will be discussed in Chapter Three and Chapter Five.

### ***3.3.1.2 Identifying Ontological, Epistemological and Methodological Foundations for Occupational Therapy research on FASD prevention***

Positioning this study within the Social Ecological Model suggests that development that occurs in various spheres is the result of interactions in and between different systems. FASD prevention initiatives inevitably involve women and their participation in certain health related activities. Research on the characteristics of women at-risk of abusing alcohol during pregnancy abound. As will be discussed in this chapter the existing research on FASD is mainly framed by a bio-medical approach. Rifkin and Kangere (2001) identified three approaches within which health promotion and disability inclusion programs can be framed: the medical approach, health planning approach and community development approach. Within the health planning approach the participation of affected individuals is expanded to include financial, material and human resource contributions by consumers of services. Community development involves affected individuals in decision making from the beginning of any health initiative and accountability is shared among such individuals and health professionals. Expansion of FASD prevention initiatives into health planning and community development approaches may need more attention. The medical approach to FASD prevention can be classified under the heuristic framework.

According to the Stages Heuristic Framework, public policy process is divided into four stages namely: agenda setting; formulation; implementation; and evaluation (Brewer and deLeon, 1983). This top-down approach often only represents the interests and values of the policy elites as bureaucratic authorities (national managers, politicians, global interest over national actors). Despite the fact that this approach to policy implementation presumes linearity to public policy, it enforces the implementation of policies at the levels of service delivery. Although the heuristic framework offers limited contribution and autonomy of patients in the public policy process, efforts have been made since to adapt the framework to meet cultural requirements (Barrera, et al., 2008)

In contrast to the heuristic approach, a bottom-up approach to policy implementation allows front-line staff to contribute to and influence the policy-making process. The bottom-up approach allows staff members who are often more aware of the realities at the level of service delivery/policy implementation to influence the policy-making process.

### **3.3.2 Doing critical ethnography with subaltern populations**

According to Brocklesby and Cummings (1996), Foucault asserted that the oppressed can know and speak their conditions. However, when doing research with subaltern populations the researcher should approach research participants with the appreciation that they come from a community where intergenerational injustice, oppression, exposure to violence of oppressors and dehumanization may have created and established a “culture of silence” (Freire, 1972:12).

Freire (1972) suggests that dispossessed groups present with ignorance and lethargy as direct products of economic, social and political domination. Due to paternalism, the Pikeville residents were kept submerged in a situation in which critical interaction with concrete realities, such as the impact of violence on the health of women, was impossible. All participants in this study were therefore viewed as a subaltern group (Spivak, 1988) who have no voice and who are represented by individuals who function in structures that serve the purposes of the dominant class (Guha, 1982).

#### **3.3.2.1 Focus of the study**

The focus of this critical ethnography was to explore the cultural beliefs and practices of participants in relation to alcohol consumption during pregnancy. An exploration and deepened understanding of what participants experienced as ‘real’ within their context illuminated the structural barriers to abstinence from alcohol during pregnancy. This information offered useful insight into gaps in existing approaches in FASD prevention in this community. Everyday practices around individual and communal use of time in the home environment as well as in the spaces in and around the community were explored to understand how individual beliefs and practices directly and indirectly impacted on alcohol consumption of the female participants in the study who consumed alcohol

during pregnancy. Influences in the home environment as well as in the community environment were identified. Clear links were made between the participants and their home environments. Influences from the broader community were highlighted throughout the investigation. Personal opinions on general as well as maternal alcohol consumption were recorded. This ensured that participants' contributions were valued and recognized. This approach met the first three criteria of the five cornerstones of social inclusion namely valued recognition, human development and involvement in terms of recording and integrating participants' contributions (Laidlaw Foundation, 2005). Suggestions for the focus and method of FASD prevention message were elicited (See Appendix E).

### *3.3.2.2 Community entry*

The Pikeville Community Advisory Board that coordinated and facilitated all health related and public health activities and which served as the initial entry point into the research community had been disbanded by the time the research process commenced. The initial research plan and activities were discussed with its members and agreed upon. Representatives on the Pikeville Community Advisory Board were from the Departments of Education, Social Services, Health and Correctional Services, faith-based organizations and non - governmental organizations (NGO's) as well as informal structures (such as advocacy and interest groups). Other service providers that did not fall into the mentioned categories were invited as the need arose.

Formal entry into the community was negotiated through the Community Advisory Board who also granted access to the Comprehensive Fetal Alcohol Syndrome Prevention Program (CFASPP). Access to specific contexts and activities was gained via informal networks such as gatekeepers and informal sponsorships. Due to previous research and clinical work as an occupational therapist, I already had extensive experience of a context similar to that of the research context. The skills that I gained from previous encounters were refined even further to enhance sensitivity to the dynamics within the community. I was committed to learning as much as possible about the community norms before and during the research process by watching and asking appropriate questions. I showed respect at all times and while some boundaries set by participants were kept, others were renegotiated as trust developed. Appropriate language use, as an

intricate part of cultural competency was considered as I picked up on the local lingo and adapted my language accordingly.

#### Procedure for recruitment of participants for individual and group interviews

Some participants were recruited via referral from health personnel at the clinics and screened by a research assistant. Other participants were recruited through snowballing. A group of women who lived in the construction camp in Pikeville were recruited via snowballing. At the first point of contact with prospective participants the research purpose and process was explained and a consent form signed. A screening question on research involvement over the past 12 months was used to exclude all participants who had been part of the CFASPP study. Eligible participants read the information sheet while I and/or a research assistant read and explained the information sheet to illiterate participants. Participants signed the informed consent form (Consent form B1 in Appendix C and/or Consent Form C1 in Appendix D) for participating in individual interviews and/or group interviews. Upon completion of Consent form B1 or Consent form C1 participants completed a general information form. My research assistant and I assisted illiterate individuals to complete the form. The general information form contained demographic information such as age, gender, family income and education levels, drinking patterns and contact details of partners/and or a close family member.

The reason for including partners or close family members in the study was explained to participants, i.e. to contact them and arrange for focus group interviews. Although all women were encouraged to invite their partners, only one woman invited her partner to accompany her in the interviews. Further explanation was given that if partners are not available then the female participant could invite a close friend or family member to participate. Only one participant invited a close friend. If participants were willing to grant me permission to contact partners and/or family members, Consent form B2 (form to grant the researcher permission to contact a spouse, partner or family member) was signed. It was clearly stated that participants who declined to sign Consent form B2 could still participate in the study.

The same procedures that were followed for women and service providers who participated in the study applied to partners and/or family members who participated.

After signing the consent forms dates and venues for the first interview session were confirmed. Follow-up dates were set at the end of each meeting. Privacy was ensured during the recruitment process by extending invitations to information sessions on healthy pregnancies to all women. A total number of thirty women, one family unit (consisting of a mother, her partner, her aunt and her grandmother) and nine service providers were recruited via snowballing from community health services, educational institutions and political organizations. Women who participated were also asked to identify service providers whom they recommended to participate in the study.

### **3.3.3 Study population**

Participants were drawn from people who lived in Pikeville or in one of the surrounding farms. The study population included all the women between the ages of 18 and 44 and who lived in Pikeville. Some of the women who lived in the town area made use of the public health services (fixed or mobile clinics).

The study was designed to collect data from the partners of women or from a family member or friend. This would include any individual that a drinking mother identified as someone that she would like to accompany her to interviews and who could provide support during the research process. Service providers from Pikeville in the Health sector, Social Development sector and Education sector also formed part of the study population. Service providers were in a position to give a different perspective on social trends related to alcohol use within the Pikeville community. This contributed to a multidimensional picture of the trends exhibited by mothers who consume alcohol during pregnancy. In this way ethnographic knowledge was co-produced (Denzin and Lincoln, 2005) between a variety of participants and me.

As the available maps of the research area did not indicate the names of the surrounding farms, a list of the farms within a 20 km radius was requested from the municipality. Once this list was secured individual meetings were held with available farm owners within the vicinity. The farms in the area varied from grain and sheep farming southwest of Westcoast/Winelands region, grape and citrus farming in the northwest and southeastern areas, to protea and berry farming in the north-eastern parts of the region. Follow-up meetings were held with owners who were interested in collaborating in the

research. The commencement of the research study coincided with the harvesting season and turnout from farms were generally poor. Two of the participants who lived on farms were unemployed at the time and were able to participate. These two participants travelled into town to join the group interviews with other female participants who were recruited from the local clinic.

### **3.3.4 Sampling**

The Community Advisory Board (who comprises representatives of clinics and organizations across the Portside and Pikeville) were invited to discuss ways of obtaining a varied sample across different areas as well as across fields of specialization and services. The Community Advisory Board assisted in distributing information about the research and inclusion criteria to different service providers. Purposive sampling was used (Warwick and Lininger, 1975). The three main dimensions along which sampling took place included time, people and context (Atkinson and Hammersley, 2007). Maximum variation sampling was used as a form of purposive sampling, with snowballing as recruitment technique whilst purposive sampling was used to select participants.

#### **3.3.4.1 Selecting participants according to time:**

I made observations of differently selected places (i.e. shops, playgrounds, schools, and libraries) and activities at a wide variety of timeslots that included weekdays, weekends, long weekends and public holidays. At times observations were done during the daytime and at other times during the night time (between 7-12pm) after which all activities would cease. Duration of observation varied between one to eight hours per occasion.

#### **3.3.4.2 Considering different groups of people:**

I collaborated with gatekeepers (Atkinson and Hammersley, 2007) to get into contact with information-rich individuals as well as with individuals who voluntarily offered to introduce me to their circle of acquaintances (also referred to as informal sponsorship) (Liebow, 1967). People from different parts of the community and from different sectors were included.

Exclusion criteria:

All women who had been part of the life skills intervention group as well as in the motivational interviewing intervention from the CFASPP study were excluded from this study. This ensured that as many women as possible received benefit from involvement in the research activities in the area.

### **3.3.4.3 Considering the spheres of influence within the context**

#### **Micro systems**

The micro system for a mother who is at risk of bearing an alcohol exposed child consists of individual or interpersonal features and those aspects of groups that comprise the social identity (Gregson, 2001). It includes the roles that the mother plays (mother, partner, daughter, friend, sister) or characteristic she might have in common with the people with whom she interacts. These interpersonal attributes are strong predictors of self-perception. These qualities and factors can be learned (also an attribute of culture) as in membership to group (family or friends). These characteristics may be seen as ingrained and integrally part of an ethnic group or particular gender. Psychological and cognitive factors also form part of microsystems and these may include personality, knowledge and beliefs (Gregson, 2001). The mother in her microsystem is constantly shaped, not only by the environment, but also by any encounter or any individual she comes into contact with e.g. partner (drinking or non-drinking), employer, friends (drinking and non-drinking), school teacher, culture, parental support and education level, Opportunities to engage in certain types of activities (such as alcohol abuse) may also be an influencing factor within this system.

#### **Meso systems**

These systems refer to organization or institutional factors that shape or structure the environment e.g. rules, policies, and acceptable business etiquette within a more formal organization. Examples include schools that children attend and the norms that become acceptable during schooling years, companies, churches, and sports teams. Mesosystems are essentially the norm forming component of a group or organization. Due to a lack of involvement in a variety of organizations or institutions the primary

school environment would be a crucial mesosystem for individuals who leave school early and become mothers at a young age. Girls who leave school at an early age seldom reach high school and often have an average educational level of grade four (May et al., 2008). Such individuals turn out to be the mothers who are most at risk of children with FASD. Although reasons for leaving school at this early stage may vary, it is common for children who have been prenatally exposed to alcohol to present with less severe problems of fetal alcohol effects (FAE), such as deficits in learning and memory (Willford, Leech and Day, 2004), impairments in academic achievement (Goldschmidt, et al., 1996), mild mental retardation, or birth defects (Floyd, O'Connor, Sokol, Bertrand & Cordero 2005; Hankin, 2002). Exposure to interactions of these women through their life course may therefore be limited to the time they spent in primary school and that of the farming or town community in which they live. The richer the medium for communication related to the effect of prenatal alcohol consumption during pregnancy and possible support structures in this system, the more influential it may be on the microsystem.

#### Exo systems

Exo systems are essentially any setting that affects the individual, although the individual is not required to be an active participant (Bronfenbrenner, 1979). Exo systems refer to the influences at community level. The influences at this level include fairly established norms, standards and social networks (Gregson, 2001). A distinction was made between the institutions that are within the Pikeville community (most accessible and influential) and those that are outside of the community (least accessible and least influential). The power relations in the interactions between different participants (drinking mothers and service providers) in the study were recorded and incorporated in the data.

#### Macro systems

These systems refer to cultural contexts (Bronfenbrenner, 1979). These influences are not solely geographical or physical, but also emotional and ideological. The nature of these influences is such that they are more easily seen than the other factors. While examples of influences at this level may include Communism, Western Culture, Islam and Christianity, this study proposes that the impact of Colonialism and its after-effects

and the way these effects were internalized and expressed by oppressed groups (of which participants in this study are representatives) fall under this category.

The majority of participants lived in the town area. A total of twenty three women participated. Twenty one of the women lived in town and two came from two farms in the surrounding areas. Nine service providers lived in town and one lived in a small town outside Pikeville. Participants were selected to fall within the three groups i.e. women of childbearing age, husband/partner (or family member) and service providers. In the absence of a husband or partner a close family member was selected. The sample consisted of:

- Nine mothers who were referred by staff at the local clinic were screened for participation. Three mothers agreed to participate in the study. Eleven of the mothers from the construction camp in Pikeville participated in the study. All women consumed alcohol and were between the ages of 18-44 years old. All the mothers were unemployed at the time of the research. All the mothers used alcohol during any one of their pregnancies. Occasional drinkers, moderate drinkers (less than seven drinks per week) and binge drinkers (drinking more than seven drinks a week or who had a history of binge drinking - i.e. five or more alcoholic beverages on one occasion - (Naimi et al., 2003) were selected. One of the mothers introduced her family, who also participated in the study. This family had three generations of women (including an 80 year old woman) who engaged in binge drinking. Since the grandmother shared rich information on occupations held in the past, she was also included in the study. As the project evolved I realized the importance of including older women into the study. These were the women who often took care of their grandchildren when parents had to work away from home or when parents were unable to take responsibility for their children. Consequently three of the female participants who were older than 44 years were included. Their stories were recorded, analyzed and interpreted together with the rest of the data. Incidentally these grandmothers once were mothers who also consumed alcohol during pregnancy. Ten of the women had never been married, but lived with their partners. Five women were separated from their partners and eight were single.

- Service providers from the research community were selected based on their involvement with the mothers, their knowledge of Pikeville as well as their availability and willingness to participate. The service provider group consisted of three participants from the health sector, four participants from the adult basic education and training sector, a local counselor from a political party and three development workers from a local non-governmental organization that focused on FASD prevention.
- Only one partner agreed to participate and was selected. The rest of the mothers invited a family member or friend to accompany them to interviews. Nine friends/family members participated in the study.

### ***3.3.5 Data Collection***

Within this ethnographic study the following two strategies of data collection were used:

- Information interviewing - Individual interviews and group interviews were held with women, partners/family members and group interviews were conducted with service providers. All interviews were audio-taped.
- Participant observation - I participated in activities in Pikeville community and surrounding farming areas (Wolcott, 1998). All thoughts and conversations were written up as journal entries. Journals included important considerations that were viewed as essential to the research process (Atkinson & Hammersley, 2007). While cultural influences were the main focus, political, economic and social issues that influence maternal alcohol consumption were recorded as a main feature (Viljoen et al., 2002; Townsend, 1999; London, 1999a) and analyzed.
- Collection of historical material of Pikeville - historical legislation and documents on the establishment of Pikeville were studied and incorporated as data.

#### ***3.3.5.1 Interviews***

An interview guide was used for all interviews (See Appendices 8.18 & 8.19). I spent a period of two years full-time and one year part-time doing monthly visits in the research

setting. This allowed for the building of trust as well as saturation of data collection. Individual and group interviews were used to generate data on the underlying influences from the micro, meso, exo and macro systems for maternal alcohol consumption during pregnancy. Throughout individual and group interviews I attempted as far as possible to elicit stories that would uncover what Rubin and Rubin (1995) referred to as cultural icons. They define cultural icons as physical objects, statements or notions that represent tacit cultural beliefs and norms (including alcohol drinking norms) commonly shared by a community. Some of the interviews were conducted at the local clinic or the local school, while other women invited me to their homes. All the women who participated in the research (even the women who were involved in group interviews) had one thing in common: they valued the interview space as a place where they could share life experiences with other women. This was a non-judgmental space in which all the women agreed to listen while others speak uninterruptedly. Individual and group interviews were recorded on tape, transcribed and analyzed. Appendix E (Interview Guide) outlines the questions covered during all interviews.

#### Individual Interviews

The process of data collection commenced with individual interviews at the clinic. While the initial plan was to have semi-structured interviews with female participants as well as their partners, only Wanda's partner responded to an invitation for an interview. Two interviews were conducted with this couple after which the partner had to leave town for a job. Since Wanda was information-rich in terms of the stories she shared and making her immediate family (mother, aunt, cousin and grandmother) available for participation, she continued her involvement after expressing her interest in doing so. In addition to two further individual interviews with Wanda, there were numerous opportunities to observe and participate in activities with the family.

While all the other female participants gave written consent that either a partner or family member be involved, none was forthcoming. As a result female participants were interviewed individually or in a group. Between two and four interviews were conducted with each participant, depending on when data saturation was reached.

## Group interviews

Three group interviews as well as one member checking interview were conducted with the mothers as well as with the service providers<sup>34</sup>. Mothers who participated in group interviews preferred to be in the same groups as their friends. This arrangement offered a special type of support and created an affirming experience. Confidentiality was a central norm during interviews. Confidentiality in these group discussions was ensured by involving participants in drawing up a group contract that included a list of group norms. Group norms were referred to as 'rules' so as to make it easily understandable for participants.

With prior written permission from participants all group interviews were recorded. Morgan (1997) suggested that group discussions generate ideas and allow participants the opportunity to share experiences and listen to agreements and disagreements. I therefore had the opportunity to explore these agreements and disagreements in relation to social alcohol consumption between the different participant groups. Since some of the issues related to the research topic included domestic and sexual violence, some participants preferred individual interviews. The interview structure was thus adapted to meet the needs of participants and individual interviews were conducted upon request.

A group interview structure was used with all service provider groups. General questions that provided additional information to assist me in understanding contextual issues better were also posed. Participants preferred to listen to the account of one participant and waited for me to repeat the question so that they could start telling their own stories instead of building onto previous accounts. Participants would also ask questions to gain information on what they needed to do to ensure a safe pregnancy. The space thus lent itself to the sharing of stories as well as the provision of information regarding healthy pregnancies. The interview space was co-created by the participants and me to engage and discuss with women all relevant issues and provide answers where it was possible. After all the data was collected women were provided with printed material and they watched a video clip on the dangers of alcohol consumption during pregnancy.

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<sup>34</sup> The same questions were asked for drinking mothers and service providers. The only difference between the interview processes for these two groups was that service providers did not have to confirm alcohol consumption.

This interaction between the participants and me provided a dynamic space in which some of the information that was disseminated regarding safe pregnancy prompted the quieter participants to share their stories. Participants also had the option of arranging for an individual interview shortly after the group interview if they felt the need for individual conversation with me. The interview process was flexible and allowed for individual and group interviews to be run interchangeably and in no specific order. The sequence of interviews was based on the availability of participants and the type of information that still needed to be collected. All interviews were conducted in Afrikaans.

### ***3.3.5.2 Participant observation***

Participant observation took place in between interviews and during other spontaneous or arranged times with community members. I began by making observations and describing general occurrences. Observations were narrowed down to situations/incidents that were related to general beliefs, norms and practices as well as beliefs, norms and practices related to the excessive use of alcohol by individuals as well as by groups of people. According to what DePoy and Gitlin (1994) suggested I also described my own actions, the actions of those involved in what was being observed as well as what was observed from the research context. While participation in some activities such as sitting and socializing in a backyard on a Saturday afternoon happened spontaneously, I sometimes requested to be included in other activities (such as attendance of a rugby match or social event held at the local hall). All descriptions and reflections on participation in activities were recorded in the field notes. Field notes were analyzed as part of the data.

### 3.3.6 Approach taken to data collection

The approach to collecting data ensured that people from different sections of the community were included in the study. For example, mothers, their friends and/or families as well as service providers from different sectors were interviewed. I took extensive notes on the interactions between people as some of these interactions uncovered the values of those involved. While it may seem arbitrary to record and discuss values of a group of people, it was important to capture the values of this group of people for the following reasons. There is very little information on the practices, beliefs and norms of contemporary Black communities. In relation to FASD in South Africa, the only information available refers to characteristics that place women at risk of having children with FASD (Croxford and Viljoen, 1999; Viljoen et al., 2002; Viljoen et al., 2005; May et al., 2005). Incidentally, all of these at-risk factors are negative and relate to low education and literacy levels, poor health, high parity, and excessive drinking patterns. In contrast to this individualistic approach this study explored how culture, as one of the macro influences<sup>35</sup>, impacts on alcohol consumption during pregnancy. Bronfenbrenner's perspective (1979) was founded on the person, the environment, and the continuous interaction of the two. He suggested that it was not only the environment that directly affected the person, but identified layers in between (i.e. micro-, meso-, exo- and macro systems).

Occupational storytelling, a construct of narrative, or story making within Occupational science (Clark, 1993), was utilized to illuminate issues experienced by participants. Occupational storytelling emphasizes an emic (insider's) perspective within the occupational science field and offers the potential to access information on the culture of participants that would not have been deemed credible in many a researcher perspective (McGruder, 1998). The commonality in concepts such as occupation, health and culture between occupational science and occupational therapy created an opportunity for further exploration of these concepts among participants. Exploration around the health of women within the study was based on Manderson's (1990) statement that (like race) health is also a culturally constructed experience.

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<sup>35</sup> Wilcock (1998a) and Scaffa, Reitz and Pizzi (2010) identified culture, economy and political priorities as the three macro influences on health and occupational engagement.

I consciously reinforced the relational dynamics described below in my approach to collecting data. These influenced the way questions were asked or the way participants were encouraged to participate in activities or discussions:

- I needed participants' assistance in understanding the research context better;
- I do not have answers to problems. My role was to pose problem scenarios and participants contributed by suggesting solutions
- I reiterated my role as temporary 'resident'. Participants were encouraged to give their own ideas for developing a sustainable solution to maternal alcohol consumption during pregnancy.

This approach fostered ideal conditions for having a dialogue with participants. Freire (2002) defined dialogue as an encounter between two people who trust each other and who experience each other as equals. Dialogue lends individuals the opportunity to name their world. Freire listed the preconditions for dialogue as follows:

- Both parties should participate in expressing their word and naming their worlds.
- Each person should name their own realities and not that of somebody else.
- An atmosphere of trust, mutual respect and appreciation for the world and its people.
- The listener should be open to the ideas of the speaker and not be offended by his/her contribution.
- Those in the dialogue should rid themselves of the fear of being displaced as well as the need to be self-sufficient.
- Horizontal relationship and mutual trust are critical components of a dialogue.
- Believing in one's own expressions of reality.

When I entered the research context, I acknowledged my status as a visitor and a novice in the lives of participants. The value of assuming this attitude was that a rightful space was assumed by both researcher and participants. It acknowledged the participants' position as primary occupants and encouraged a relationship in which participants could introduce me to people and places around the community as well as usher me into participating in everyday community practices. I ensured that I was dressed in informal clothes that were appropriate for the context. I familiarized myself with the local dialect

and avoided professional lingo. Introductions and the decision of who should be contacted first and when, was vital in determining the success of the rest of the research encounter. I explained that I was from Cape Town and I was doing work in Pikeville on preventing alcohol use during pregnancy. I placed emphasis on the fact that I was also looking for ways of helping or supporting women to have a healthy pregnancy and therefore, healthy babies.

A positive approach that equalized positions of power emphasized the giving and receiving of support. Instead of looking for women who consume alcohol during pregnancy (a fault finding approach) this approach fostered an atmosphere of care. My introduction was genuine and I was cautious of creating any expectations that I was not able to meet. I noted the following in my field journal:

“[I] have to be careful in how I introduce the study. I really want to make sure that participants don't feel ostracized or judged.”

I reflected upon the different ways in which participants could read my intentions for approaching them. Ultimately, this interaction would have to have benefits for both me and the participants. A less desirable approach, which is often taken by health professionals who are doing research, may create an impression of the researcher as the expert. Such an approach could give participants the impression that the researcher is there to offer solutions to their problems or even to provide a service<sup>36</sup>. An alternative, more useful approach could give participants the impression that I needed some help in understanding the context in which they lived<sup>37</sup>. Both of these approaches have underlying philosophical assumptions and I decided to apply an approach that would assign me the role of a visitor and learner in the research context. I therefore decided to use the second approach of wanting to learn more about the research context. I was aware that the first impression would influence how participants view and experience the research process. I therefore deliberately selected an approach that reinforced an equal

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<sup>36</sup> When health professionals act as experts they may be expected to 'fix' problems rather than to involve participants in exploring their own solutions to the problems.

<sup>37</sup> This approach is based on the adult education principle of mutual learning where the researcher and the participant can assume roles of both learner and teacher.

relationship of mutual respect and dialogue<sup>38</sup> between the participants and me. A great part of researcher-participant interaction involved observation in public spaces such as the clinics or at the local shopping center. As soon as trust was established participants became at ease and some would even initiate contact. If the participant indicated willingness to participate I responded promptly by initiating a conversation on alcohol use and FASD prevention or by inviting the potential participant for an interview. Expectations of the researcher and the participants were clarified during the first meeting and revisited as the need arose.

In line with the preconditions for dialogue the six principles below were applied to develop relationships in which power was shared. These principles were reiterated to initiate and establish common ground between the participants and me:

#### *1. All human beings have to face challenging circumstances.*

I named the challenges in my reality and listened to how participants named their realities. The following excerpt captures a section of my introduction:

*“I also told [participants] that I [grew] up in a [rural town] similar to the one they live in currently.... [I shared about my family structure ... and told them about my life as a young girl]. I [told about how I witnessed] some of the struggles that many of my friends and family went through... I told them how my parents also used to live on the farm many years ago...long before my birth. As I was sitting there and telling them about myself, many of the stories of survival my mom used to tell me flashed through my mind. The life on the farm was not what I had in common with these women. Rather, the problematic alcohol use, the domestic violence, helplessness and hopelessness. And even though I did not experience [violence or physical abuse first hand], I could see my parents in them ..... I could see myself in their daughters ..... So, in a way I come from this place and in a way I don't! I find myself moving / slipping to and fro between... two places of knowing and belonging and one of total estrangement.”*

Freire (2002:91) states that hopelessness is a “form of silence, of denying the world and fleeing from it”. During this moment in the dialogue participants had the opportunity to

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<sup>38</sup> Dialogue allows participants to name what is relevant to them and in the process initiates critical conscientization (Freire, 2002).

share in a part of my life. They might have been encouraged to share similar and sometimes worse incidents from their lives. A common space was thus created and shared. Participants were invited to share the interview space and other spaces where interaction occurred between me and them as equal spaces. In extending this invitation I selected and shared specific information regarding the context of my upbringing with participants. This made the dialogue between us authentic and gave both parties the opportunity to name their worlds (Freire, 2002:88). In this case dialogue created a foundation for honest sharing and a safe space to share life stories.

## 2. Sharing interests and occupations fostered dialogue:

*“As I was saying goodbye I commented on Dobby Gray’s music that was playing in the background (the music brought memories of my childhood). Rob said that it was one of his favorites. He offered [to lend] me the disc and said that I could take it home and return it on the next visit.”*

The excerpt above demonstrates how the only male participant began to show trust. I was pleasantly surprised with the spontaneity of this participant. This was a confirmation that our interactions developed from a distant researcher-participant relationship where I would often be asking questions and he would answer, to a more equal relationship where the interaction shifted away from a question-answer format to an equal interaction where both of us could give something at some times and receive on other occasions. My acceptance of this offer was crucial to Rob’s belief that he had something worthwhile to share and offer.

This was a genuine person-to-person interaction in which the background music reminded me of the songs my father played during my childhood. In this short person-to-person interaction the participant and I established common ground in music preference. This interaction was not only about the exchange of music with a participant. It was more about establishing a relationship and building trust with Rob, Wanda’s partner. During this moment in the dialogue Rob did not use words to name his world, but he shared that in which he was interested in addition to what he had already shared earlier in the visit. The sharing of music was a sign of trust. It was his way of sharing that his world consisted of more than the pre-occupation with FASD prevention. The visits that followed

at home were more relaxed than at those initial visits at the clinic. Upon returning his music track I spent valuable time in further understanding the life of this small family.

### 3. Sharing interests fosters mutual learning:

Sharing interests allowed both participants and researcher to learn from one another. While participants learnt about the scientific facts regarding FASD, I learnt more about their lives and how they spend their free time. Kato, a female participant, kept a beautiful flower garden. Incidentally, I also started a garden during that time, but had difficulty in getting my flowers to grow. As shown in the excerpt from my reflective diary below, Kato was keen to share her gardening tips:

*“Kato and I struck a common point of interest. I was really impressed by her neat garden. I asked her whether she had planted the whole garden. She started telling me about the flowers she planted. She gave me a few tips on how to feed the soil to make sure the plants get enough nutrition. I admitted that I don't have green fingers at all! This was a great opportunity for Kato to share all her wisdom on gardening. She was very excited and told me about the Velvet rose and promised to give me a branch as soon as she'd pruned the roses. Our mutual interest in gardening set a relaxed atmosphere. I was glad that the interest in gardening came up so early in our acquaintance.”*

Kato realized that she could also teach me. This opportunity allowed Kato to be the teacher and me the learner. This interaction echoed Freire's principle of the adult education philosophy namely mutual learning. The principle of mutual learning within this situation denoted that the facilitator learns about the lives of community members and in turn community members learn about issues of development from the facilitator.

### 4. Admitting to not knowing all the answers

The excerpt below demonstrates how I introduced myself as a specialist in my field, but emphasized that I was there to learn about the cultural beliefs and practices of the community:

*“I introduced myself to the group and told them that I was interested in learning more about how we as women first, and then as broader community can assist and support pregnant mothers in having healthy pregnancies”*

Participants often had many questions on issues that were outside of my personal or work experience. Participants tended to revert to the typical health professional-patient interaction in which the health professionals ‘fix’ their problems and often tell them what to do. I admitted that I was not able to answer all questions or meet some of the expectations held by participants; participants were encouraged to reflect on their perceptions of the researcher-participant relationship. I encouraged them to suggest solutions to some of the unresolved issues. In this way responsibility for searching for answers was fostered. This also initiated the process in which participants follow their own suggestions and then later take responsibility for the outcomes of their decisions. This is one of the cornerstones of development among vulnerable populations. The ability to take responsibility for the results of one’s own actions is the precursor of radical transformation (Freire, 1972) and thus true development.

##### 5. There is no “us’ and ‘them’ in this fight against FASD, it is only us...

The preceding four principles provide a foundation from which participants and researcher can operate as a unified force in the fight against FASD. In making a shift from blaming the community members for their health status towards creating a space in which such problems can be discussed openly, researchers, health professionals and the community can collaboratively search for solutions. Dan, a FASed<sup>39</sup> development worker, who also grew up in a community similar to Pikeville community said:

*“...’n uitdaging wat ons dalk het is wanneer dit kom by probleme oplos in ’n gemeenskap dan die storie van kom met ’n ’ons’ en ’n ’hulle’ attitude. ‘Us’ and ‘them’...Oms is die...ons weet van beter ons gaan vir julle wat nie weet nie gaan ons nou iets aanbied. Dit is gewoonlik iets wat mense...mense wegdryf...” (Dan, interview 2)*

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<sup>39</sup> Pseudonym

*[...a challenge that we have when it comes to solving problems in the community then there's this attitude of 'us' and 'them'. We are the...we know better we will teach you something. This is usually something that...drives people away...]"(Dan, interview 2)*

In line with the philosophy of dialogue the central purpose of the interview technique within critical ethnography is to democratize the research process. Participants were given a chance to have a voice in the research process and to challenge material produced by the researcher (Carspecken, 1996). I realized that if participants felt heard and respected they were more likely to work with researchers and health professionals. When they felt judged they withdrew information and interaction. This required retroactive listening (Murray, 2009; Laub, 1992) with an attitude of genuine empathy. An awareness of my own assumptions and prejudices was helpful in developing empathy with the participants. As part of this principle I avoided singling out participants who had problems. Leoni, another FASed development worker, who also grew up in a community similar to Pikeville community supported this approach:

*"[Plaaswerkers] ken mekaar. Nou sien hulle, maar hoekom is dit dan ons spesifieke groep mense en nie ander mense nie? Nee, nou wil hulle nie meer betrokke wees nie, want dit lyk nou amper asof dit net hulle is in die hele wêreld." (Leoni, interview 3)*

*[Farm workers know one another. Now they see, but why is it our specific group and not other people? No, now they refuse to get involved, because it seems as if it is only them in the whole world.] (Leoni, interview 3)*

## 6. Creating an atmosphere of respect and dignity

Initially it was challenging to initiate and establish relationships with female participants. Participants were skeptical of my presence and I knew that it would not be easy to gain their trust and collaboration. The first step was to show them that I respected their boundaries. If participants refused to share information I would accept this, but still continue to take interest in the other topics they wanted to discuss. It was critical to show consistent respect and be aware of interacting in a way that affirmed participants' dignity. Since this community was ridden with accounts of alcohol consumption during pregnancy I took into consideration that many of the participants may already have

deficits in adaptive abilities i.e. performance of daily activities required for personal and social sufficiency (Sparrow, Cichetti and Balla, 2006). Deficits in adaptive behavior may decline even further with ageing (Whaley, O'Connor & Gundereson, 2001) and as a result these individuals face serious challenges with getting needed supports and services. Ensuring that participants felt respected and dignified was therefore maintained to enhance continued participation and collaboration.

One way of showing respect in this community was the way in which younger individuals address older people. While most participants introduced themselves by first name, others would offer their nicknames. One participant preferred to be called Mrs. Williams. I noted in my dairy:

*"It was awkward to establish a way of addressing the women [participants], I could not remember all their names and I was so aware that calling them "Mevrou" or "Mrs." created a very formal atmosphere. It also set me apart so distinctly from the rest of the women as the young[er] women called the older ones, Aunty "something". Most of them had nicknames like "Oumeid", "Ounooi" or "Noientjie" or "Kleinmeid". The older ones were called Aunty "Oumeid" and so on. I gathered that two of the women had association with church organizations. They were called Sister "something"."*

In general, the type of jobs that drinking mothers and other mothers from this community hold, places them in a position whereby they are called by their first names. During the apartheid era in South Africa, the title of 'Mrs.' was reserved for European females in the workplace and even in social spaces. Regardless of their age, Black females were called by their first names. When health professionals enter into a community the community members and patients will almost always introduce themselves by their first name only. Health professionals then have a choice whether patients should address them by name or whether a title like "Doctor", "Sister" "Missus" or "Miss" is used in combination with the health professional's surname. This suggested that respect was showed by patients toward health professionals and not the other way. During a first interview at the local clinic I introduced myself by my first name. I addressed the participant as 'Mrs. Swarts'. Martha, a mother of two children, explained why it was difficult to address me by my first name. Despite the fact that we were the same age at the time of the interview, she

insisted on calling me 'Mevrou' (Mrs.). Martha then also asked me to call her by her first name:

*“Daar wat ek werk ook... Ek roep Mevrou, vir die vrou waar ek werk. My ma en my pa het my baie mooi maniere geleer ek sê 'Mevrou' vir iemand wat sulke werke [soos in die kliniek] doen, hou ek daarvan om te eer as hulle my kan reg leer.” (Martha, interview 1)*

*[Even where I work, I say Mrs., to the woman for whom I work. My mother and father taught me good manners I say 'Mrs.' to people who do work like you, I like honoring people who can teach me the right things] (Martha, interview 1)*

This quote shows how Martha struggled to negotiate a space as an individual with equal standing in the research process. This is the type of participant that is difficult to collaborate with in a horizontal relationship (Freire, 2002) where power is equally shared. This last principle underscores the importance of not generalizing, stigmatizing or marginalizing individuals when working within these communities, but rather to identify individual weaknesses and strengths that should be considered in the planning phases of prevention efforts.

### **3.4 Data Management**

According to Dey's suggestion (Dey, 1993) data was dated and filed according to the sources of data collection. Tapes were clearly labeled after each interview. All electronic data (i.e. field notes and reflexive diary) were stored on computer and back-up copies were stored on disc together with paper data. All paper data was securely stored and locked in a file cabinet at the University of Cape Town.

#### **3.4.1 Data Analysis**

QSR N'Vivo 7 (2006 version) was used to manage and analyses data. Inductive thematic analysis was used (Patton, 1990). The analysis of data took place in three stages. The initial analyses involved coding words and phrases that were meaningful and that presented obvious units of meaning that related to the research topic. This stage of the analysis commenced soon after the first interviews were transcribed. Analysis was done

systematically throughout the research process (See appendices 8.11-8.14). Follow-up interviews were only held once the first round of interviews was analyzed. Follow-up questions were posed in second round interviews. This method allowed for gradual immersion (Marshall and Rossman, 1999) into the data and deepened my understanding as a richer and fuller picture was built on. Immersion created openness to the subtle undercurrents of the text. Various meanings and particular words were carefully deconstructed (Seale, 1999) into codes, which facilitated the organization or grouping of similar or related concepts into subcategories.

The next stage involved looking at words or phrases that repetitively seemed to draw attention to the meaning as implied by participants or to the way in which participants emphasized its significance during the interview. Similar words and phrases were linked together and collapsed into larger meaningful categories (DePoy and Gitlin, 1994). Categories were repeatedly reviewed and examined and then rearranged. Differences and similarities between subcategories and overarching categories were identified. Finally, links and relationships among categories were examined in order to reveal the underlying meaning in categories (Rubin and Rubin, 1995). Categories were examined for overlap and/or hidden meaning among them (Ibid). Expressed beliefs, values, norms and perceptions of individual participants were compared to beliefs, values, norms and perceptions of the larger participant group. Comparisons were made with analyzed field notes to identify commonalities that reflected the social context, the socialization processes and routines (Atkinson and Delamont, 2005) related to maternal alcohol consumption and Fetal alcohol syndrome.

During stage three of the analysis process I re-examined the data and searched for correlation with the objectives of the research. Quotes and examples were extracted to substantiate the identified subcategories, categories and themes. The possible symbolic and cultural meanings of excessive alcohol use as commodified cultural artifact in Pikeville and its influence on the past three to four generations was also considered by studying material on past legislation. Data that was generated from one of the drinking mothers (Wanda) also provided information on this trend. I drew links between how legislation impacted on the occupational engagement and development of marginalized groups in South Africa. In order to understand the contextual background of participants' stories I studied material on alcohol abuse as an occupation with a particular focus on

farm workers, their immediate families and their extended families. The influence of policies on occupational engagement and alcohol use practices of farm workers as original indigenous groups was also considered. The historical and current meaning derived from alcohol abuse as occupation as expressed by participants was investigated. The process of how excessive alcohol use was incorporated into routine practices was explored. My interpretations from the historical data were compared with and used in combination with dialogical data.

To add more meaning to the findings all possible connotations (including meanings that were read from timing, tone, gestures, and postures of each act) were named (Carspecken, 1996).

### **3.4.2 Establishing trustworthiness**

During the research period, I kept a daily journal on my assumptions about the participants in relation to the different spheres in the research context. Keeping a daily journal enhanced reflexivity (Atkinson & Hammersley, 2007) as an important feature throughout the research process. The keeping of reflective logs and informal discussions with experts in the field of ethnography allowed me to continually ask critical questions upon reflection. Due to the pragmatic philosophical foundations of critical ethnography, truth was defined in terms of the commonality identified between and across themes. While I acknowledged that all truth claims made during the research process were fallible the focus was more on veracity of data. Objective, subjective and normative/evaluative data was thus judged against its ability to meet certain criteria. These criteria included the participant's account of personal alcohol consumption or alcohol consumption by friends and family members; accounts on micro and macro factors that impact on occupational engagement of people living in Pikeville and contributions of messages that would be most appropriate in the Pikeville context. All data that met these criteria was regarded as useful and valuable as they "made sense" (Carspecken, 1996:89).

Although the goal was not to reach consensus on 'truth' between the different participant groups (service providers vs. mothers) provision was made to reach consensus within the participant groups. An example of a contrast between 'truth' statements emerged when

service providers expressed the need for better, more positive role models. In contrast, mothers referred to older women within the village as their role models. Analyzing data from different participant groups separately allowed contrasts to be highlighted. It also allowed me to form a sense of the 'voice' of each participant group in relation to practices related to excessive alcohol use in the community. I therefore used subjective interpretations of the data from individual and group interviews as well as from observational data to derive at themes. The themes that emerged were thus a combination of extracted data from all participant groups.

#### ***3.4.2.1 Interrogating data***

A peer reviewer independently followed the same process of analysis. She posed questions and highlighted areas that needed further analysis. The peer reviewer also assisted in highlighting underlying meanings of categories and sub-categories (Rubin and Rubin, 1995). I attended an occupational science symposium as well as an occupational therapy conference where research papers on the interface between occupational science and occupational therapy were presented by international and local experts in the profession. This assisted in further deepening my understanding of occupation as a construct and facilitated the interrogation of codes, subcategories and categories that emerged from analyses.

#### ***3.4.2.2 Trustworthiness/Rigor***

To ensure rigor of this study, Krefting's model of trustworthiness was used (Krefting, 1991a). This model proposes four strategies, namely credibility, transferability, dependability and confirmability with which to establish trustworthiness.

Prolonged engagement within the research setting ensured credibility (Leininger in Krefting, 1991b). Credibility was further ensured by keeping a field journal. Member checking interviews were held with all participants after the data was analyzed. Member checks ensured that the analyzed information was confirmed by giving participants the opportunity to correct and confirm the accuracy of developed categories and themes.

Dependability and transferability was ensured (Lincoln and Guba, 1985) by keeping a dense (thick) description of the research methods. This description included the following information:

- a) Daily schedule and logistics of the study
- b) Methods log in which decisions about methods and rationale were described.

Confirmability was addressed by keeping a personal diary. The diary reflected my thoughts, feeling and ideas that were related to and influenced the research process (Lincoln and Guba, 1985). It also facilitated reflexivity and prevented over involvement with the research context or research participants (Krefting, 1991b). Peer debriefing was facilitated by discussing research related problems, the research process and findings with the supervisor, who is experienced in qualitative methodology as well as one experienced researcher who was independent of the study. While I acted as the research instrument, I was able to observe phenomena, that would otherwise be described by participants as familiar, and reflexively explored these as 'strange' or unknown and worthy of investigation.

### **3.4.3 Ethical considerations:**

The study proposal was submitted to the Ethics and Research Committee of the University of Cape Town and was presented and discussed with the Community Advisory Board for approval before commencement. All participants were treated as meaning making and defended individuals (Holloway and Jefferson, 2000:26). When participants are being referred to as being "defended" it means that they may be rendered vulnerable as a result of having been selected from a population who can easily be exploited and who, because of their dependence on state health services are unlikely to refuse participation in research related activities. These individuals often do not have any other alternative places from which health care services can be purchased and might feel obliged to participate. Care was therefore taken that participants understood the right to refuse to participate in the study very well. It was explained to prospective participants that they could decline participation in the study or withdraw at any stage during the research process without any negative consequences. Participants were assured that the services at the clinic would not be influenced by their participation or any decision to decline participation (The Declaration of Helsinki. 2000).

Participants were not exposed to any risks as a result of participation in this study. All participants were approached with the utmost respect. Confidentiality was maintained throughout the research process and only the initials of the person and a reference number were used on the transcripts to identify information of different participants. It was my responsibility to ensure that these values were maintained throughout the research process in addition to upholding the principles of respect, autonomy and dignity. In order to protect participants' rights and ensure that maximal participation in and benefit from the research process, the ethical principles of autonomy, beneficence and justice were utilized (Beauchamp and Childress, 2001). All participants received information pamphlets on FAS as well as on appropriate services available in the community. Participants were referred to the needed services, especially if pregnant mothers who consume alcohol were identified. An indirect benefit was the opportunity participants had to contribute to the development of FAS prevention material. Participants could leave the study with raised awareness of FAS and prevention campaigns.

Power, as a core element in relational ethics (Austin, Bergum and Dossetor, 2003) was explored and discussed. The power balance between the participants and me was discussed openly and norms for ultimate collaboration were negotiated. Mutual respect was emphasized and reinforced by facilitating effective communication. I explained my role clearly and clarified this role throughout the research process.

All participants had the opportunity to study the purpose and objectives of the research as stipulated in the information sheet (Appendix B). Illiterate participants had the study read to them first. They could also choose to have the information regarding the purpose and duration of the research study explained to them by myself or the research assistant. After all questions had been answered to their satisfaction participants could make an informed decision about their participation. It was explained that participation is voluntary. Participants who were willing to participate signed Consent form B1 (form on which informed consent is granted) (Appendix C). Upon their agreement I contacted a partner or family member to also participate in the study. These participants also had to sign Consent form B2 (Appendix C). I read the information to all participants who preferred listening to the information instead of reading. Explanations were offered

where necessary. All participants were literate and were able to sign their names. Oral consent (Benitez, Devaux, & Dausset, 2002) was available as an alternative, but this method was not used. All informed consent procedures took place in the presence of a trusted adult of the participants' choice. All the options for gaining consent had been discussed with the Pikeville Community Advisory Board prior to the commencement of the research. Transcripts of interviews were made available for all participants to check accuracy.

Raw data containing the participants' details were securely stored away from the research site and were retained until after publication of all research results. This ensured availability of raw data should the need for re-analysis arise. Distributive justice was addressed by translating the developed message/s into the main local languages within the community. Confidentiality was ensured by running interviews in a private space at home or at the local clinic. I assigned pseudonyms after interviews were transcribed and safely stored a list of real names and pseudonyms.

#### **3.4.4 Critique on critical ethnography**

An advantage of ethnographic methodology was that it provided the opportunity to describe the individual, group and community in detail and great depth. It also allowed for a multi-level analysis of social events (Krept, 2011). One of the mostly cited weaknesses raised by researchers positioned in the positivist paradigm is that ethnography focuses on a single setting. Care should therefore be taken when making inferences from the findings and applying these to other settings. While generalizability is not a concept that is used in qualitative research, trustworthiness and rigor would have to be considered. Devers and Frankel (2000) and Mantzoukas (2004) commented on a second weakness of ethnography. This relates to participant selection and the fact that participants are selected via purposive sampling instead of random sampling. A third concern about ethnography is the subjectivity of the interpretations during the analysis of data.

Despite the long history of ethnography research methodology in research on health care systems and health behavior (Becker, et al., 1977 and Kleinman, 1980) it is still not as

well accepted as quantitative methods within the mainstream of health care and health promotion (Kreps, 2011).

Britten (2011) contradicts this statement and states critics should not publicly dismiss qualitative research as 'anecdotal' and 'unscientific' (Pope and Mays, 2006). Britten (2011) criticizes qualitative methodology in general when he suggests that while this methodology offers comprehensive descriptions it does not provide adequate explanation of concepts and interrelatedness of factors. He further states that quantitative research is higher in the research hierarchy than qualitative research. One of the reasons relates to the measurability of treatment effectiveness in quantitative methodology. Within this script the relevant constructs were well explained and links were made explicit between these constructs. While there is a definite need for quantitative research in areas of measuring improvement in FASD prevention and development initiatives in Pikeville, qualitative methodology offered a starting point for this direction by suggesting a different approach to health promotion and prevention in FASD.

## **CHAPTER FOUR**

### **FINDINGS**

The first part of this chapter (section one) will provide information on the research context. In Section One the participant groups will also be introduced and demographic data of individual participants provided. In Section Two I will elaborate on the two themes (with categories and subcategories under each) that were derived from the data and show how imbedded the two themes are into the context. Section Two concludes with two of the participants groups' (drinking mothers and service providers) suggestions on the approach that should be taken to future FASD prevention initiatives.

#### **4.1 Section One**

##### **4.1.1 Contextual background on Pikeville**

Upon entering Pikeville community I expected to find the typical struggling group of people troubled by the effects of problematic alcohol use. In contrast to this expectation the situation at first sight did not speak of dire desperation or, in fact, the need for any kind of intervention with FASD. This observation was confirmed by the information participants offered in the early stages of the research. The quotes of participants are used in addition to my descriptions to introduce different participant groups as well as the research context. The participants welcomed me into their home spaces and into their community. My first impression of this community was of people who had a positive outlook and welcoming attitude towards me. As I spent more time and was invited with even more ease into participants' homes, a more trusting relationship developed. Over time participants would share stories that exposed the harsh realities of living in Pikeville. The next section therefore provides information on the context in which participants live, from the perspective of participants. It also gives the reader a picture of the challenging life situations and living conditions in the research context and the positive and endearing characteristics of the people. Firstly, the attributes of people who live in Pikeville will be discussed. Then the structural aspects (places in which they make

a living) will be described. Lastly, residents' accounts of living in Pikeville will be presented.

Historically, the greater town area of which Pikeville forms a part was the home to the Free Blacks and slaves who were born in South Africa. Between the 1670s and 1720 Free Blacks featured prominently at all social levels in the Western Cape and some even owned farms. Griqua and Chariagariqua Khoe people intermarried with white farmers who arrived later in the district. The current population of the greater town area is thus the offspring of freed slaves that were born from the Griqua, the Khoe and white farmers. Pikeville is situated close to the local clinic, but further away from the central town area.

As I entered the village I was met with what is generally observed in South African townships: small groups of adults and youth who gathered on street corners or at the back of a house (signifying that these people are at home and without jobs); signs of dilapidation (street and home infrastructure that needed renovation) and isolation from the centralized business center. Residents seemed relaxed and comfortable. There was a mismatch with the calm in the setting and researcher's initial urgency to get to the root of the FASD problem. This is where the strength of this qualitative enquiry came into play. A qualitative approach allowed me to fill the gaps and add to the existing knowledge on mothers who consume alcohol during pregnancy. This study illuminated the less obvious aspects of the context as well as of the participants. The main attributes of people and the community are discussed below.

#### ***4.1.1.1 People caring for one another***

I was struck by the vibrancy, enthusiasm, and most of all the care for others displayed by this community. The group of mothers who partook in the study exuded tremendous humility. They were not only concerned for their own well-being, but also cared for friends and neighbors in need. I approached the people and the context with an attitude of wanting to get to know the mothers and the community better. This approach offered a comprehensive picture. I took extensive notes from my observations during the research process. The extracts below were taken from my field notes and reflective diary. Participants of the study and the wider community made a lot of effort to show care in how visitors are welcomed. Upon my first visit to her house one of the participants

borrowed glasses from her mother, especially for the meeting that was going to be held at her house. Kato, a 38 year old female participant agreed to participate early in the study and acted as cultural broker in the setting. Kato's husband worked for the general dealer in town. Her husband's employer provided financial and other support to Kato and her husband. A visit to Kato's house was my first exposure to Pikeville:

*"Kato's hair was neatly plaited in 4 squares and she looked very excited. We got into the car and drove towards her mom's home to borrow some glasses. Kato's mom was very friendly. Kato took the four glasses from the display cabinet. I thought that these must have been very special glasses as it looked as if they were not used often. Kato confirmed my suspicions when she said that her brother bought these glasses for her mom's 50th birthday". (Excerpt from reflective dairy, May 2008)*

Later that same day we went to Kato's house for the meeting. I was surprised when I noticed that she had changed the arrangement of her furniture specially in preparation for a meeting with a few women.

*"The house was neat and tidy. Kato even decorated some flowers in two vases. I felt special. Kato went to a lot of trouble to prepare the house for the meeting. I could see that she was the proud woman, mother, wife of this house. (Excerpt from reflective dairy, May 2008)*

I was introduced to some of Kato's other roles - home maker, mother and wife. These roles seemed in contrast with the image of a 38 year old woman who engaged in binge drinking during pregnancy. This was the first time that I appreciated Kato as a person fulfilling all these roles in her home context. She was not only a research 'subject', but a person with many dimensions and responsibilities. After this encounter there was less of a boundary between me as the researcher and Kato as participant. I related to Kato as a person, woman to woman.

The care for other people in the community was evident when neighbors came to ask for food. People who did not have income would share whatever they had with others who had less:

*“hier't eenkeer 'n vrou gekom vir my 'n stukkie kos kom vra. Maar sy't nou net te laat gekom toe's my kossies op. Ek het self nie inkomste nie. Ek lewe ook maar van my ouers af. Ek het vir haar gesê, 'Jy kom nou so laat, ek het nie meer nie.' Toe lyk dit daai vrou wil huil,...”*

*(“Once a woman came to ask me for a piece of food. But she came too late because I had just finished my food. I don't have an income either. I depend on my parents. I told her: 'You've come too late, I don't have anymore.' It looked as if that woman wanted to cry...”)* (Second interview with Jane)

Jane, a central figure in the lives of the many young women who lived in a small accommodation settlement similar to Pikeville, took care of one of her neighbors who lived with HIV/AIDS. Jane visited this woman regularly before she passed away shortly after the birth of her baby:

*“En ... ek het gegaan tot by haar ... ek het al my ... ek het opgeoffer teenoor haar. Ek het vir haar groente gekoop, al die gesonde kosse het ek vir haar gekook. Net om dit te vermy laat die babatjie nie dit [HIV/VIGS] kan kry nie.”*

*(“And... I went up to her... all my... I sacrificed it for her. I bought her some vegetables; I cooked all the healthy foods for her... Just to avoid [prevent] the baby from getting it [HIV/AIDS]”).* (Group Interview one with mother in Pikeville)

Younger participants, for example Johanna, an unemployed mother of three, who lived in a shack aspired to be like one of the older woman (Jane) who found ways of sharing the little resources and food she had. With the quote below Johanna suggested that the older you become in this community the more resourceful you are:

*“op die ouderdom...maar is mos nou nie laat ek genoeg het laat ek vir die mense ook 'n ding of twee kan doen nie. As ek gehad het, sou ek enige tyd dit gedoen [vir ander mense gegee wat hulle nodig het] het. Maar ek het ook mos nou nie. Ek moet ook maar kyk waarvan af myne vandag of môre kom.”*

*(“At the age... but it's not like I have enough in order to do one or two things for other people. If I did, I would've done it [given people what they need] anytime. But I don't have either. I also have to look and see where mine will come from today or tomorrow.”)* (Group Interview one with mother in Pikeville)

Even limited space is not spared. I noted how Evora, who lived in a 2 roomed house, provided accommodation for a homeless man:

*“Evora recently took in a homeless person (a male), who is sleeping in the kitchen on a mattress. She said that when this person asked her for a place to stay she just couldn't say no, especially in this cold weather” (Field Journal, June 2008)*

Wilma, a 23 year old mother of two, engaged in binge drinking during her first pregnancy. She shared how her mother provided support and care for both her and her first child, soon after the birth:

*“...as die kind nie dit het nie dan vra ek vir mamma as my kind iets nodig het nie. En ek weet nou nie eers wat om te koop nie.”*

*(“... if the child doesn't have it then I ask mamma if my child needs anything. And I don't even know what to buy now.”) (Second individual interview with Wilma)*

Martha, a mother of three, was living with and caring for her parents at the time of the research. She received most of their financial support from family members. She recalled her first pregnancy and the time following the birth. Her family offered support despite of their own need:

*“Toe't my ma en pa so gesukkel, so gesukkel... En my suster - twee susters wat ek het - hulle het vir my gesôre. En die dag toe ek nou klaarmaak, die Dinsdag ... kwart oor drie het Mamma daar gekom. Toe's ons vroeër klaar. Kwart oor tien het ek vir haar gekry. Mamma ... het my kind se geld kom gee, die honderd rand. Mamma't vir my kind nog nappies gekoop, weggooi nappies. En ek het [geen toiletware] gehad nie. Ek het nie [’n vars stel klere] gehad nie. Daai het my ma als vir my gekoop. Ek ... ek maak ook nie staat op myself nie. Ek maak staat op my ma en my pa, want niemand anders help vir my nie, net my ma en my pa.”*

*(“Then my mother and father struggled so much, struggled so much... And my sister – two sisters that I have – they cared for me. And the day I finished, the Tuesday... quarter past three Mamma came there. We finished earlier. I got her quarter past ten [the baby was born at quarter past ten]. Mamma... came to give me my child's money, the hundred rand. Mamma still bought my child some nappies, disposable nappies. And I didn't have any [toiletries]. I didn't have a [fresh*

*pair of clothes]. My mother bought all of that for me. I... don't depend on myself. I depend on my mother and father because nobody else helps me except my mother and father.”) (First individual interview with Martha)*

The above quotes show how limited resources are from which the people in this community draw. In general resources are stretched beyond capacity. It was remarkable that even if people had limited resources from which to make a living, there was always something left to spare for someone else in need.

#### **4.1.1.2 Not too much crime**

In comparison to other townships in South Africa, the town in which Pikeville is situated is fairly safe. Although the other participants did not particularly refer to crime in this community, it does not mean that this is not an important consideration within the research context. Rony the councilor was the only participant who claimed that crime was not a problem in Pikeville and surrounding areas. His response was in contradiction to what female participants shared regarding domestic violence. The quote below shows that he mainly referred to organized crime and the quote demonstrates how he restricts his comments to gangs in the area:

*“wat vir my positief is dat [die dorp] nie so hoë misdaad syfer nie...oor die algemeen is [dit] 'n rustige dorp. Jy kan saans laat buite loop jy kan saans buite op die stoep nog slaap wat vir my sê dis rustig daar's nie daai skolli element...ons sit nie eens met bendes op [die dorp] ....”*

*(“What's positive for me is that [the town] doesn't have such a high crime rate... in general, [This] is a quiet town. You can walk around late at night. You can still sleep on the stoep at night, which tells me that it's peaceful. There's not that gangster element... we don't even have gangsters in [this town]...”)*

In the quote below he minimizes illegal sales of alcohol even if criminal activities were starting to take root in one of the prominent problem spots in Pikeville and surrounding town areas, namely illegal taverns. Crime syndicates were increasingly targeting taverns as set-off points for drugs:

*“Jy het nou jou mense wat onwettig alkohol verkoop of miskien dwelms verkoop maar dis ook in die kleine...”*

*(“You do get people who sell alcohol illegally or maybe sell drugs but that’s in the least...”)*

Rony further suggested that the close collaboration between the police and the community forum curbs criminal activities:

*Daai’s alles wat dit vir my positief maak dat daar is beheer deur die polisie en die gemeenskapsforum oor die elemente.*

*(“All of these make it positive and the police and the community forum have control over these elements”)*

Without accounting for domestic and interpersonal violence Rony claimed that police in the area have control over crime in Pikeville.

#### ***4.1.1.3 Variety of organizations***

As a service provider, Rony saw the benefit of having a number of organizations that focus on a variety of issues in the community. He said:

*“...nou ek dink...’n plek of ’n dorp wat organisasies het wil vir my sê dis ’n dorp wat verstaan dat jy georganiseer moet wees. Uhm om iets te wil doen. En so dit wys dat [die dorp] met sy baie organisasies, dit wys die attitude wat die mense het...dis ’n attitude van ons verstaan dat ons dit nie op ons eie kan doen nie ons het ander mense [nodig].”*

*(“... Now I’m thinking... a place or a town that has organizations is a town that understands that you have to be organized. Uhm to want to do something. So this shows that [the town] with all of its organizations, it shows people’s attitudes... it’s an attitude that shows that we understand that we can’t do it on our own and that we [need] other people.”)*

He went ahead and identified a few organizations that are involved with valuable work in the community:

*“En 'n organisasie waar daar is doen goeie werk in die gemeenskap. Uhm...As ek byvoorbeeld nou vat die die die homebased care program. Ek dink die home based care program doen baie goeie werk. In die gemeenskap...jong mense wat betrokke is in die program ...wat uitgaan en wat 'n diens doen vir vir siek siek siek en kranklike mense in die gemeenskap. So home based care is onder andere een van die programme. So is daar ook ander programme wat baie goed werk. Die volwasse onderrig...uhm, program wat deur deur die skool wat deur Gillian van Loweren<sup>40</sup> aangebied word, uhm wat ook baie goeie werk doen. As ek byvoorbeeld vat die die bestuurder van die volwasse onderrig groep was aangewys verlede jaar as die beste volwasse onderrig uhm persoon in die land verlede jaar. So dit is die kaliber van mense wat sodra hulle georganiseer is dan styg mense regtig uit...uhm en mense werk baie baie nice in 'n groepverband saam. So, dis 'n goeie goeie ding. Gillian van Loweren werk met gestremdes ook.”*

*(“And an organization there does good work in the community. Uhm... If I take the home-based care program as an example ... (pause).. I think the home-based care program does very good work. In the community... young people that are involved in the program... who go out and deliver a service to sick and frail people in the community. So, home-based care [is] amongst these programs. There are other programs that work very well too. The adult basic education and training... uhm program presented by Gillian van Loweren at the school uhm also does good work. For instance, the manager of the adult basic education and training group was named the best candidate in the country last year. So this caliber of people really rise up once they're organized uhm and people work very well together in group contexts. So this is a good thing. Gillian van Loweren also work with the disabled.”)*

It is noteworthy that Rony emphasized the value of medically oriented programs such as home-based programs and education based programs such as the adult basic education and training program. Unfortunately, none of these organizations or programs directly addressed any of the specific needs of women and mothers in this community. While the organizations mentioned were having a positive effect in general, their usefulness in combating FASD was certainly limited.

The mismatch between what is available and what women need in order to support a healthy pregnancy has to be taken into consideration when developing sustainable prevention strategies for FASD. While existing efforts of individuals, groups and organizations should be acknowledged, any attempt to ensure sobriety during pregnancy

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<sup>40</sup> pseudonym

may be effectively undermined by the impact of other structural factors in this context. The following two headings speak to the issues relating to structural factors that participants described as limiting their possibilities for pursuing occupations that would enhance and maintain health and well-being during pregnancy.

#### ***4.1.1.4 Living in a RDP house***

Some RDP houses were expanded into larger homes. Kato was one of the few residents who lived in an extended RDP house. The physical structures and the spaces inside the home environment and around the research community are of great significance in this study. The government funded homes in which all the participants lived measure between 36m<sup>2</sup> and 40m<sup>2</sup> (Cape Business news, 2012) and pose challenges to adult privacy. The space inside the house is very limited and the way in which the homes were constructed (the type and quality of material and the design of the space) makes it difficult to utilize spaces in the ways that are often needed by participants. The original houses were built according to the council house style. A vast extension of RDP housing was established since the beginning of 1994.

*“[Kato’s] house was surrounded by a solid brick fence. It looked very secure and stood out among the rest of the houses that only had wire fencing. Kato’s house also had a secure gate that locked with a chain and padlock”.*

*(Researcher’s reflective dairy, 21 May 2008)*

Kato had a larger plot than her neighbors, and unlike all the other RDP houses there was more than enough space to extend the building should they need to. What would commonly happen in this community is that if people did not qualify for RDP houses they would arrange with family or friends to erect a ‘wendy house’ (a housing structure build from wood) in the backyard of the family member. A ‘wendy house’ operates as a normal house with different rooms or areas such as a kitchen, a lounge and a bedroom. Wanda, a 27 year old mother of three children, lived with her boyfriend in a ‘wendy house’ in the backyard of her aunt’s house. A description of her house follows:

*"This 5m<sup>2</sup> 'wendy house' was divided into three areas. As you enter the house you stepped into a [small] kitchen area with a kitchen cupboard, a table with a container of water on the table and another cupboard on the opposite side of the room. As you walked further into the house the next area was the lounge with a two seater couch. Speakers were propped against the wall. This was my second visit to Wanda and Rudy's house and each time there was very nice music playing in the background. Rudy had a good taste for music and the variety of songs that he was playing was pleasant. The last area of the house was the bedroom. It was so neat you would never say that there was a newborn baby in this house. In the one corner there was a DVD player, a CD player and a TV set neatly stacked. The house was small but well equipped."*

*(Researcher's reflective notes, 18 February 2008)*

A large number of female participants lived in an accommodation camp just outside Pikeville. This accommodation camp was constructed as temporary accommodation for construction workers. A few months after the construction workers moved out local homeless residents moved into the empty structures and have been living there for the past five years. The site consists of 22 fiber board 'wendy houses' which are located one meter apart from each other. During the early stages of the research I made the following entry in my diary:

*"These houses felt particularly cold on such rainy days. It's dark inside and people sit behind closed doors in the rainy weather. I got the smell of dirty clothes and damp bed sheets where I stood at the door. I think that the best place to be on a day like this and in a house like this one is in bed, under the sheets. And this is literally where many of the residents in this village spend their winter days. Children cannot play outside since there are huge puddles of water between the homes. We had to jump over some of these puddles to get to Nikki's mom's house".*

*(Researcher's reflective dairy, 21 May 2008)*

The dirt roads that connect the homes in the areas in which the research was done were generally inaccessible for vehicles during the winter months as puddles of stagnant water filled the roads for days on end. It was clear that the physical home structures did not only present restrictions on the residents' mobility around the camp and access to it, it was also a breeding ground for disease.

### Hoe lê mens in 'n RDP huis? (How does one lie down in a RDP house?)

One of the major problems with this type of accommodation was the limited space. RDP houses and the 'wendy houses' in which people lived had very little space and no privacy. Lorna, a 43 year old sister at the local clinic, made the following comment:

*“Die ander iets is weer...mmm as ons vat ons huise wat gebou is in ons gemeenskappe. Ek bedoel dis vir my so ongesond om in 'n HOP huis te bly. Waar twee, drie gesinne bly. Dan praat ons soos grootmense en dan se ons as daar 'n ma en 'n pa in 'n huis is wat getroud is, is die mense seksueel aktief? Want hoe lê jy in een huis? ... ek meen maar. Daai mense kan nie hulle drange of whatever hulle wil doen of hoekom moet hulle buitekant gaan? So as ons weer die vraag vra: Hoekom is ons kinders so vroeg seksueel aktief? Want die kinders sien dit daar”*

*(“The other thing again...mmm if we take our houses that are being built in our communities. I mean, for me it is so unhealthy to live in a RDP house! Where two, three families live. Then we talk like adults and then, let's say there are a mother and a father in a family who are married, are they sexually active? Because how do you lie in one house? I mean...Those people cannot see to their urges or whatever they do or why should they go outside? So if we ask the question again: Why are our children sexually active so early in life? Then it's because they see it there...”)*

The above quote speaks not only to how relationships between partners are impacted by the little space. This quote also highlights Lorna's concern about exposure to and sexual engagement of children early in life.

Another concern is about the spread of communicable diseases in the crowded space offered by RDP houses:

*“Another problem is the size of the RDP housing. More and smaller RDP houses are being erected and this is the breeding ground for social and medical problems. The small space (one-roomed houses) makes it impossible to create any private space where individuals can escape from the chaotic family life. There are not bathroom and toilet facilities and people wash in buckets. Privacy is out of the question. These HOP houses are overcrowded and a good breeding space for tuberculosis.” (Reflective notes on conversation with Lorna)*

Martha's grandmother stayed with her forty year old daughter (Lena) and her six year old granddaughter. I reported on how she uses spaces in ways that are generally uncommon for people who are used to living in larger homes:

*"Lena was sitting and doing washing in the bedroom area. This was a two roomed RDP house with one large room that was divided into a bedroom area, a kitchen area and a loose standing bookshelf was positioned next to the door. The smaller room, into which I could not see, looked like a toilet or bathroom."*

It was even challenging to arrange a meeting in one of the participant's homes:

*"The arrangement of chairs stretched from just next to the kitchen table, next to the door through which we entered, along the short wall, in front of the kitchen cupboard, past the entrance, to another room. (This entrance was covered by a curtain, which also served as a door to that room.) One last chair fitted in just in front of the medium-sized fridge. Next to the fridge was a single bed that stretched down to the other wall. Four women fitted onto this bed. There were a total of nine women in this tiny space for this first meeting".*

*(Researcher's reflective notes, 18 February 2008)*

#### ***4.1.1.5 Life in Pikeville is a struggle***

This section describes issues related to the income status, participation and limited or no access to alternative financial resources. Family members from previous generations have commonly been recruited as seasonal farm workers. As a result of the low levels of education unemployment is pervasive. There is a great reliance on old age pensions, child care dependency grants or disability grants of family members. This phenomenon is common within the South African context. Dan said the following:

*"['n] Groot groep mense [in Pikeville] sukkel, hulle kry swaar"*

*("[A] great number of people [in Pikeville] struggle, they are having a hard time")*

Joan is one such person who confirmed Dan's statement:

*“Omdat my ouers my uit die skool uitgehaal het vir swaarkry, ...[het ek] maar gaan werk op my ouderdom van veertien jaar oud, het ek toe beginne werk.”*

*(“Because my parents took me out of school... I started working at the age of fourteen years.”)*

While Joan is only one of the many individuals who have similar stories in this community, the result of low educational levels can be seen in the type of low-skilled, low-paid jobs that are available to most of the working age adults in this community (London, 2003).

#### Little or no income

Joan is a 38 year old woman who lives in a temporary house in the accommodation camp outside Pikeville. She lost her house in the village when she became unemployed. She stopped working as a farm laborer when she injured her back at work and needed back surgery. She has since been on a temporary government disability grant. She explains how she stretches her grant to make it through the month:

*“maar jy kry nou daai min geld en byvoorbeeld háár ma (wys na ander vrou). Hulle kry nou, daai pension kry hulle mos nou.En dan gaan daai pension mos nou uit, want dis dak wat moet betaal raak, né? En ons maak mos nie hier en daar maak ons mos nou ‘n los skuldjie, ‘n aartappeltjie wat ‘n mens nou by daai ene kry op rekening tot daai tyd toe. Sien jy? Nou daai geld wat jy nou op daai dag ontvang gaan maar uit. In die middel van, sê maar nou die next dag, dan het jy niks nie.”*

*(“But you get that little money and for example her mom (point to other woman) they get that pension. Then they spend the pension because they pay for accommodation. Then we make debt here and there, a potato that one gets on the book from someone until a certain time. You see? Now, the money you get on that day goes just like that. In the middle of, say, the next day, then you've got nothing left.”)*

Joan further explained the predicament of workers who are employed but their income is so little that it hardly begins to cover the personal needs of the working individual, let alone providing for the needs of dependents:

*“Hier in ons omgewing is baie mense wat swaarkry, wat se inkomste minder is verstaan, hulle werksiklus, maar watter salaris? Wat kan jy maak met ‘n R250? Wat maak jy? Jy het net kos tot Sondag. Wat van die persoon se kinders, ly daaronder deur want is ‘n skoolgaande kind. Verstaan? Wel gee die skool voeding, maar wat van by die huis?”*

*(“A lot of people struggle in our area; their income is small, [as well as] their work cycle but for what salary? What can you do with a R250? What do you do [with it]? You’ll only have food till Sunday. What about that person’s children who are the ones that suffer the most really because they still go to school? Understand? The school does feed them but what happens at home?”)*

Martha, a 35 year old mother and sole provider of three children left school before completing grade six. She recalled leaving school to earn an income to supplement the family income. She did not work as a farm laborer for long, but managed to secure a casual job at the local carwash. She had never had a permanent job since she started her working career. Her only consistent income was the child care grants of her three children:

*“Ek kry R600, R600 van die kinders en as ek ... ek werk hier by die car wash agter die garage. Nou ... is nie ‘n vaste werk wat ek het nie ... Ek moet gephone word as ek moet werk. Ek werk nie elke dag nie (inaudible phrase) ... laerskool en die babatjie is in die crèche. Ek is al ene wat sôre vir hulle.”*

*(“I get R600, R600 for the children and if I... I work at the car wash behind the garage. So... it’s not a permanent job... I get a call whenever they need me to work. I don’t work every day (inaudible phrase)... primary school and the baby is at the crèche. I’m their sole provider.”)*

The above quotes show how the available job opportunities were not enough for the number of people who needed work. For some participants it was contestable whether they would be able to secure a job of any kind and retain it, without the appropriate treatment and support for their alcohol dependence. These conditions were exacerbated by the chronic, structural poverty that sets the tone for their existence in this community. The challenges mentioned in this section partly contribute to the struggle participants were experiencing. The last section captures service providers’ perspectives on problematic alcohol use in relation to the challenges mentioned in the above section.

#### *4.1.1.6 Alcohol abuse only a symptom*

Dan understood the dynamics of excessive drinking in the family as well as in the community too well. He emphasized the importance of seeing the problematic alcohol consumption in perspective. He believed that alcohol abuse was only a symptom of the problems that are prevalent in the greater society and how these problems impact on a small, rural community like this one:

*“Ja, kyk die problem is die symptoms van die [eintlike] problem. Dis obviously drankmisbruik en dit is, you know, teenage pregnancy en dis ander klomp goeters, you know?”*

*[“Yes, look the problem [of FAS] is the symptoms of the [actual] problem...it’s obviously alcohol abuse and it is, you know, teenage pregnancy and it’s a whole lot of other things, you know?”]*

He continued by stating that the issues around FASD have been misread by health personnel and government officials. FASD is a universal problem and should not be associated with a specific ethnic group:

*“In die eenkant kry ons nou baie experience in die actual data goeters, maar aan die ander kant sou ons wou sê ons moenie laat skade aan die mense en uh... - in die sense van daai man, you know, soos statistieke oral, fetale alkohol word gemis-’read’ en so aan. En dan word dit gekoppel byvoorbeeld aan ‘n ras. Dit word gekoppel aan ‘n kultuurgroep of word gekoppel aan dit en so aan.”*

*(“On the one hand we gain a lot of experience with the actual those things but on the other hand we want to say that it shouldn’t cause any damage to people and uh... in the case of that man, you know, like statistics Everywhere, fetal alcohol are being misread and so on. And then it’s associated with a particular race for instance. It’s associated with a cultural group or with that and so on.”)*

Rony, the local councilor suggested that the role of the economy and history should not be ignored:

*“Uhm maar nou ja, praat van armoede en swaarkry in relation tot morele verval en goed soos fetale alkohol sindroom, dit het dalk 'n baring, maar ek...dis hoekom ek gesê het aan die begin dat die ekonomie bepaal die samelewing. (The causes of alcohol abuse) As jy vat baie van ons mense nog steeds daar buite sit met die resultaat van hoe hulle betaal was in die verlede, met*

wyn bedoel ek op die plase. Uhm nou baie van ons wil verstaan ja maar dis al verby ons praat van tien jaar twintig jaar terug. Wat gebeur het het gebeur en daar is uitsonderlike gevalle vandag. Maar die resultaat van daai [dopstelsel] is nog steeds daar want daar is kinders wat gebore is in daai situasie. [Wyn drink] is al wat jy het vir recreational fasiliteit. Daar is niks anders wat jy doen..dis dalk 'n ander ander ander...'angle' tot die storie.”

*(“Uhm but yes, speaking of poverty and struggling to make a living in relation to moral decay and stuff like fetal alcohol syndrome, it might have a bearing but I... that’s why I said at the beginning that the economy determines society. (The cause of alcohol abuse) You should consider that a lot of our people still sit with the result of how they were paid in the past, I mean with alcohol on farms. Uhm a lot of us want to understand [argue] that it’s over and that it happened ten or twenty years ago. What happened happened and there are exceptional cases today. But the result of that [‘dop’ system] is still there because there are children who are born into that situation. Children grew up with this: our mother and father work for wine so today our young people go out to work and make money to buy wine. That’s the only recreational facility you have. There’s nothing else you can do... perhaps this is a different ... angle to the story.”)*

I echoed this perspective in the following field note entry:

*“From the stories I could pick up that fetal alcohol syndrome (and excessive drinking patterns) was a very, very small part of all the numerous problems these women had to face. There were issues of verbal and physical abuse between mothers and children, food insecurities, financial shortages, misuse of social grants, child abuse .... The list goes on and on .... Suddenly I felt embarrassed, as if I was trying to tackle a minute problem in the midst of such disturbing and miserable conditions. How do I address FASD if all these other issues are interrelated? You cannot attempt to solve one without touching on the other..., all these [other] problems aggravate the problem of FASD”*  
*(Researcher’s reflective notes, 21May 2008)*

The last two quotes emphasize the need for taking a different perspective to FASD and its prevention.

#### **4.1.2 Background information on participants**

The section that follows provides a detailed description of each participant in terms of their position in the research context, age, onset of drinking, parity, alcohol consumption

during pregnancy, marital status and current alcohol status. Table 3 introduces the mothers who consumed alcohol before, during and after their pregnancies. Wanda's partner (Rob) is also the father of her children. All the mothers who participated were encouraged to bring a partner, friend or family members. Except for Wanda, the rest of the mothers invited a friend.

Table 4 provides information on the service providers who participated in the study. Although the majority of participants were mothers and fewer participants were service providers it is useful to note the issues that the different groups of participants discussed. Service providers tended to comment extensively on service issues and on issues related to the current developmental aspects of Pikeville community. Mothers on the other hand, told stories that detailed their alcohol use practices. Only some of the mothers made suggestions for a possible new way of approaching FASD prevention. Quotes are provided under each heading to provide the reader with a description of each one of the groups. The quotes within this section also assist the reader in positioning each participant group in relation to maternal alcohol consumption, the drinking mother and other FASD related issues.

**Table 3: Information on mothers**

Pseudonym	Role in the research	Age	Onset of drinking	Parity	History of alcohol use	Marital status	Current alcohol status	Additional information	Interview setting/Number of interviews/Type
Wilma	Participant referred by clinic staff.	23	14	2- Pregnant with second child.	Used to binge drink during first pregnancy. Stopped drinking when she discovered she was two months pregnant with her second child.	Single parent never married, lived with partner during second pregnancy	Stopped using alcohol when she discovered she was 2 months pregnant	Attended two interviews. Was pregnant with second child at the time of data collection. Was very excited about second pregnancy. Preferred not to involve her partner or a family member.	Local clinic/2/Individual
Martha	Participant referred by clinic staff.	34	13	3	Used to binge drink during all three pregnancies.	Single parent, never married, lived with parents	Alcoholic	Attended one interview. Provided rich information on her experience as drinking mother. Preferred not to involve her partner or a family member	Local clinic/1/Individual
Kato	Cultural Broker no.2	38	13	3. Two of her children died shortly after birth.	Used to binge drink during all pregnancies.	Married	Used to drink excessively with husband and friends.	Attended three interviews. Was keen to start mobilizing women in the neighborhood for FASD prevention.	Local clinic/1/Group/At neighbor's house/2/Group

**Table 3: Information on mothers (continued)**

Wanda	27	13	3	Used to binge drink during all three pregnancies	Never been married. Lives in a 'wendy house' in her grandmother's backyard with Rob and three children.	Still occasionally abusing alcohol with her mother and aunts	Attended three interviews. Wanda was also one of the women referred by clinic staff. She was the only participant from this group who invited her partner after the first interview.	Local clinic/1/with partner Couple's home./2/One interview with partner and one interview individual
Rob	33	14	2	Used to binge drink and used drugs during two pregnancies	Never been married. Lives with Wanda	Occasionally drinks with the rest of the family	Attended two interviews. Found job out of town after second interview	Local clinic/1/with partner Home/1/with partner
Lena	40	Unknown	1	Unknown	Never been married. She took care of her 70 year old mother (Martha's grandmother).	Binge drinks frequently.		

<sup>41</sup> A **cultural broker** is a person who facilitates access of the researcher into the research community; usually a well known person who knows a large portion of the research participants involved.

*Table 3: Information on mothers (continued)*

Pseudonym	Role in the research	Age	Onset of drinking	Parity	History of Alcohol use	Marital status	Current alcohol status	Additional information	Interview setting/ Number of interviews/ Type
Girty	Participant	45	17	1	Used to binge drink during pregnancy	Single	Alcoholic	Attended one interview. Fell pregnant because of rape. Had an emotional interview. She moved to another farm and could not be followed up because contact was lost.	Local clinic/1/Group
Danelle	Invited by Kato as a friend.	21	12	1	Occasionally binged on alcohol during pregnancy.	Single	Used to drink occasionally at functions.	Attended four interviews. She was recruited by Kato. Had difficulty in falling pregnant with second child.	Local clinic/1/Group At neighbor's house/3/Group
Sandy	Participant	21	17	Pregnant with first child.	Uses alcohol occasionally during pregnancy.	Lives with partner.	Uses alcohol occasionally during pregnancy	Attended one interview. Abused by her partner who threatened her to make her stop birth control. Lost contact – no follow-up.	Local clinic/1/Group
Hettie	Cultural broker no.3 – introduced by pastor.	23	14	Pregnant with first child.	Used to binge drink on occasion.	Lives with partner. Never been married.	Used to drink occasionally.	Attended two interviews. Softly spoken and shy. Caring nature.	At neighbor's house/2/Group

**Table 3: Information on mothers (continued)**

Jane	Matriarchal figure in Pikeville community – invited by Hettie.	45	Unknown	2 adult children	Unknown	Lives with partner, never been married.	Used to drink occasionally with the women in the village.	Attended two interviews. Often acted as spokesperson for the group in her settlement.	Own home/1 At neighbor's house/2/ Group
Johanna	Participant – invited by Hettie.	36	Unknown	3	Unknown	Lives with partner.	Drinks regularly with other women in village.		At neighbor's house/2/ Group
Lisa	Participant – invited by Hettie.	19	N/A	Pregnant with first child.	No alcohol	Never been married, lives with partner.	No alcohol	Youngest in the group.	At neighbor's house/2/ Group
Evora	Matriarchal figure in Pikeville community – invited by Kato.	63	17	3	Used to binge drink with all three pregnancies.	Single, never married.	No alcohol	Attended two interviews. Cared for elderly parents. Parents have since passed on. Currently caring for her 2 grandchildren. She was a drinker when pregnant with her daughter. Her daughter is currently an alcoholic and unable to care for her own children.	Own home/2/Group
Jenna	Participant – invited by Hettie.	20	N/A	1	No alcohol	Single, lives with mother.	No alcohol	Attended 2 interviews. One of the younger women in the village.	At neighbor's house/2/Group

#### *4.1.2.1 Mothers*

The first group of participants consisted of mothers who consumed alcohol in previous pregnancies or who used alcohol during their pregnancies at the time that the research was done. They were referred by the clinic staff. Screening interviews were held to determine whether participants were willing to share on this topic and whether they were information rich<sup>42</sup>. Screening interviews were followed up with in-depth individual interviews during which participants were encouraged to invite a partner or family member for follow-up interviews. Wanda also invited me to her house. She introduced me to other family members such as her mother, her aunt and her grandmother. No formal interviews were held with these family members, but all observations were recorded in a field diary.

The next group of women who were referred by clinic staff was interviewed in a group. Kato was part of this group of women (details reflected in Table 3). Later in the research process Kato requested me to address a group of women at her house. Kato took on the role of cultural broker in this instance and introduced me to other women in the community. The purpose of these meetings was for grandmothers to share their personal stories of alcohol consumption during pregnancy. These women also showed interest in mobilizing other women in the community to support young pregnant mothers. Details of these women are not presented in this thesis as this process was separate to the research process. Upon the women's request the discussions at these meetings were also not recorded on tape. The women gave permission to make notes and use my observations to inform the research.

Except for Girty and Sandy all the mothers in Table 3 were interviewed at their own homes or the home of their neighbor. The local pastor introduced me to Hettie, who invited fourteen women to the first group interview. Only five of the women showed interest in attending follow-up interviews. All the participants from this group were drinking mothers who lived in Pikeville and in the accommodation camp just outside Pikeville. I spent time in the homes and social spaces of these women (Refer to Chapter

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<sup>42</sup> Information rich participants are able to share stories that are 'rich' in information that relates to the research topic. A screening interview would consist of questions related to the research topic. If a participant shares stories that would provide 'rich' data that would offer thick descriptions to the research topic, this participant is described as information rich and would be invited for a follow-up interview.

Three for detail). The mothers made use of clinic services. The clinic was the nearest point of access to health service for women. In the following quote Jane suggested that many parents know that alcohol use during pregnancy is not good for the baby:

*“Daarom sê ek alkohol... Baie ouers ... hulle is swanger dan weet hulle hulle gebruik verkeerde goeters.”*

*(“That’s why I say alcohol...many parents...they are pregnant then they know that they are using wrong things.”)*

She further explains that younger women may not be deterred from drinking if there are no visible effects immediately after birth...

*“Soos jong mense dan drink hulle. Maar partykeers het die kind niks oor nie, maar mens weet nooit as jou kind ouer raak nie.”*

*(“Like the youngsters they drink. But sometimes the child does not show anything, but you never know when the child grows older.”)*

Although she was not very specific, Jane showed awareness that a child who had been exposed to alcohol prenatally may encounter problems when s/he grows older. The fact that some women who drink alcohol during pregnancy cannot see apparent disabilities of children at birth may have to be considered when planning prevention campaigns.

Some of the participants like Wilma and Danelle stopped drinking as soon as they realized they were pregnant. Others like Wanda and Martha continued for different reasons. I noted the following quote in my field diary after a conversation with Danelle:

*“...she had heard that it is desirable to stop drinking alcohol during pregnancy, but she doesn’t know why [she should stop drinking]”*

After interviewing all the mothers it was clear that all of them knew that alcohol use during pregnancy was not desirable. The few women who did comment on this fact (Wilma, Martha, Danelle and Jane) only went as far as stating that they were aware of this. They did not offer any explanations of why women continued drinking during pregnancy despite knowing.

#### *4.1.2.2 Partner/friend of mothers who consume alcohol*

##### Partner

Rob was the only male partner who participated in the study. The fact that Wanda was the only woman who invited her partner was significant in the sense that it raised questions about the role of male partners and the fathers of the affected children. Without suggesting that the female participants did not trust their partners, it was clear that these mothers invited somebody along whom they could trust. As part of an empowering research process it was important to provide these mothers with an opportunity to choose who this person would be. As the only male partner Rob made a few comments that came across as judgmental. He claimed to be aware of the dangers of prenatal alcohol consumption, but did little to support Wanda to stop drinking while she was pregnant.

During the first interview Rob said the following:

*“Ek bly vir haar sê sy moet ophou drink want sy’s swanger.”*

*(“I keep telling her that she should not drink because she's pregnant.”)*

Although Rob expressed his concern for Wanda’s drinking habits during her pregnancy he continued to drink and therefore did not show much support for her in abstaining from alcohol. He expected her to stop drinking but did not commit to changing his own drinking practices in support of her. According to his understanding Wanda just needed to make a decision to stop drinking.

*“Ek kan haar nie **force** (emphasizes word) om op te hou nie...sy moet die besluit maak!*

*(“I cannot **force** (emphasizes word) her to stop...she has to make that decision!”)*

The next quote shows Rob and Wanda to be drinking partners. For a while Rob considered the impact of his drinking habits on Wanda’s. He wondered whether reducing his alcohol intake would help Wanda to drink less, and vice versa:

*“Ek kan miskien iets doen om haar te support. As ek totaal ophou...miskien sal sy ok minder drink...en miskien heeltemal los...Dit werk altwee kante toe. As sy ophou drink, sal ek ok later miskien ophou...en so...”*

*(“Maybe I can do something to support her. If I stopped drinking completely, maybe she will drink less and ultimately stop altogether. It works both ways. If she drinks less and eventually stops, maybe I also stop later...and so forth....”)*

## Friend

Kato introduced me to Evora, her friend. After Kato gave a short explanation of what fetal alcohol spectrum disorder was and what the research was about Evora shared her personal experience with alcohol consumption during her pregnancies. I derived from her stories that Evora’s two adult children were possibly also affected by alcohol. She told us about her challenges of raising her daughter’s children (2-year old son and 6-year old daughter), who were also prenatally affected by alcohol. Evora’s daughter fell pregnant while she was still in grade nine and not ready to assume the responsibilities of a mother and caregiver. These roles inadvertently ended up as Evora’s responsibility. This story showed how a daughter’s excessive alcohol use could place an extra burden on her mother. Besides the responsibility of caring for her grandchildren Evora also looked after her terminally-ill father and her mentally ill sister:

*“Evora started talking about her challenges. She cares for her bedridden father who is a cancer-sufferer. She also takes care of her sister who has a psychiatric [condition]. She also looks after her two grandchildren whose mother is an alcoholic.”*

*(Researcher’s reflective notes, 21 May 2008)*

Evora’s stories of having to look after grandchildren who have been affected by alcohol during and even after pregnancy, during infan[cy] and childhood, evoked questions of what the future held for children who have been affected by alcohol and who live in conditions where they don’t have a grandmother to take care of them.

Just like Evora’s daughter, Wilma also fell pregnant when she was just fifteen years old. Evora did not state whether her daughter stopped drinking alcohol during her pregnancy. After watching an informational DVD on prenatal alcohol consumption and its consequences, Evora could identify some of the behavioral and developmental problems

in her two grandchildren. She was very concerned when she realized that the condition was irreversible.

Just like Evora's daughter, Wilma continued to abuse alcohol during and after the birth of her first child. Wilma explained her experience of how her mother automatically assumed responsibility for her baby:

*"...Ek was nog jonk en my ma-hulle het altyd alles gedoen...stilte...miskien die kind se pa stuur nou geld vir die kind. Dan sê sy (ma): Kom ek sal dorp toe gaan. Ek het nooit daai ervaring van self vir my kind...[te sorg]"*

*[Wilma-interview 1]*

*("...I was still very young and my mother-them always did everything...silence...when the child's father sends money perhaps. Then she (mother) says: I will go to town. I never had the experience of [caring] for my child...")*

*[Wilma-Interview 1]*

#### **4.1.2.3 Service providers**

The significance of the service providers' perspectives was that all of these participants grew up in Pikeville. They experienced similar economic and social pressures. Group interviews with service providers focused on their awareness and perceptions regarding FASD in their community. I also probed for possible root causes of alcohol abuse in the community. Participants from this group shared their views and suggestions for solutions. This group consisted of two nurses who worked at the local clinic, a community development officer, the local councilor of a political party, three adult basic education and training teachers and two youth workers. Information on participants for this group is shown in Table 4. Service providers were not asked about their drinking patterns. Individuals who referred to their own drinking habits volunteered this information.

**Table 4: Information on service providers**

Pseudonym	Role in the research	Age	Onset of drinking	Parity	History of Alcohol during pregnancy	Marital status	Current alcohol status	Additional information	Setting of interviews/ Type
Lorna	Senior sister at Pikeville clinic – referred first number of women for individual and group interviews	43	*	2	No alcohol	Married	No alcohol	Grew up in a missionary town just outside of Pikeville	Local clinic/ Group/2
Amanda	Sister no.2 at Pikeville clinic – referred first number of women for individual and group interviews	35	*	Un-known	Unknown	Un-known	Unknown	Grew up in a different community and has a different socio-political background to participants.	Primary school/ Group/1
Stanley	Community development officer	27	15	Un-known	N/A	Single	No alcohol	Grew up in different town in the district. Has experienced excessive alcohol use in his family	Local clinic/ Group/2
Rony	Local councilor	40	15	3	N/A	Married	Occasionally	Grew up with his grandmother in Pikeville	Local clinic/ Group/2
Sally	Teacher 1 at local adult basic education and training center	50	*	Un-known	Unknown	Un-known	Unknown	Father occasionally used alcohol	Primary school/ Group/1

**Table 4: Information on service providers (continued)**

Pseudonym	Role in research	Age	Onset	Parity	Alcohol during pregnancy	Marital status	Current alcohol status	Additional information	Setting of interviews/ Type/Number of interviews
Dan	Community development worker for FAS prevention NGO. Also a rapper of songs that focus on FASD prevention	32	*	1	None	Married	None	Comes from a family where he experienced excessive alcohol use and domestic violence.	NGO offices/Group/2
Leonie	Community development worker for FAS prevention NGO	23	*	1	None	Single	None	Strong leadership qualities and well-spoken. Comes from a family where strong, stable relationships were maintained.	NGO offices/Group/2
Gillian	Teacher 2: Coordinator of local adult basic education and training center	48	*	3	Unknown	Married	Unknown	Lives and works in Pikeville.	Primary school/Group
Monica	Teacher 3 at local adult basic education and training center	45	*	Unknown	None	Married	None	Lives and works in Pikeville	Primary school/Group

Lorna was fortunate to grow up in a supportive home. She did not comment on whether her parents used alcohol. She never used alcohol excessively as a teenager. She also did not use alcohol during any of her pregnancies. Lorna's parents supported her in furthering her education and gaining her nursing qualification:

*“As ek myself vat op die vlak wat ek begin het sê van opgroei af en 'n mens vat die voordele wat jy gekry het om te gaan studeer..ek het op Wagendal<sup>43</sup> gebly wat vir my plaas is, jy't nie alle voordele gehad nie.”*

*(“When I take myself on the level that I started say since I was small and one takes the opportunities that one got to study further...I lived in Wagendal which is a farm to me, you did not have all the opportunities.”)*

Although she refers to her childhood as a time of getting by with little she realized that she did not have to get stuck on the things that were once part of her reality:

*“...dat 'n mens nie hoef te bly klou aan dit waarvan af jy kom nie,...”*

*(“...that one does not have to cling to that which dictated your life in your past ...”)*

With the above quote Lorna is trying to illustrate how she was able to use her qualifications to escape a life of limited opportunities. It should be noted, though, that Lorna did not mention excessive alcohol use as an issue for her family. The challenges that her family therefore faced might have been markedly different to the issues of alcohol dependence that the drinking mothers in the research had to deal with. When read in relation to alcohol consumption during pregnancy Lorna is saying that with the right amount of resolve these mothers should be able to rise above their circumstances.

#### Development workers from FASed and adult basic education and training teachers

The second group of service providers consisted of a combination of teachers and community development workers. The teachers worked at the local adult basic education and training center based at one of the high schools in town whose clients were mostly

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<sup>43</sup> Pseudonym

adult learners. The community development workers were employed by a non-governmental organization FASed<sup>44</sup> who provided experiential learning FASD programs to grade 6 and 7 learners across the Boland and some parts of the West Coast region.

The three development workers from FASed grew up in different rural towns in the West Coast and in the Boland regions. Although these youth workers grew up in similar communities to Pikeville, they had the opportunity to further their personal development. As a teenager Dan used to binge drink with his friends. He stopped drinking at the age of seventeen (after his father died). He was committed to providing a positive influence in the lives of youth affected by alcohol by involving them in art and music. Dan understood the odds which the drinking mothers in the study were facing too well. These development workers were perceptive and empathetic to the social, economic and political circumstances of women who consume alcohol during pregnancy. However, they were convinced that women who are pregnant have the ability to choose to avoid alcohol during pregnancy. They emphasized the importance of experiential learning and other developmental activities as strategies for breaking the cycle of excessive alcohol use and binge drinking among youth.

While participants from this group lived in the more affluent area, closer to the center of town, a few kilometers outside of Pikeville, the four educators mainly worked with adult learners who lived in Pikeville. These participants discussed the excessive use of alcohol as it took place on a daily basis. Sally was the only participant who shared that her father occasionally drank excessively. In her childhood home alcohol would be freely available and generously used at family celebrations like birthdays or weddings. A common phenomenon at these gatherings would be some family members overindulging on alcohol. This was usually not considered a big problem because it was regarded as social drinking. The participants from the service provider group made a clear distinction between people who drink alcohol responsibly and for their own 'benefit' and those people who would appear drunk in public. For the service providers the act of appearing drunk in public was associated with shameful behavior and showing disrespect for

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<sup>44</sup> FASed is a pseudoname for a nongovernmental organization that offers FAS oriented experiential learning programs to grade six and seven learners in specified areas in the Boland region.

others. Sally's opinion seemed to favor drinking respectfully and in the privacy of your home as opposed to appearing drunk and disrespectful in public.

In addition to understanding the situations, the settings as well as the dynamics of each individual's story, it is also imperative to take note of how the different participant groups positioned themselves in relation to the issues around FASD. It is also important to note that Table 3 presents the drinking mothers who live in Pikeville. Table 4 represents the service providers who are salaried workers and who live outside of Pikeville. This group has a higher socio-economic status than the drinking mothers. These differing positions of power should be taken into consideration when reading Section Two of the findings.

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## 4.2 Section Two

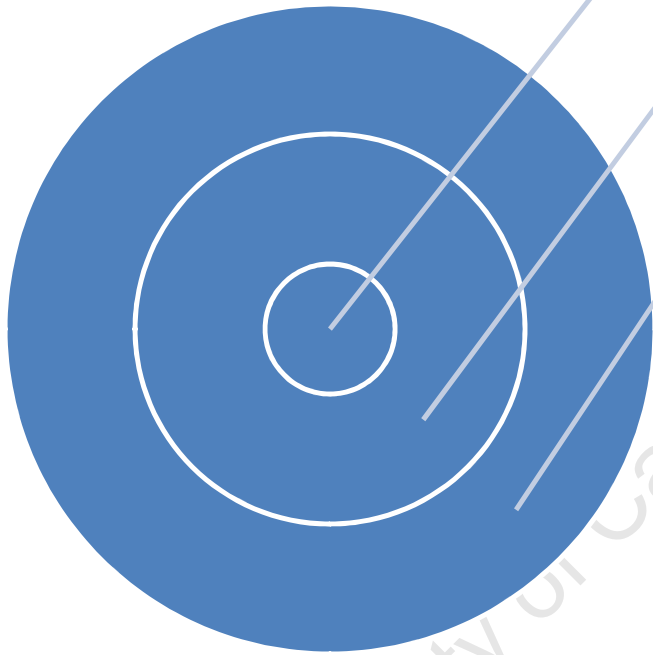
Excessive alcohol use generally generates both shame and stigma. People who are directly and indirectly affected by it are often reluctant to own their contribution to a situation of excessive alcohol use. For this reason I took particular interest in the position that each participant group held in relation to excessive alcohol use and binge drinking during pregnancy in relation to:

- (i) Excessive alcohol use in Pikeville community, in general, and
- (ii) Binge drinking specifically during pregnancy.

Two themes were identified namely: 'Being drunk is the norm'; and 'Ek is 'n drinker en klaar (I am a drinker and that's it). Both themes (as depicted in Figures 4 and 5) should be understood as firmly embedded in the contextual background that was described in Chapter One.

### **Figure 4: Depiction of themes embedded in the context.**

In Figure 4 the contextual background of Pikeville is represented by the outer layer of the concentric circles. The second layer depicts the practices, beliefs and norms of the community. It is at this level that alcohol abuse exists as normalized practice (Theme One - Being drunk is the norm). The innermost circle represents alcohol abuse among women of childbearing age. It also signifies the identities of women who drink during pregnancy (Theme 2 - I am a drinker and that's it!). Theme Two elucidates identities that drinking mothers hold. Identities vary between drinking mothers. The identity of 'drinker' is partly being reinforced by having women as local role models. Besides feeding into the identity of being a drinker, local role models also tie in with the identity of being a mother and caring for others in the community.



THEME 2: Ek is 'n drinker  
en klaar! (I am a drinker  
and that's it!)

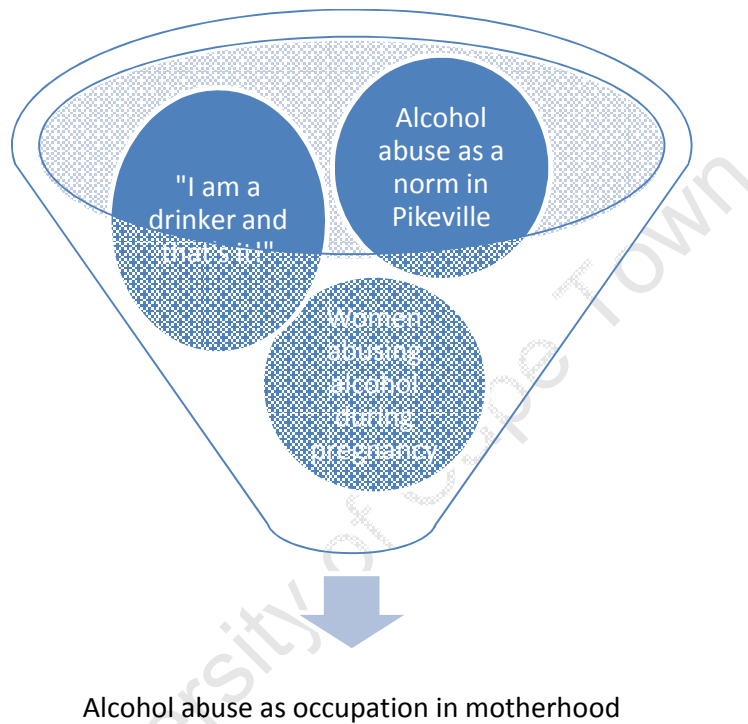
Theme 1: Being drunk is  
the norm

Historical and Socio-  
political factors - alcohol  
abuse as embedded  
imposed occupation

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Figure 5 shows how alcohol abuse as norm in Pikeville and the drinker identities of mothers combine and contribute to alcohol abuse during pregnancy. As a result of contextual enforcement of alcohol abuse this had become an occupation in motherhood.

**Figure 5: Alcohol abuse as occupation in motherhood.**



#### 4.2.1 THEME 1: BEING DRUNK IS THE NORM

Table 5

Theme 1	Category	Subcategory
Being drunk is the norm	<i>Maintaining cycles of excessive alcohol use</i>	A culture of excessive drinking
		Mothers who abuse alcohol

This theme is embedded in the contextual background of Pikeville. Participants spoke about how excessive alcohol use was endemic in this community and has been normalized in the Pikeville. The theme also illustrated how the process of normalizing excessive alcohol use already started in childhood with children having to witness excessive alcohol use by parents. The theme has a specific focus on contextual factors that created circumstances in which some participants were kept in the cycle of excessive alcohol use that was maintained during pregnancy and motherhood.

##### 4.2.1.1 *Maintaining cycles of excessive alcohol use*

Martha, one of the drinking mothers, was dependent on alcohol at the time of the interview. She explained what became apparent as a cycle of excessive alcohol use across generations in her family. When asked about her parents, Martha stated the following:

*“Hulle (my ouers) het baie jare lank toe ek nog nie gebore gewees het nie, het hulle gedrink.”*

*(“They (my parents) drank for many years, long before I was born.”)*

Amanda, a senior nurse who had been working in the clinic with clients who live in Pikeville shared her understanding:

*“...people drink[ing] excessively... Mothers and fathers abuse alcohol, grandmothers and grandfathers [also] abuse alcohol. Children see alcohol abuse all the time and this becomes part of what they see as their existence. Children then abuse alcohol and their children see them and also abuse alcohol - and this [cycle] transfers from generation to generation.”*

The two quotes above are from two different participant groups. Martha, a drinking mother commented in response to a question regarding the drinking practices of her parents. She did not express a link between her parents drinking practices and her own at any time during the interview. On the other hand Amanda made a direct link between the drinking practices of previous generations and the current generation of mothers. Amanda thus claimed to know one cause of alcohol consumption during pregnancy. The only other participant who attempted to reflect on the root causes of FASD was Rony, the local councilor. He identified the root of one (of many) social problems in this community as being 'attitude towards alcohol'. By this he meant the value that some members from this community placed on alcohol and how it was used to serve this value:

“Ek sê nie alcohol is noodwendig die problem nie. Ek sê die attitude towards alcohol is die probleem. Hoe jy dit gebruik...”

(“I’m not saying alcohol is the problem necessarily. I’m saying the attitude towards alcohol is the problem. How you use it...”)

He continued by stating that excessive alcohol use led to a situation in which people from this community were being viewed in a negative light:

*“...die misbruik nie soseer die gebruik van alkohol nie, want mense is seer sekerlik geoorloof om alkohol te gebruik,...maar die misbruik daarvan. Dit is eintlik die kern van van van die saak. En die gevolge wat vloei uit die misbruik...en die partye wat ly onder die misbruik...dit is dit is die goed wat wat wat mos nou maar 'n effek het op 'n samelewing..So die misbruik daarvan [van wyn], dis dit wat so die negatiewiteit na vore bring”*

*(“...the abuse and not so much the use of alcohol because people are certainly permitted to use alcohol,... but the abuse of it. That is actually the core of the matter. And the consequences that flow from the abuse... and the parties who suffer because of the abuse... that is, that is the stuff that that that has an effect on society... So the abuse of it [wine/alcohol], is what brings the negativity to the fore.”)*

The actual question being discussed was “why is excessive alcohol use such a big problem in this community?” Admittedly, this was a difficult question to answer and it becomes even more complex when the solution was linked to the drinking practices of

the individual. In defense of other community members who were responsible drinkers Rony concluded:

*“Jy't sekere jongmense wat drink maar wat nie noodwendig losbandig leef nie en dan het jy ander jongmense wat drink en losbandig is.”*

(“You get certain young people who drink but not necessarily live licentious and then you get other young people who drink and live licentious.”)

*“Jy't regtig mense wat.. sekere jongmense wat 'n mens kry wat alkohol verantwoordelik gebruik.”*

(“You really have people... you get certain young people who use alcohol responsibly.”)

In an interview with Rob, Wanda's partner, he explained how alcohol had been normalized in this community:

*“Mense drink **alewig**. Dit het vir die samelewing aanvaarbaar geword dat mense drink en a spektakel van hulle maak in die openbaar. Jy weet al wie alewig dronk gesien word: Ag, dis Johnny, hy's al weer dronk...”*

(“People drink alcohol **all the time**. It's become socially acceptable for people to drink and to make a spectacle of themselves in public. You already know who would always be drunk: Ag, it's Johnny – he's drunk again...”)

The emphasis that Rob placed on the phrase “all the time” indicated that excessive alcohol use was ever present. This phrase also alluded to how normalized excessive alcohol use was in this context. The two service providers (Rony and Amanda), and two of the participants (Martha and Rob), therefore explained the causes of FASD as a result of individual factors.

#### A culture of excessive alcohol use

During the first meeting with service providers Rony was very concerned and suggested that a lack of positive role models in the Pikeville community was one of the root causes.

Upon asking who the role models in the community were Rony's opinion was that parents were modeling behaviors that supported excessive alcohol use. Below follows a description of what he observed on a daily basis:

*'Daar's kinders wat grootgeword het: ons ma en pa werk vir wyn so vandag werk ons jong mense jy gaan en jy werk en maak geld en koop vir wyn.'*

*("Children grew up with this: our mother and father work for wine so today our young people go out to work and make money to buy wine.")*

Stanley made the following comment regarding positive role models in Pikeville. According to him the people who made positive achievements usually moved out of town to bigger city centers:

*"maar dis soveel keer die geval dat iemand word in die gemeenskap groot, maak 'n lewe vir homself dan beweeg hy uit. Hy kom nooit terug om...(inaudible) so ons kinders in die gemeenskap het nie noodwendig 'n rolmodel wat hier grootgeword het na wie toe hy kan streef nie...dit vat ons terug na die ding as jy iets kan doen dan moet jy uit Pikeville uitgaan jy kan nie hier bly want jy sal kan jou potensiaal hierso kan...jy moet dit daar buite gaan. Dis hoekom, mense wat 'n lewe vir hulleself maak, beweeg liever uit en kom nooit weer terug nie...En dan het jy daai spinoffs van daar is nie rolmodelle in die gemeenskappe nie. Uhm...niemand om na op te kyk nie, daar's nie discipline in skole nie."*

*("but so often it's the case that someone grows up in the community, makes a living for himself and then moves out [away]. He never comes back to... (inaudible) so our children in the community don't necessarily have a role model who grew up here whom they can strive [look up to] towards...this takes us back to the thing of if there's something you can do then you have to leave Pikeville, you can't stay here because your potential here can... you have to go outside [out there]. That's why people who make a living for themselves rather move out and never come back. And then you have those spinoffs of not having role models in the community. Uhm... nobody to look up to, there's no discipline in schools.")*

Stanley made it clear that Pikeville was not a place that fostered personal development. According to him those who wanted to make progress needed to leave Pikeville, never to return. When Rony and Stanley referred to role models they were referring to sober role models.

### Normalization of alcohol in Pikeville

Based on the discussion of available role models in the community, it became clear that drinking mothers identified actions such as supporting neighbors with food and shelter as behavior that they aspired to. The daily actions by some youth, parents and other adults in the community indicated that excessive alcohol use was a normal part of life in this community. Early perceptions were formed of alcohol use practices being an accepted form of behavior in this context during relaxation or when socializing with friends. Stanley who did not use any alcohol believed that young people see excessive alcohol use and binge drinking as a way of socializing:

*“Ek ek ek dink ons ons jong mense begin eintlik met dit as en hulle sien ook dit as sosialisering”*

*(“I, I, I think our, our young people actually start with it and they also see it as socializing”)*

Sally, an adult educator at the local center whose father occasionally drank excessively at family celebrations, seemed to distance herself from the ‘drinking crowd’ when she described it as something that other people do. Judging by Sally’s experience with her father, who also abused alcohol, drinking privately, is not as big a problem as drinking large amounts of alcohol in public:

*“As 'n mens in die dorp stap, dan sien jy maar daar is die spanne wat drink”*

*(“When you walk in town, you see those who are drinking”)*

Within Pikeville the sight of drunken persons on a daily basis was therefore not uncommon. Rob, who is a drinker himself stated:

*“Hulle drink soms Sondae amper asof dit Saterdag is...”*

*(“They sometimes drink on Sundays as if it were Saturday...”)*

It is important to note the use of the word “they’ instead of ‘we’ in the above quote. A pattern was identified amongst service providers in which they described excessive alcohol use as a common phenomenon while distancing themselves from it.

Wanda provided another explanation for why she ended up drinking. Her story relates to losing a father figure and subsequently getting together with friends to experiment with wine.

#### Losing a father figure:

For Wanda early exposure to excessive alcohol use was compounded when her parents separated. Wanda was thirteen years old when her parents separated. Like Wanda her mother was also addicted to alcohol. Wanda recalled:

*“Toe't sy [my ma] nou 'n ander man gevat en nie geworry van ons nie...nie tyd vir ons gehad, aandag gegee en so nie. Toe't ek nou beginne uitgaan kuier naweke,...maar toe hulle, my ma en my pa bymekaar gewees het, my pa was baie streng. Ons mag nie uitgegaan het en so nie of gekuier het nie. As ons gekuier het moet ons altyd saam met hulle gekuier het. Toe hulle twee nou mekaar los toe my ma nou meer vir ons traak of so nie, toe dink ek ek is nou my eie groot meisie...”*

*“Then she [my mother] took [got involved with] another man and didn't worry about us... didn't have any time for us, didn't pay attention to us and things like that. Then I started going out and visiting over weekends... but when they, my mother and father were together, my father was very strict. We were not allowed to go out or to visit. If we visited, we always had to go visit with them. When they left each other, when my mother didn't bother with us and things like that, I thought to myself that I was my own big girl...”*

It was at this stage that Wanda started to experiment with alcohol:

*“[toe my ma nou nie meer traak met ons nie] toe doen ek nou my eie goete en op dertien toe begin ek vir die eerste keer...toe begin ek drink. Nou daai Saterdag, dit was 'n Saterdag gewees toe my niggies van Paarl wat toe, gaan skool op die hoëskool op weggaan. Toe kom hulle nou huis toe. Toe't hulle 'n bottle brandewyn toe besluit ek maar ek gaan nou saam drink. Toe's dit nou die eerste keer wat ek so dronk gewees het. Toe ek by die huis kom toe't my ma vir my 'n deftige pak gegee, maar dit het nog altyd nie gehelp nie. (Lag)”*

*“[when my mother didn't bother with us anymore] I started doing my own things and at [the age of] thirteen, I started to drink for the first time... I started to drink. So that Saturday, it was a*

*Saturday when my cousins from Paarl, they went to a high school in Paarl. Then they came home. Then they had a bottle of brandy and I decided that I was going to drink with them. That was the first time that I was so drunk. When I got home, my mother gave me a decent hiding but it still didn't help. [Laughs]"*)

Lorna highlighted another aspect of parents who have to work nightshift at the local factory:

*"Baie keer is dat jou kind al so ver in alkohol is of in dwelms betrokke is maar jy kom dit nie agter nie, want wat? Ma of pa moet miskien nagskof werk so jy sien nie wanneer jou kind huis..die middag as die kinders uit die skool uit kom, die ouers is nie daar nie"*

*("A lot of the time your child is so deeply involved with alcohol and drugs but you don't realize it, because why? Mother or father maybe has to work nightshift, so you don't see your child when they come home... when the children get home from school in the afternoon, the parents aren't there.")*

When young children do not have adult supervision and spend lots of time with their group of friends, peer pressure is another contributing factor towards ending up in abusing alcohol.

### Peer pressure

Rony recounted one of many conversations he had with youth in the community. He stated:

*'En ek sê baie kere vir hulle: okay- soos ons wil in wees in die groep in en dis hoekom ons saamdrink. Dis 'n...jy wil nie afsteek nie... , ...maar ons wil drink soos hulle [sterk drinkers] drink. Ons drink tot alles op is ons ons ken nie ons terme het, jy kan nie...jy't nie 'n limiet nie..ons jongmense is nog by daai. Hy wil gesien word as 'n een wat drink. Want môre praat ons mos daaroor: Hey ons het soveel drank opgedrink... hulle, hulle spog daaroor."*

*("And I often tell them: Ok, like we like to be in with the group and that is why we drink with them, It's a...you don't want to stand out...but we want to drink like them [heavy drinkers]. We drink until there's nothing left and we don't know our terms [limits]. You cannot...you don't have a limit... our young people are still there. He wants to be seen as someone who drinks. Because we brag about it the next day: Hey we drank up so much wine...they brag about it.")*

Wilma had firsthand experience of peer pressure. She recalled the reasons why she started drinking:

*[Waar't jy gesien om te drink?-vraag] Is nou van maatjies, en nou van kêrel ontmoet, saam 'n bier drink, 'n bier drink"*

*([Where did you learn to drink? –question] It's because of friends, and because of the boyfriend I met, drinking a beer together, drinking a beer.)"*

She continued:

*"Ek het gedrink van net by vrinne wil inpas en as jy nie drink nie dan voel jy so uit...en...ek het baie gedrink..ek praat van as jy nou geld het vir wyn dan het ek gedrink."*

*("I started drinking just to fit in with my friends and if you don't drink then you feel left out...and...I used to drink a lot...I mean whenever I had money for wine, I used to drink.")"*

*'Culture pressure' (more than just peer pressure)*

Drinking would very seldom happen in isolation. People would get together to drink in groups or partners would share a drink. Martha explained why she prefers to share a drink with friends and family:

*"Maar ten minste is daar dan company om saam te drink en jy voel beter want jy's saam met ander mense. Jy vergeet van jou sorges tot daar wat jy weer nugter raak (lag)"*

*("But at least there's some company to drink with and you feel better because you are with other people. You forget your troubles until you sober up [laughs loudly]"*

According to Martha, you feel better when you share a drink with other people. At least she can forget about her cares for the time that she spends with her friends or family this way.

Like any other occupation, people with the same interests may end up as life partners. In a similar way there is a great likelihood that drinkers who meet up in social circles and who become life partners, will continue sharing this occupation even when they start a family. Rob stated that Wanda would drink with him or with family and friends during all three of her pregnancies. Although he reminded her that it was unhealthy for the babies,

he was not aware how helpful it might have been had he abstained, especially during her pregnancies.

In addition to peer pressure children and adolescents were bombarded with pressure from parents and other adults in their community who used alcohol excessively. The environment was 'saturated' with pressure to use alcohol excessively and to binge drink.

Johanna told how drinking parties started and how the party kept going when more money was discovered:

*"Nou sit en nooi hy, 'Kom drink by my, kom drink by my.' As daai op is ... 'Nee!, daar's mos nog geld, ek gaan nou nog vat en gaan koop."*

*("Now he sits and invites, 'Come over and have a drink with me, come over and have a drink with me.' Once that's finished... 'No! there's still more money, I'm going to take more [money] and buy [more alcohol]'.")*

Johanna concluded that excessive alcohol use became a habit...

*"...maar hulle drink ook maar net omdat dit so is of omdat hulle gewoon is daaraan, ..."*

*("...but they only drink because it's like that or because they're used to it...")*

Alcohol abuse and binge drinking were exacerbated by traumatic events in the lives of young mothers. When teenage girls fell pregnant there was very little support for reducing or stopping alcohol use. The overwhelming influences from family, friends and community members reinforced excessive alcohol use and binge drinking. Upon further exploration of what the mothers' experiences were they were asked why they continued to abuse alcohol during pregnancy. Excerpts from the mothers' stories are illustrated under the next heading.

### **Mothers who abuse alcohol**

Under this heading the practices of general alcohol consumption in the wider community are narrowed down to the mother who grew up in a community where excessive alcohol use was common. In the following accounts Girty, Sandy, Wanda, Wilma and Martha

shared their own experiences of being a drinking mother. The vignettes that follow share some of the realities of the drinking mother within the research context. While Girty, Sandy and Wanda provided a more comprehensive account of specific challenges, Wilma and Martha did not necessarily tell a story, but rather offered incidences that were relevant to them.

Girty's story shed light on how planning for a Friday night get-together turned into an experience of shame and trauma. A large part of Girty's story was not about her experience as a 'mother', but rather as a rape survivor. The striking part to this story was how memories of her first pregnancy was tarnished by the traumatic recall of the rape that took place that night. Unresolved feelings and lingering trauma was clear in her account.

Sandy's story illustrated how sexual abuse and gender violence inflicted trauma in her life. She also told how she fell pregnant as a result of emotional and physical abuse from her boyfriend.

Wanda's story gave a perspective of a teenager who came from a broken home and who experimented with wine. This story progressed into how she fell pregnant with her first child and how her binge drinking continued until after the birth of her third child.

Wilma's short account focused on how she needed reorientation toward her life goals after falling pregnant for the first time.

Martha had a vivid, but sad recollection of when she fell pregnant for the first time. Although it was many years later she was too emotional to share this part of her story. Her short account illustrated the disappointment of failing her parents and the subsequent rejection she experienced by her mother.

#### *Girty's story*

Although Girty, a 45 year old woman, falls outside of the range of women of childbearing age, her experience of becoming a mother a number of years ago added much value to this study. Girty lived on a farm just a few kilometers outside of town. Girty used to be a

social drinker, but reported drinking excessively after a rape that happened 21 years ago. She was deceived by a girl friend who arranged a blind date between Girty and a male friend of hers.

Girty's traumatic experience of rape did not only result in her first pregnancy, it was also the onset of her history of excessive alcohol use:

*“Ek het begin drink na die verkragting en nooit weer opgehou nie... [Sug en lyk baie ongemaklik...]... stilte..... Omdat dis was nie eintlik... die kind was nie eintlik beplan gewees nie. Dit was 'n... amper sal ek sê, 'n strik gestel gewees vir my...”*

*(“I started drinking after I was raped and I never stopped... [Sighs, looking very uncomfortable]... [silence]..... Because it wasn't really... the child wasn't actually planned. It was a... I'd almost say it was a trap that was set for me...”)*

Girty did not know the man who, as a result of rape, became the father of her son. She was invited along to this man's house on the premise that they were collecting beers for a weekend party. Upon arrival the 'friend' disappeared and Girty was raped by the man she did not know. She discovered soon after this incident that she was pregnant. This incident happened 21 years ago. However, when the participant told me her story it appeared as if she was reliving the incident of the rape. She was sobbing as she gave this very emotional account:

*“Ek het opgestaan en [my vriendin] het vir my klere gebring ...so onderklere gebring en ...toe ek daar opstaan,... hy't vir my waswater ingegooi en ek het my gewas daar en voordat hulle nog vir my koeldrank gegee het...en hulle het nog bier ook gedrink, toe loop ek, toe loop ek al aan. Totdat ek by die huis kom, toe sit my broer nog daar, toe vra my broer waarvandaan kom ek...Ek het nooit vir hom die waarheid vertel nie, ...vir hom vertel daarvan nie. Ek het ook vir hulle gevra hulle moenie praat daarvan nie anders sal my broer my slaan. Ek het vir almal gevra wat is die Bantoe<sup>45</sup> man se naam. Hulle het tot hierdie oomblik nog steeds nie vir my gesê wat is sy naam nie.”*

*(“I got up and (my friend) brought me some fresh clothes...like underwear and...when I got up there, ...he poured out some water and I washed myself there and before they could give me*

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<sup>45</sup> The term 'Bantu' was used to refer to the black majority in South Africa (Fischer, 2007).

*some cool drink... they also drank some beer... I left...I just left. When I got home, my brother was still sitting there, and he asked me where I'd been...I never told him the truth... told him about it. I also asked them not to talk about it otherwise [because] my brother would have given me a hiding. I asked everybody what the name of the Bantu man was. They still haven't told me his name to this day.")*

Upon asking her whether she ever followed this incident up with any sort of legal action Girty responded negatively. It was clear that the fact that this incident remained unresolved and unattended to may have contributed to extreme psychological conflict. Girty admitted to drinking excessively (drinking until she lost consciousness) at times. She would often look for opportunities to drink with friends. And while the tendency would be to search for a link between this tragic incident and her binge drinking, it would be more useful to focus on issues that relate to lack of support services and safe shelter at a time when Girty needed it most.

This incident changed Girty's life irrevocably, but few people really understood the impact of this experience on Girty's life. Other women in her community encouraged her to change her drinking practices without necessarily providing the support that she actually needed. She is aware that her drinking is a problem, but she can't seem to bring about the change all by herself. Girty ended her story with the following quote. The emptiness in her voice resounded in the silence that followed:

*"Daar is baie mense wat, daar waar ek nog bly is bekeerde mense wat altyd praat met my saam oor die drinkery."....stilte...*

*("There are a lot of people that, there are converted people where I live and they always talk to me about my drinking.")...silence*

It was clear that Girty never dealt with this trauma. She continued to drink in her current relationship. When asked why she continued to use alcohol even after her pregnancy, she attributed part of her reason to a relationship from which she is unable to escape:

*"(Ek drink nou) Omdat die "boyfriend" wat ek nou het...ek kry nie kans om van hom af weg te kom nie."....*

*([I now drink] Because the 'boyfriend' that I have at the moment... I don't get a chance to get away from him...")*

In Girty's case the life of excessive alcohol use that started early in her life, continued.

### *Sandy's story*

Sandy, a 21 year old seasonal farm worker lived on a farm just a few kilometers outside of town. She knew her boyfriend for a few years when they started dating. She was 18 when she moved from the farm where she grew up to her boyfriend who lived and worked on another farm that was situated 32 kilometers away from the farm where she grew up. She did not want to fall pregnant before obtaining a job. As part of her planning for her future she started using contraceptives when she was 17 years old. However, her boyfriend wanted to have a child and started nagging her about falling pregnant with his child. After a few months, when he discovered that she was still using the contraceptives, he became violent and threatened her to stop using contraceptives. He would monitor her movements to ensure that she did not visit to the clinic. When he discovered that she secretly arranged with her sister in law to collect her contraceptives, he was furious. Her boyfriend threatened to beat her if she continued using contraceptives.

*"En die inspuiting, in die eerste plek, die inspuiting het nou newe effekte gewerk. ["Mm?"] Toe met die inspuiting, eers was ek op die Nordette [Ja] en na 'n tyd toe sê... want toe sien hy ek gebruik die Pil, toe sê hy, 'Ja, nou mors jy my tyd' en die Pil is nou en ek het..., die Pil het ek drie maande gelos. Daarvandaan nie weer die pille gebruik nie, want hy het my so ge-monitor, gemonitor. Dan gebruik ek sy suster se pille..ons het een en dieselfde (voorbehoedpille) [Ja]; Dan sê hy vir my, 'Ja, jy gebruik nou alweer die pille' en dan sê ek vir hom 'Nee ek gebruik nie die pille nie!'"*

*("And the injection, in the first place, the injection had negative effects. ["Mm?"] Then with the injection, first I was on Nordette [Yes]... and after some time he said... because he saw I was on the Pill, so he said: 'Yes, you are wasting my time' and the Pill [is the culprit] and I... I stopped taking the Pill for three months... I never used the pills again after that because he would monitor me, he monitored me. Then I used his sister's pills... we used the same [contraceptives] [Yes] so he said to me: 'Yes, you're using the pills again.' And then I said to him: 'No, I'm not using the pills!'")*

Sandy fell pregnant with her first and only child just before she turned 21. Her experience of pregnancy was negative because she only wanted a baby later in her life. She recounted one of the many sexually violent incidences with her boyfriend. He often abused her verbally and physically in the presence of others. When this incident happened they were on their way home. Her sister and a few friends were walking in close proximity.

*"Ek wil nog hardloop, ek hardloop nog, 'Wag vir my!, wag vir my!' (terwyl hy haar isoleer van die groep)... uhm mmm toe het hy my weer daar en hy klap my daar en hy (wurg) my weer, hy sê, 'Ek het jou mos gesê, "Vanaand is vanaand. Jy gaan nie weg nie."' Toe sê sy suster, maar sy suster het die polisie gebel en die polisie sal nou kom. O hene hy moes dit nie gehoor het nie. 'O, jy bring die polise?... jy gaan nou sien! Nou gaan jy... ' - hy (trek) my daarvandaan en hy sê vir my, 'Nou gaan ek jou berg toe vat, veld toe vat en daar sal ek jou...' - ek het nou nie die gedagte gehad nie, maar nou sal ek [maar moet saamspeel], 'Nou sal jy sien wat ek met jou gaan... ' ; hy trek hy trek (sy lag hysteries)... vir my en hy trap en skop vir my. Hy sê, 'Ja, jou ma se die , jou ma se dat, en goete 'Ek sê, 'Maar ek het niks gedoen nie. Asseblief, los vir my.' ...Hy se: 'Jy dink seker jy kan nou weggom, jy kom hier!' En hy het my arm vas vir al wat hy het en hy sleep my daar in die bosse in en hy sê vir my: 'Trek af jou broek!' Ek sê, 'Hoekom moet ek nou dit doen?'".*

*("I just wanted to run away...I was still running... 'Wait for me!...wait for me...!' (while he isolated her from the group) uhm... mmm then he grabbed me and slapped me and (choked) me again. He said: 'I told you, tonight is the night. You are not getting away.' Then his sister said, but his sister called the police and that they would come soon. O dear! He should not have heard that! 'Oh, you are bringing the police...now you will see! Now you will...' He pulled me from there and he told me... 'now I'm taking you to the mountain, to the veld and there I will...' I did not mean for it to happen this way...but I will have to [play along] 'Now you will see what I am going to do with you...'. He pulled, he pulled (she laughs hysterically) ...me and he stepped on me and kicked me. He said: 'Your mother this and your mother that, and things'. And I said: 'But I have done nothing. Please leave me,' He said: 'You probably think you can get away now, you come here!' And he grabbed my arm with all his might and dragged me into the bushes and told me: 'Take off your pants!' I said: 'Why do I have to do this now?'"*

I was shocked at the extent of the abuse Sandy was experiencing on a daily basis. Violence had become a frequent interaction between Sandy and her boyfriend. It was sad

that this would often take place in the presence or in close proximity of other people. It became clear that Sandy (and the other people who watched her being abused) became desensitized to domestic violence. Sandy's story provided insight into why the use of contraceptives was not a viable method for preventing a pregnancy in her case. She experienced violence on a daily basis as the boyfriend continually intimidated her into falling pregnant:

*"Ons het net by die huis gekom [die volgende dag], toe sê hy vir my, 'Ja, jy dink seker dis gisteraand. Jy dink seker ek het vergeet. Ek het nooit vergeet nie, ek is nog altyd daarop.'"*

*("We just got home [the next day], then he said: 'Yes, do you think it's last night? Do you think that I forgot? I did not forget, I am still on your case.'")*

The violence continued the very next day:

*"'Ek begin alweer daar waar ek opgehou het. Ek is nog nie klaar nie.' ...toe het hy 'n stuk hout en hy mik en hy slaat my hier op my hand en toe ek nou weer terugkyk toe druk hy die deur toe en ek maak al die vensters, maar ek is te laat met die kamervenster..."*

*("'I'm starting again where I left off. I am not finished yet.'... then he got hold of a piece of wood and aimed it at me and he hit me on my hand, and when I looked back, he shut the door and closed all the windows, but I was just too late for the room window...")*

This participant found it difficult to get away because she was afraid of another beating should her boyfriend find out that she was trying to leave him:

*"'n Lorrie het gekom (inaudible phrase)...Toe dink ek, as hy nou die oggend gaan werk, dan gaan ek nou ontglip. Ek het nie die kans gekry nie (sy lag hysteries). Ek weet nie hoe hy dit weet nie toe sê hy vir my, 'Ja, jy dink seker jy gaan weggom. Jy gaan nie weggom nie'"*

*("A lorry came (inaudible phrase)...Then I thought, if he goes to work then I can escape. I did not get the chance (she laughs hysterically). I don't know how he knew but he said: 'Yes, you think you are going to get away. You are not going to get away'"*

She finally managed to get away when the last incident was forgotten and he did not suspect that she would try to flee the farm...

*“En die Saterdag, die Saterdag het gekom en toe gaan ek dorp toe en gelukkig daai Saterdag, toe gaan hy nie dorp toe nie. Toe gaan ek alleen dorp toe en in die dorp kom, toe koop ek vir my twee biere. Toe sê ek, ‘Nou gaan ek, ek is nou moeg. Ek is nou...(gebruik haar hande om te wys dat sy keelvol is) met my opgekropte gevoelens. Nou gaan ek drink’ En dis een bier na die ander. En dis lateraan vaalwyn en dis lateraan ’n gedrinkery. Later van tyd toe dink ek, ‘Nee, nee, nee, dit kan ook nie so aangaan nie.’”*

*(“And this Saturday, the Saturday came and I went to town and luckily he did not go to town that Saturday. So, I went to town alone and when I arrived there, I bought myself two beers. Then I said [to myself]: ‘Now I’m going to, I am fed-up now. I am now... (gestures with her hands that she is fed-up)...with my pent-up feelings. Now I am going to drink’. And I drank one beer after the other. And later it was Vaalwyn (locally made cheap wine) and later it was a whole party. Later on I thought; ‘No, no, no, it can’t go on like this’”)*

*“...toe gaan ek hier na ’n Antie toe in Pikeville (in die buurt), by die aflaai hekkie, toe gaan ek na haar toe. Toe koop ek vir my weer twee biere en vir hulle ’n litertjie. Maar ek het net ’n glasië daar uitgedrink, toe’s ek uit...”*

*(“...then I went to an aunty in Pikeville [in the neighborhood], at the drop-off gate, I went to her. I bought myself two more beers and a small liter for them. But I only drank a glass there, and then I passed out...”)*

By the time this participant’s sister located her she was reported missing from the farm for two days and still staying with the lady where she took her last drink before passing out. On the third day she found her way to her sister, her only relative, who lived on another farm and stayed there. Her boyfriend traced her and pleaded with her to come back. Sandy retorted:

*“Toe sê ek, ‘Ja, maar na al die dinge wat gebeur het en jy het nie gedink aan daai tyd toe het jy my so gekasty het en amper sê ek doodgemaak het, het jy nie gedink aan my “pregnancy”skap nie. Wat sal gebeur het met die kind in daai tyd?’”*

*("Then I said: 'Yes, but after everything that happened and you never thought of those times that you harassed me and I almost said killed me, you didn't think of my pregnancy then. What would've happened to the child then?")*

However, he managed to convince her to move back with him. Sandy agreed to return to the father of her child after a short period of separation. She changed her mind and gave the relationship another chance after he promised to change his behavior. Not having access to people or services which could assist in preparing her emotionally or cognitively to better deal with the situation that awaited her, it was clear that Sandy was making herself vulnerable to the same situation of abuse all over again.

#### *Wanda's story*

Wanda is one of the participants who started to binge drink at the age of thirteen. Wanda and her friends experimented secretly. A group of youngsters would get together to consume large amounts of alcohol in a short time. She fell pregnant for the first time when she was fifteen years old:

*"...ek was vyftien toe ek swanger is met my eerste kind, my oudste kind...swanger geraak het..."*

*("I was fifteen when I fell pregnant with my first child, my oldest child... when I got pregnant.")*

Wanda shared her experience of her mother's reaction to her pregnancy:

*"My ma wou eers ... sy't my uitgesit toe wou sy net hê ek moet gaan vir aborsie toe weier ek om dit te doen"*

*("At first my mom wanted... she kicked me out and wanted me to go for an abortion but I refused to do it")*

Wanda engaged in binge drinking throughout her first two pregnancies. She abused alcohol until she discovered that she was pregnant with her third child:

*“Ja ek meen met Anna het ek net so gedrink. Met Rufus het ek tot op die laaste toe gedrink. Met Aylah, toe ek uitvind ek is swanger toe's ek drie maande swanger. Ek het ook daai tyd baie gedrink nog voordat ek uitgevind het ek is swanger.”*

*(“Yes, I mean I also drank [while I was pregnant] with Anna. [When I was pregnant] with Rufus, I drank right until the end [of my pregnancy]. When I found out I was pregnant with Aylah, I was already three months along. I also drank a lot during that time, even before I found out that I was pregnant.”)*

When asked about her alcohol consumption during her last pregnancy Wanda tried to explain what triggered her bouts of excessive drinking. She told about how arguments with Rob tended to upset her and although she did not elaborate on whether it was the content of the argument that was the cause, she did mention that she would end up drinking instead of talking about her problems. In the following excerpt she explained her reaction after a major fall-out with Rob:

*“As ek 'n probleem het, dan...ek praat nie ek gryp...gaan drink net...praat nie met iemand daaroor nie...”*

*(“When I have a problem, then...I don't talk, I just grab...just go have a drink...don't talk to somebody about it...”)*

On another occasion she was overwhelmed by her pregnancy and as a result of family issues she also felt disillusioned by her family members. Again she decided to drink:

*“Ek het nie eers geweet die kind gaan daai kom nie...Ek het net gedink die kind moet net uitkom. So, ek het net, want, want ek was hard toe teen almal.”*

*(“I did not even know the baby was due on that day...I was just thinking the child should come out. So, I just, because, because I was set against everybody.”)*

Wanda shared how she was still drunk during the delivery of her third child:

*“Ek het nie eers geweet ek gaan in nie. Ek was so kwaad vir hom toe't ek sommer geld gevat en my gaan bier koop en beginne drink. Die einste Sondag toe gaan ek in toe's ek so lank kraampyne gehad het dat ek eers die Woensdag klaargemaak het. En ek het al van die Sondag*

*al so pyn gehad. Toe ek by die die huis kom toe sê ek vir hulle dis seker...die kind was seker nog dronk gewees dis die wat sy so lank gevat het om gebore te raak. Dis seker een van die redes hoekom sy voor die tyd gebore is...Want daai Sondag het ek nie getraak nie, ek het gedrink.”*

*(“I didn’t even know that I was being admitted [to the hospital]. I was so mad at him, I just took some money, went to buy beer and started drinking. I was admitted that very Sunday and I had contractions for such a long time that I only gave birth on the Wednesday. I was in pain since Sunday. When I got home, I told them it was probably... the child was probably still drunk and that’s why it took so long for the baby to be delivered. That’s probably one of the reasons why she was born prematurely... Because that Sunday I didn’t care, I just drank.”)*

*“Maar, ek het baie gedrink.Ek is nie skaam om te sê nie. Ek het baie gedrink met daai kindjie saam.”*

*(“But I drank a lot. I’m not ashamed to admit it. I drank a lot [while I was pregnant] with that child.”)*

Being drunk during the delivery of her child unfortunately did not make for a very pleasant delivery experience at the local clinic. I recorded the following account in my diary after Wanda told her story:

*“Wanda... told auntie Gerrie about her delivery. She told how she screamed and shouted and how the sister closed the door of the delivery room until she calmed down. They would not assist her while she was hysterical. Incidentally, I know that Wanda was not sober with Anna’s delivery. She told me this herself on a previous occasion.”*

Wanda’s story raised questions regarding the right of these women to access health care (even when under the influence of alcohol). What is of concern is that the nurses, who were supposed to support Wanda during labor refused to assist and left her to her own devices. Similarly, this account raised concerns about the understanding of clinic staff of the identification and treatment protocols for alcohol dependence. This issue will be discussed in more detail in Chapter Five.

### *Wilma's story*

As a result of falling pregnant while she was still at school Wilma experienced a major transition (from carefree teenager to mother) in her life. She therefore had to put her aspirations of becoming a doctor on hold:

*“Ek wil ek wil eendag 'n dokter geword het. Ek het toe ek klein was as een seerkry het ek altyd gedokter daar. Ek is nou nog so, as een by die huis seer kry, ek sal altyd... my ma hulle is altyd so bang. Ek sal altyd gaan en loop dokter daai een. So... en my uncles het saam my gepraat. Ek het 'n visie... sê hy jy moet jou visie nastreef. Toe ek swanger is het my ouma my baie geskel. My pa het my uncles almal groot gewerk toe en hulle het gevoel hulle wil dit vir ons ook doen en nou (inaudible...) Daai tyd dink ek: 'Ag! Los maar!'. Maar vandag as ek terug dink...ek kan dit nog gedoen dit. En kyk nou, vandag moet jy nou werk. Jy't 'n kind om na te sien. Nou sê hulle vir my laas jaar: 'Gaan college toe ons sal na jou kind kyk.' Toe wil ek nie gaan nie want dis my verantwoordelikheid. Ek meen ek kan nie op ander mense staat maak nie. Dis my skuld dat ek sit waar ek vandag sit. Ek moet verantwoordelikheid vat daarvoor.”*

*(“I wanted to become a doctor someday. When I was small and someone got hurt, I would always go and help that person. I'm still like that, if someone gets hurt at home then I always... my mother and the others are always so scared. I would always go and help someone. So... and my uncles talked to me. I have a vision... he says you have to pursue your vision. When I was pregnant my grandmother used to scold me a lot. My father worked and he raised all of my uncles and they felt they wanted to do the same for us but now (inaudible)... That time I thought: 'Oh! Just leave it!'. But when I think back today... I could've done it. And look now, today you have to work. You have a child to take care of. So they told me last year: 'Go to college. We'll look after your child.' But I didn't want to go because that's my responsibility. I mean I can't depend on other people. It's my fault that I'm in this situation today. I have to take responsibility for that.”)*

Women like Wilma have intellectual insight into the importance of abstinence during pregnancy however, still have no guarantee that they will be able to maintain sobriety during future pregnancies without the needed support. Fortunately, Wilma could rely upon the support of her partner and close family members during her second pregnancy and she was hopeful and positive that this pregnancy would be alcohol free.

### *Martha's story*

Martha, a 34 year old mother of two, shared how she started to experiment with alcohol:

*“[Ek het begin drink] Toe gaan ek nog skool. Toe's ek hier nog Standerd 5. Vrydag agtermiddag kan ek nie ophou uit die dorp uit nie. Ek wil dorp toe gaan, ek wil depot toe gaan, wyn koop. Dan gee Mamma my soggens geld ..Syt (my ma) nie eers geweet (wat ek met die geld gaan doen) nie..”*

*“[I started drinking] when I was still at school. I was still in standard 5. Friday afternoon I couldn't stay away from town. I wanted to go to town, I wanted to go to the depot, to buy wine. Then mamma gives me money in the morning... She (my mother) didn't even know [what i did with the money]...”*

Martha did not share the details of her life or the details of how she fell pregnant. She tried to tell her story, but she broke down in tears:

*“Is my kinders se pa, man. Toe die kind gemaak is ... (stilte) ... En ... ja ... (oë skiet vol trane) (emosiewol stem) Toe ... (stilte)”*

*“It's the father of my children, man. When the child was conceived... [silence]... and... yes... [eyes became tearful and voice is filled with emotion]. Then...” [silence... she starts to cry silently]*

She started drinking excessively when her boyfriend abandoned her after she told him that she was pregnant. In addition to this disappointment her mother strongly expressed her discontent. Martha stated:

*“En toe kom sê ek vir Mamma. En toe skel Mamma. Mamma het baie aangegaan dat ek ... want sy wil nie gehad het... Ek ... want ek is die een wat in die huis werk, die enigste broodwinner.”*

*“And so I came to tell Mama. And then Mama scolded me. Mama was so upset that I... because she did not want... I... because I was the only breadwinner in the house”*

Martha admitted to not knowing what responsibility awaited her:

*“Ek meen ek was daai tyd [met my eerste swangerskap] jonk en onverantwoordelik. Mos nou geen benul gehad wat dit is om 'n kind groot te maak en daai dinge nie...”*

*(“I mean I was young and irresponsible that time [with the first pregnancy]. I obviously had no idea what it was like to raise a child and things like that.”)*

The above statement summarized the disillusionment Martha experienced when she was faced with the reality of raising her own child. Martha spoke as if her life as a mother was removed from her life as an alcohol addict. However, it should be noted that alcohol was always a part of Martha's life, even long before she became a mother herself and she continued drinking through all three of her pregnancies. The next section further explores the phenomenon of mothers who consume alcohol during pregnancy.

#### *Drinking during pregnancy:*

In the accounts provided by Girty, Sandy, Wanda, Martha and Wilma the personal experiences of drinking during pregnancy were shared.

Since drinking alcohol on a daily basis became the norm in this community, excessive alcohol use, even during pregnancy, seemed to be normalized. When a woman consumed alcohol during pregnancy it did not seem problematic in relation to heavy alcohol consumption of other people in the community. In the following excerpt Jane did not show concern that her daughter used alcohol 'now and again'. It is not clear if Jane understood the possible link between her daughter's prenatal alcohol consumption and her grandson's lung deficiency:

*“Want somtyds, wel, my dogter was nie 'n drinker met haar kind se geboorte nie. Kyk af en toe het sy gedrink maar toe die seuntjie gebore is, toe kom die seuntjie ook met 'n long probleem...”*

*(“Because sometimes, well, my daughter wasn't a drinker with the birth of her child. Look now and again she would take a drink, but when the little boy was born, he came with a lung deficiency...”)*

Drinking mothers were convinced that they could stop drinking whenever they wanted to. Whenever participants who admitted to drinking on a regular basis were asked whether

they thought they were in control of their alcohol habits they responded that they could stop whenever they wanted to. In fact, many of the accounts presented in this study provided adequate evidence of alcohol dependency among mothers. However, all mothers reported having control over their alcohol intake. Alcohol dependence was never mentioned as a possibility. None of the female participants therefore admitted to continuing to drink during pregnancy as a result of dependence on alcohol.

Martha said:

*“Ek gaan baie lank sonder drank ... baie lank,”*

*(“I can go without wine for a long time... a long time”)*

In the following quote Johanna rationalizes the frequency with which they drink in the group. Without her realizing it she admitted to only being without wine for two days (Tuesday and Thursday) in the week:

*Johanna: “Omrede ... ons drink net wanneer Vrydae tot en met Maandae en dan weer Woensdae wanneer die ander gaan werk. En daarvandaan is ons sonder wyn tot en met Vrydae.”*

*Johanna: (“Because...we only drink Fridays to Mondays and then again on Wednesday when the others go to work. Then we are without wine until Friday.”)*

Johanna clearly did not see the frequency with which she drank as a problem. Her quote indicates that she drinks five out of the seven days of the week. She was also under the influence of alcohol in both of the interviews she attended.

Wanda stated that in the past she could always stop drinking whenever she wanted to:

*“Ek het nog nooit berading gesoek as ek wil ophou drink nie. Ek het altyd self, op my eie.”*

*(“I have never sought counseling when I wanted to stop drinking. I have always done it on my own”)*

After hearing from the mothers, it was useful to get a different perspective. Leoni, a community worker who worked for FASed, coordinated a program that involved educating

Grade 7 learners about the dangers of alcohol consumption during pregnancy. She shared her understanding of the alcohol dependence the women were battling with. She argued:

*“Ons almal weet drank is verslawend maar nie, nie een van die mense... En dis mos nou maar tipies van mense wat 'n probleem het met alkohol. Voordat jy nie erken dat jy hulp nodig het nie kan jy nie gehelp word nie.”*

*(“All of us know that alcohol is addictive, but not one, not one of these people...and that is typical of people who have a problem with alcohol. If you don't admit that you need help then you will not get the help [you need]”)*

Although Leoni's response would be viewed as accurate with regards to alcohol dependence, she seems to forget the environmental and contextual factors that might play a role.

After a sister at the clinic explained the harmful effects of wine on the baby to Wilma she shared how she warned one of her friends:

*“Sy drink verskriklik,...sy's swanger, sy's twee maande. Toe sê ek vir haar: ‘Nee, jy kannie drink nie, jy's swanger.’ En sy drink nie nou bier en so aan nie, sy drink vaalwyn ook. Dan moet ek met haar praat dan sê hulle ek moet met haar praat oor sy so drink.”*

*(“She drinks immensely. She's two months pregnant. Then I told her: ‘No, you can't drink. You're pregnant.’ And she doesn't drink beer and that, she also drinks cheap wine. Then I have to talk to her and then they tell me to talk to her about her drinking.”)*

The message that Wilma thus got from the clinic sister is that the choice to stop drinking lies with the expecting mother. This view also excludes the possibility of external factors. Unlike Wilma, her friend and many other women might not be able to stop abusing alcohol on their own. Lack of insight into alcohol dependence and an unsupportive environment might make it impossible to have an alcohol free pregnancy.

Theme One provided a comprehensive background on the phenomenon of excessive alcohol use in the Pikeville community. The personal stories of mothers offered insight into the reasons how and why some of the mothers in the study started and continued to

use alcohol throughout their pregnancies. The question that emerged: “Aren’t women in all contexts confronted with issues of abuse and trauma?” The answer is undeniably: “Yes, they are”. So what make these women different to all the other women? Theme One showed that women cannot be viewed in isolation from socio-political and environmental factors. Under these circumstances the notion of personal choice for a healthy pregnancy or choosing occupations that will ensure safe pregnancies only becomes viable when these women receive external structural and emotional support.

Theme Two will discuss drinking mothers’ and service providers’ suggestions of what could be done to support women of childbearing age to abstain from prenatal alcohol consumption.

University of Cape Town

#### 4.2.2 THEME 2: Ek is 'n Drinker en klaar ((I am a drinker and that's it)

Table 6

Theme 2	Category	Subcategory
<b>Ek is 'n Drinker en klaar ((I am a drinker and that's it)</b>	<b><i>Having local role models</i></b>	“Ek sal vir hulle alles doen wat ek kan...” (“ I’d do everything I can for them...”)
		“Dis almal se verantwoordelikheid” (“It’s everyone’s responsibility.”)

This theme introduces the mother who identifies herself as a drinker. The four drinking mothers (Sandy, Martha, Girty and Wanda) had been living in Pikeville for the greater part of their lives without any support for their alcohol dependency. They continued to drink while being pregnant, raising their children and making a living in Pikeville. The category supporting this theme captures the positive as well as negative personal characteristics behind the drinker identity further.

The first subcategory narrows the focus on the caring mother behind this ‘drinker’ identity. Drinking mothers shared what they would do to support other women in the community to have healthy pregnancies. The second category reveals service providers’ suggestions of how to prevent FASD in this community. Service providers situate alcohol consumption during pregnancy as an issue that could only be addressed effectively if strong networks of collaboration are established and maintained. Although this subcategory demonstrates the commitment of the community to support rather than to ostracize these mothers even further, this dedication is not evident in the support mothers were receiving while living in Pikeville.

Because alcohol consumption among pregnant women in Pikeville community is a common phenomenon, one would expect that talking about it would be relatively easy. However, mothers who participated in the study were aware of the stigma attached to alcohol abuse during pregnancy and would only discuss their drinking patterns and everyday practices when they trusted the listener.

Although other participants engaged in binge drinking during pregnancy also presented with alcohol dependency, Martha, a mother of three, was the only participant who called

herself a drinker. She abused alcohol during all her pregnancies. She described how she usually drinks:

*“As ek nou vandag of môre ‘n bietjie wyn gaan drink en my maatjies of so ... dan gaan ek dit drink, want ek is ‘n wyndrinker. So, ek is ‘n drinker en klaar.”*

*(“If I should drink some wine today or tomorrow and my friends [offer me some] or so... then I would drink it because I’m a wine drinker. So, I’m a drinker and that’s it.”)*

In identifying with being a drinker, Martha admitted to enjoying a drink whenever she was offered one. In making this statement Martha’s identification with being a drinker was separate from being a mother. However, in her opinion being a drinker did not make her less of a mother. She viewed herself as a drinking mother and that was that. A painful confession followed:

*“Ek het baie ... uitskel gekry hierso [by die kliniek] en die kindjie was baie klein in my maag. Ek het nooit amper vir haar gevoel nie. En ek het ... toe sy gebore ook was ... sy’t TB ook gehad. Ek is nie skaam om te sê nie, want dit was my fout...”*

*(“I got a lot of... scoldings here [at the clinic] and the baby was very small in my stomach. I hardly ever felt her. And I... when she was born... she had TB. I’m not ashamed to say it because it was my fault...”)*

Martha was very emotional when she discussed this incident from her third pregnancy. Yet, having the knowledge that her alcohol dependence was dangerous for her unborn baby was not enough to encourage her to maintain sobriety. The fact that Martha was accepting responsibility for her actions was also not adequate because it was clear that she needed help to manage her alcohol dependence during the time. The onus was upon her to change her behavior in this regard. Upon asking Martha what message she would give prospective mothers in her community she illustrated by using role play on how going to the tavern to buy wine and raising a child was intermingled. In this role-play she described the growth retarded child and explained how they first needed to go to the tavern before they went to the doctor with the child. She also reprimanded her partner and told him to stop drinking. This suggested role play painted a part of Martha’s life:

*“Nee, dan moet ek nou ’n pop gehad het, of iets by my gehad het. En dan sal ek sê, maar dit moet ’n maer poppie, want my kindjie was baie klein gewees. En dan ’n ou bottel by... Dan sê ek: 'Sies! Ek kan nie...' As ek die kind optel dan [begin ’n deuntjie sing - oe, oee, oe][Se vir haar man] 'Moet ek alweer smokkelhuis toe loop! Nee man! Kom saam!' En dan moet die jong mos nou sê, 'Kyk hoe lyk dié kind!' Dan sê ek, 'Laat die kind net kom!Kom saam!!' En dan moet ons gaan en as ons daarvandaan terugkom, dan moet ek sê: 'Heyyy! Kyk hoe lyk onse kinders van die wyn. Ons gaan nie meer ... grootkinders kry nie! Die kinders word op in ’n mens se maag. Kyk hoe klein is my kindjie! ... En jy sal moet ophou suip ook, dat ek kan geld in die hande kry dat ek kan by die dokter uitkom ...”*

*(“No, then I should’ve had a doll or something with me. But I’d say it would have to be a thin doll because my baby was tiny... and an old bottle. Then I would say [to my partner]: ‘Sis! I can’t.’ When I pick up the child [starts to sing a tune – oo, ooo, oo] ‘Do I have to go to the tavern again?! No, man, come with.’ And then the guy has to say: ‘Just look at this child!’ Then I’d say: ‘Just let the child come! Come with!!’ And then we have to go and when we come back, I have to say: ‘Heyyy! Look what the wine’s done to our children. We’re not going to... have big children! The children are vanishing in a person’s stomach. Look how tiny my child is!... And you also have to stop drinking so I can get some money to go to the doctor...”)*

#### **4.2.2.1 Having local role models**

A difference was discovered between the mothers’ perception of role models and that of service providers. While the service providers’ view of a role model was defined by sobriety, social standing and public conduct, Jenna and Lisa suggested that support in basic amenities like food and shelter are essential in qualifying as a role model. When I posed the question to mothers: ‘Who are your role models?’ some participants stated that they had no role models. The question was rephrased to: ‘Who do you look up to and respect in your community as well as in general?’ It was clear that these drinking mothers were respecting local women. The role models they identified were generally the older women in the settlement. Some of these women would also use alcohol and even occasionally engaged in binge drinking (as the rest of the people in the settlement). Binge drinking among the majority of women related to the practices and norms that were embedded in this community, rather than to a tendency of alcohol dependence. However, their drinking status had nothing to do with qualifying as role models. Instead,

these women were identified as role models for their ability to provide food and shelter for others who were in need.

From the larger group of fourteen drinking mothers only two responded to this question on role models. Jenna indicated that she finds her inspiration from her mother-in-law:

*“Ek bewonder my skoonma vir die dade wat sy doen. Omrede sy's ook 'n persoon wat rondkom by mense wat ook 'n kossietjie gee vir die wat nou nie het nie. Daarom, ek bewonder vir haar. ... sy loop rond, sy gee vir die mense wat nie het nie, 'n dingetjie of twee of so. Dis hoekom ek vir haar bewonder.”*

*(“I admire my mother-in-law for her deeds. Because she's also a person who comes around to people, who gives some food to those who don't have any. That's why I admire her... she walks around, she gives to people who don't have any, a thing or two or so. That's why I admire her.”)*

Lisa stated:

*“Ek bewonder dié vrou wat hier sit (wys na Jane wat langs haar sit). Vandat ek hier in Pikeville kom bly het, het ons niemand geken nie en hulle was die eerste mense. En toe ons beginne nou ... agterkom, ons kry swaar en my ma was al een wat gewerk het, daai tyd nog. En as ons nie [kos] gehad het nie, dan vra my ma by haar en sy't altyd gegee en as ons weer het en dan gee ons weer ...”*

*(“I admire this woman sitting here (points to Jane sitting next to her). When I came to live in Pikeville, we didn't know anyone and they were the first people [we befriended]. And when we started... noticing that we were struggling and my mother was the only one who worked at that time. And if we didn't have [any food] then my mother would ask her and she would always give us, and when we'd have then we'd give to her again...”)*

It should be noted that none of the quotes from Jenna and Lisa made reference to alcohol consumption or sobriety. These attributes were certainly not seen as a requirement for a role model within this context. In their view a role model is someone who can offer food and shelter to others when they need it most. These two participants aspired to be like two of the older women who lived in their own community. The fact that none of the mothers referred to alcohol consumption practices in Pikeville community illustrated that alcohol consumption in general and during pregnancy are secondary

issues to the survival issues in this community. A valuable discovery though, was the importance of collaborating with older women from the community to support, educate and inspire young women towards sober pregnancies.

*“Ek sal vir hulle alles doen wat ek kan...” (“I’d do everything I can for them ...”)*

This subcategory outlines the suggestions from drinking mothers on what they would do to prevent FASD. Wilma, a 23 year old mother of two realized after the birth of her child that, although she was young and single, she needed to experience motherhood for herself. She also realized that it was her responsibility to care for her child. This included finding a means to buy whatever her child needed and going to the shop to buy it herself.

*“Ek kan nie op mamma nie...as die kind nie dit het nie dan vra ek vir mamma as my kind iets nodig het. En ek weet nou nie eers wat om te koop nie. Jy moet self dink. Self daai deurmaak om te beseef wat 'n verantwoordelikheid 'n kind is. Dit baat nie jy wil elke keer op iemand se nek lê... hier's nie dat nie... hy gaan dit koop... Jy moet self winkel toe gaan en kyk wat die kind nodig het. Gaan tot by die winkels, gaan koop dit self. Moenie iemand anders stuur nie, of ma, ouma, auntie nie, Jy kan dit self gaan doen, want dan beseef jy jou verantwoordelikheid.”*

*(“I can’t [depend] on mom... if the child doesn’t have it then I ask mamma if my child needs anything. And I don’t even know what to buy now. You have to think for yourself. You have to go through it by yourself in order to realize what a responsibility it is to have a child. It won’t help to sponge off others all the time... It’s not like... he’s going to buy it... You have to go to the shop yourself and see what your child needs. Go to the shop and buy it yourself. Don’t send someone else, or mom or granny or aunty. You can do it yourself because then you’ll realize your responsibility.”)*

Wilma acknowledged that it took her a while to discover that this was her responsibility and that it took a while for her to adjust to her newly discovered role as mother. Wilma described an extension of this mothering role as the ability to earn money.

Upon asking what message she would give young drinking mothers, Wilma explained:

*“[Dink] Uhm... ek sal vir hulle vra as hulle sê dat soos ek mos nou voel oor die saak [they should stop drinking] en hulle verantwoordelik die kind is, hulle moet gaan werk as hulle nie werk het nie. En hulle moet om hulp gaan soek as hulle nie kan werk nie. En hulle moet dan die kind eerste sit, jy moet eers tyd vir jou kind hê. Jou kind... sorg dat jou kind aangetrek is, darem kos op die tafel het, gesond is, als dit. As dit 'n babatjie is miskien as hy nog drink, die borsie, sy melk en sy pap en sy goeters het voor jy ander dinge doen.*

*“(Think] Uhm... I'll ask them if... I'll tell them how I feel about the matter and that they're responsible for the child. They should find a job if they don't have one and they have to seek help if they can't work. And then they have to put the child first. You should first have time for your child. Your child... make sure your child is dressed properly, that there's food on the table, that the child is healthy and all of that. If it's a baby who's still breastfeeding, make sure he has his milk and porridge and everything before you do anything else.”)*

In her statement above, Wilma made a strong link between finding a job and caring for one's child. Other participants such as Hettie, Johanna and Jane also acknowledged that some mothers might need help with their responsibility of caring for their children. The type of support suggested by these participants included basic resources such as food, shelter and the need for security. Hettie explained how she would provide support for drinking mothers:

*“Ek sal vir haar vra wat sy nodig het en dan sal ek dit koop.”*

*“(I'll ask her what she needs and then buy it for her.)”*

Johanna suggested the provision of emotional support:

*“Ek sal uitvind of die vader van die kind omgee vir haar. As die vader van die kind nie omgee vir haar nie, sal ek haar help.”*

*“(I'll find out if the child's father cares about her. If the father of the child doesn't care about her then I'll help her.)”*

Jane believed that food security is critical:

*“... ek [sou] meer voedsel aangebring het, né. Om vir elkeen ‘n pakkie te voorsien het. Verstaan dat hulle midde tyd eers kan aangaan, maar dit is nie net te sê jy géé vir ‘n persoon ‘n ding nie.*

*Né, jy kan gee, maar jy's ook daar om daai persoon te ondersteun”*

*(“...I would have provided more food, right... To provide everyone with a [food] parcel... Understand? That they could go on with in the meantime. That’s not to say that you just give a person something. You can give but you’re also there to support that person.”)*

Jane’s statement emphasized that the provision of material resources was only part of the support these mothers needed. In addition to food and shelter a need for safe spaces was also identified.

#### A safe space to talk

Wanda admitted that she had difficulty trusting people. As a result she binged whenever she felt troubled. This suggested the need for talking to someone she could trust whenever she needed to:

*“As ek ‘n probleem het, dan...ek praat nie ek gryp... gaan drink net... praat nie met iemand daaroor nie... [As jou man jou so kwaad maak dat jy net wil drink dan sal ek vir jou sê...] gaan praat met iemand wat jy vertrou, maar ek vertrou niemand nie want ek het nie familie in Pikeville nie, ek kan vir niemand vertrou nie.”*

*(“If I have a problem then... I don’t talk [about it]. I grab... just go drinking... don’t talk to anyone about it... [If your husband/partner makes you so angry that it drives you to drink, I’d tell you...] Go talk to someone you can trust but I don’t trust anyone because I don’t have any family in Pikeville. I can’t trust anyone.”)*

#### A safe place for shelter:

Another critical need identified by Wilma was the need for safe accommodation within the community:

*“Dan sal ek vir my 'n erf gekoop het. Ek sou 'n huis laat bou het daar en al daai kindertjies gevat het en die ma's en hulle versorg. Ek sal met hulle gesels het en vir hulle... vir die kindertjies sal ek miskien aangetrek het... miskien het hulle nie skoene nie, nie klere nie. Verstaan jy... kos gegee het. En vir die mamas sal ek verduidelik het waarom gaan dit... daar is hulp vir hulle. Daar is 'n lig in daai tunnel wat sy deurmaak.”*

*“Ek sal al die mamas vra of hulle nie vir 'n tydperk by my wil bly nie tot wanneer hulle moet geboorte gee nie. In daai tyd sal ek vir hulle alles doen wat ek kan. Ek sal vir hulle gemaklike kooie gee, vir hulle gesonde kos gee. Ek sal laat hulle by my bly totdat almal fine is. Hulle kan nie drink nie.”*

*(“Then I would've bought myself a plot. I would've built a house and taken all those little kids and their mothers in with me and taken care of them. I would've talked to them and... I would've gotten the children dressed... perhaps they wouldn't have shoes or clothes. Do you understand... given them food. And I would've explained to the mothers what it was all about... that there is help out there for them. There is a light in that tunnel that she's going through.”)*

*(“I'd ask all the mothers if they'd like to stay with me until it's time for them to give birth. During that time, I'd do everything I can for them. I'd give them comfortable beds and healthy food. I'd let them stay with me until they're all fine. They couldn't drink though.”)*

Wilma continued with a suggestion for alcohol free spaces:

*“As hier meer ontspannings...onthale is oor die naweke vir die jongmense... en waar nie alkohol betrokke is nie... so... jong kinders moet lekker die jongmense kan gesels en goete kan doen... om meer jongmense te lok. Dan gaan dit miskien begin met 'n handjie vol dan moet daai wat gekom het die boodskap uitdra wat daar gebeur het. So dan lok dit nog jongmense en môre oormôre sien jy... dit hoef nie die hele gemeenskap jongmense wees nie, maar dat die boodskap kan uitdra, sien?”*

*(“If there were more recreational... functions over the weekend for young people... and where alcohol is not involved... so... young children should be able to have nice talks with young people and they should be able to do nice things... to attract more young people. It*

*might only start with a handful [of youngsters] but those that will have come, would then spread the word as to what happened there. And that way more young people will be attracted and before you know it, you'll see... it doesn't have to be all the young people in the community but what's important is that the message gets out there, you see?")*

In support of the mothers' suggestions for preventing FASD, service providers added a collaborative approach to preventing FASD. Whereas the mothers' contribution to FASD focused on the need of individual mothers, the contribution of service providers focused on the macro factors that need to be addressed. A combination of micro and macro approaches was proposed for strengthened FASD prevention initiatives in Pikeville.

*"Dis almal se verantwoordelikheid" ("It everyone's responsibility")*

Service providers were aware that women were not able to win this fight against alcohol consumption during pregnancy on their own. They suggested that the wider community and organizations should also provide support. Participants highlighted the importance of collaborations between organizations and even across sectors. Due to the intensive nature of prevention initiatives that are needed in this community, non-governmental organizations were identified as one of the role-players. Rony stated:

*"uhm, want ek dink die voorkomingswerk wat [NGOs] doen is baie, baie goed omdat dit intensiewe voorkoming is"*

*("uhm, because I think the preventive work that [NGOs] do is very, very good because it's intensive prevention.")*

Stanley highlighted the importance of the schools becoming involved in creating awareness among children of responsibility toward their own health as well as the health of their community:

*"n skool is 'n nodal point vir ontwikkeling in 'n gemeenskap , want elke gemeenskap het feitlik 'n skool. So alles moet by daar skool gebeur. Ontwikkeling , gemeenskapsvoortgang moet by die skool plaasvind."*

*(“a school is a nodal point for the development of a community because every community has a school, in fact. So everything has to happen at that school. Development – the prosperity of a community should happen at the school.”)*

Community members also have a role to play in guiding young people in the community. Dan said the following:

*“As, as as moral restor[ation] - ek weet dit is 'n baie steil pad, want hoe doen 'n mens dit? Maar as dit [morals] ge-restore raak, dan weet 'n persoon wat my verantwoordelikheid is as 'n mens en nie as 'n citizen of as 'n ou wat hier bly nie. Automatically as ek 'n laaitietjie sien rook, dan stop ek hom en sê, 'My broer, gee daai entjie hiersô! Jy's te jonk.' Sy ma gaan nie vir my kom staan want ... sulke, sulke goeters, man. Dit moet deel raak van mense.”*

*(“If moral restoration – I know it's a steep road because how do you do it? But if it [morals] is restored, one would know his responsibilities as a person and not as a citizen or a guy living here. If I see a little boy smoking, I'd automatically stop him and say: 'My brother, give that cigarette to me! You're too young.' His mother wouldn't then come to me and... because things like that man. It has to become part of people.”)*

Leonie, a youth worker of FASed added:

*“dit[is] almal se verantwoordelikheid om te sê moenie dit doen nie...”*

*(“it's everyone's responsibility to say don't do that...”)*

### Opportunities for socialization without wine

Gillian, the director of the local adult basic education and training center in town, shared her dream of teaching people how to socialize without having to use alcohol excessively:

*“naweke is die mense se groot drink tyd, want hulle kry Vrydae geld... daar word nie iets gerêel om daai mense rêrig te akkomodeer om hulle occupied te hou vir daai tyd dat*

*hulle sodoende afskaal totdat hulle op daai stadium kom dat daar niks meer is nie... Al kry jy dit met twee en drie reg, so be it.”*

*(“Weekends are people’s biggest drinking time because they get paid on Fridays... Nothing’s really organized to accommodate people, to keep them occupied for a certain time so that they can scale down [on the drinking] before there’s nothing left... If you get that right with just two or three people, so be it.”)*

Monica, a teacher at the adult basic education and training center suggested the following:

*“Ons moet dit [opvoeding oor alkohol] deel van ons kultuur, deel van die leerproses maak dat die kinders kan weet. Kinders is mos nie almal dieselfde nie. Die enetjie loop, hy doen sekere goeters reg dan loop hierdie drie loop die pad reguit, daai twee is weer heeltemal los!, soos weglê eiers soos my ma wou gesê het. En dan gaan hulle die, gaan hulle die pad heeltemal byster en hulle het dieselfde opvoeding gekry. Maar miskien moet 'n mens daarin gaan...”*

*(“We have to make it [education about alcohol] part of our culture, part of the learning process so that children can know this. Children aren’t all the same. The one walks, he does certain things right, these three walk down the straight path and then those two are totally out of control! Like eggs that are hidden away, as my mother used to say. And then they totally lose their way while they had the same education. But maybe one should look at that...”)*

Dan stated that the education to women should be supplemented with opportunities to explain in detail why mothers should not consume alcohol during pregnancy. These warnings should be coupled with reasons why alcohol consumption during pregnancy is harmful for the unborn baby.

*“Nie net uhh, nie net sê jy mag nie drink nie... daar’s nie vir hom iets oor hoekom hy nie mag drink nie.”*

*(“Not just uhh, not just say that you may not drink... there’s nothing about why he may not drink.”)*

Education on healthy alcohol use should be incorporated in the school curriculum:

*“’n Mens moet maar seker by die jong kinders... dit help nie jy gaan nou met grootmense begin nie. Hulle besluit wanneer hulle wil en ek sal ophou drink wanneer ek wil. ’n Mens moet maar seker by ons by ons kinders begin. Uhh uhh daar moet seker en dit moet sekerlik uhh ek meen al die jare gee ons gesondheidsopvoeding en nou is dit lewensorientering onderrig op skool.”*

*(“We probably have to start with the young children... it won’t help to start with the adults. They decide when they want to drink and when they want to stop. We probably have to start with our children. Uhh uhh, there probably has to and uhh... I mean we did health education for all these years and now they’re teaching life orientation at school.”)*

Educating on balancing occupations

Pregnant women need to be introduced to activities that can fill their time in a constructive way. Stanley suggested the following:

*“Uhm... so is is seker meer om aktiwiteite daar te stel vir swanger vroue. So ’n voorstel wat ek sou wou maak is ’n tipe van ’n ’n dat daar uhm... sê samestelling kom van vroue... swanger vroue spesifiek om vir hulle aktief betrokke te hou. Uhhh want, as jy vat jou hele dag is ledig..uhm wat doen jy?”*

*(“Uhm... so it’s probably to get more activities for pregnant women. A suggestion I’d like to make is to have a type of uhm... let’s say a gathering of women... pregnant women specifically, to get them actively involved. Uhhh, because if you think about it, you have nothing to do all day... uhm, what do you do?”)*

The programs targeting pregnant women should be tailored to their needs. Stanley continued:

*“...ek sal voorstel is dat so 'n program van stapel gestuur moet word wat direk fokus op swanger vroue en dat jy eintlik gaan en 'n studie maak van wie is swanger sodat jy nie noodwendig in die lug hoef te praat nie en net 'n general advertensie uitsit nie maar dat jy eintlik gaan en 'n behoefte bepaling gaan maak en sien die is die mense wat dit regtig nodig sal hê.”*

*(“... I would suggest the launch of a programme which focus directly on pregnant women, and that you actually do a study of who the pregnant women are so that you don't have to talk in the air and just produce a general advertisement but that you actually go and do a needs analysis in order to see who the people are that you're going to need.”)*

During these interventions pregnant women need to be assisted in understanding how alcohol affects the physical and neurological development of the unborn baby. Leoni critiqued the approach of current initiatives:

*“Al wat hulle elke dag gesê het, is 'Jy moenie alkohol drink as jy swanger is nie'. Maar 'n vrou wil mos nou nie dit weet nie. Sy wil nou maar weet, maar wat gaan dan nou gebeur?”*

*(“The only thing they said every day was: ‘You shouldn't drink alcohol when you're pregnant.’ But a woman doesn't want to know that. She wants to know what will happen [if she drinks alcohol while she's pregnant.]”)*

All the suggestions above would be important in supplementing any FASD initiative. However, none of these suggestions addressed the assistance mothers needed to stop their dependence on alcohol. From the data gathered it became clear that service providers, stakeholders and the partner expected mothers to stop drinking on their own. This expectation was however not coupled with the support mothers need to abstain from alcohol use during pregnancy. This highlights the need for an alternative approach from service providers, partners and close family members to adjust their role in order to ensure that mothers are linked to resources that will support healthy pregnancies and thus prevent FASD.

## Changing existing perceptions around FASD

Participants identified the importance of having the right attitude when addressing the issue of alcohol abuse and binge drinking among pregnant women in their context.

Dan explained:

*“...hier [in Suid-Afrika] het soveel klomp ander sensitiewe goed gebeur in Suid-Afrika... dat, ek meen nou. Vir ‘n plaaswerker, ek meen daar gaan nou duisende rande in om ‘n plaaswerker net te sê: 'Dit wat jy doen is nog steeds belangrik. Jy is ‘n belangrike persoon.’ Want wat het veroorsaak dat die stigma kom dat die plaaswerker ‘n swak persoon is, of dat iemand wat drink ‘n swak persoon is? Of dat iemand, you know?’”*

*(“... so many other sensitive things happened here in South Africa... that.. I mean. A farm worker, I mean thousands of rands are being spent just to tell a farm worker: ‘What you do is still important. You’re an important person.’ Because what caused this stigma that led to a farm worker being considered as a weak person or that someone who drinks is a weak person? Or that someone... you know?”)*

Dan’s statement highlights the legacy of colonization which resulted in farm workers being portrayed as a person with less worth in South African society just because they abuse alcohol. Stereotypical attitudes may marginalize people who are in dire need of support:

*“n uitdaging wat ons dalk het is wanneer dit kom by probleme oplos in 'n gemeenskap dan die storie van kom met 'n 'ons' en 'n 'hulle' attitude. 'Us' and 'them' Ons is die...ons weet van beter ons gaan vir julle wat nie weet nie gaan ons nou iets aanbied. Dit is gewoonlik iets wat mense...mense wegdryf...”*

*(“a challenge we may face when it comes to solving problems in the community is the story of an ‘us’ and ‘them’ attitude. ‘Us’ and ‘them’. We are the... we know better, so we’ll present something to those of you who don’t know. That’s usually something that... drives people away...”)*

Health professionals or other service providers who are at the forefront of prevention initiatives should therefore be well-trained to offer an appropriate service:

*“So ons moet net seker maak dat die mense wat ‘n channel raak vir ons - soos die susters, of ‘n pastoor of whatever - laat hulle nie ... Hulle moet ingelig wees of hulle moet vir ons net al hulle mense gee, dat ons kan ingaan en mense gaan kry. Want, ek meen, as ons kom ook by skole en dan praat jy nog net van Fetale, dan haal hulle sommer kinders uit wat hulle dink Fetale Alkohol Sindroom het. Maar dit is nie waarom...- ons voorkoming van Fetale Alkohol Sindroom... Ons wil met almal werk”.*

*(“So we just have to make sure that the people who become a channel for us – like the [nursing] sisters or the pastor or whatever – that they don’t... They have to be informed or they have to give us all their people so that we can go in and get some people. Because I mean, when it comes to schools, we only talk about [alcohol] fetal [syndrome] and then they just pick out the children whom they think have Fetal Alcohol Syndrome. But that’s not what it’s about... our prevention of Fetal Alcohol Syndrome... We want to work with everyone.”)*

#### Knowing how to work with this community

Dan and Leoni agreed that information on FASD prevention should be distributed wider than only to women of child bearing age and pregnant women. Women who consumed alcohol would always refer health workers who approach them to other women who consumed alcohol without admitting that they needed assistance too:

Leoni, a worker for FASed explained her experience as follows:

*“Maar ek dink dit is wat daar gebeur het. Hulle het ... agterna dan sê hulle: 'Daaie ene drink ook, daaie ene hê gedrink terwyl sy swanger was, so vat maar vir hulle. Hulle het dit nodig.' Maar dit is nie net hulle wat dit nodig het nie. En ‘n mens sluit dan ander mense uit.”*

*(“But I think that’s what happened there. They... afterwards they say: ‘That one also drinks. That one used to drink while she was pregnant, so you can take them. They need it.’ But they aren’t the only ones who need it. Other people are excluded this way.”)*

Rony, a local councilor suggested that the family and the whole community should get involved in prevention campaigns. He argued that by involving the family, awareness can be raised with children while they are still young:

*'Die boodskap moet gaan...ek dink nie dit sal net fokus op die vrou nie, want want dit baat nie die vrou probeer wegbly en dis die man wat wyn inbring in die huis en of die kinders of so nie.*

*"So die boodskap moet gaan na almal toe want aan die einde van die dag voel ek dat die meeste vroue vou wanneer hulle swanger en in die algemeen omdat hulle nie noodwendig die support base het in die huis nie. Uhm, sodra 'n mens daai overall ding begin aanspreek wat jy sê dat swangerskap is 'n proses en dis 'n proses nie net vir die vrou nie, maar vir die hele gesin gesamentlik... Jy't daai tipe famileband ondersteuningsbasis ding gebou... dat jy dan so 'n boodskap uitgee vir almal gesamentlik om vir hierdie kind voor te berei. Uhm, so ek sal sê die boodskap wat uitgaan om nie te drink tydens swangerskap nie moet gaan na almal, man en vrou en die ander kinders wat daar is... maar ek voel net persoonlik dit moet nie net gaan na die vrou toe nie, want dit is hoe dit in die stories gebeur. Die posters wat gewoonlik opgaan is vir is vir...target die vrou...uhm...en dit werk nie...[lag] Ons almal weet... dit is nie noodwendig so suksesvol nie..."*

*("The message should be... I don't think it should just focus on the woman because what's the point of the woman trying to abstain when the husband/partner or the children bring wine into the house. So the message should be directed at everyone because I feel, at the end of the day, women fold when they're pregnant and also generally, because they don't necessarily have that support base at home. Uhm, as soon as we address this thing overall, explaining that pregnancy is a process not just for the woman but for the entire family as a whole... You will have built a type of family bond, a support base... this message should be given to everyone collectively in order to prepare this child. Uhm, so I'd say the message not to drink during pregnancy should be directed at everyone: man, woman and children... personally, I feel it shouldn't just be aimed at women because that's how it happens in movies. The posters are usually... usually target the woman... uhm... and that doesn't work... [laughs] We all know... that it's not necessarily successful...")*

Rony argued that direct contact (in terms of ensuring that people understand the content of the written material as well as the implications of what is being explained) is needed in addition to distributing information via written media:

*"Posters alleen...dit gaan nie noodwendig, dit los nie noodwendig die problem...dit help as jy dit help deur mense te begin aware te maak...en dit stop daar... Nou, nou mense wil weet van van... nou vra hulle wat is dit? Nou die poster kan nie vir jou verduidelik wat dit is nie...uhh Jy kan net soveel goed op 'n poster sit. Pamflette byvoorbeeld jy kan drank [inaudible...] sit, maar baie mense lees nie, baie mense is ongeletterd. So, so watter tipe mens moet al die tipe...mens moet*

*eintlik 'n gesamentlike proses hê. As jy besluit op gedrukte media dan moet jy ook die tipe van kontak hê, direkte kontak saam met saam met die mense wat jy wil bereik”*

*(“Posters alone... won’t necessarily... doesn’t solve the problem necessarily. It only helps to make people aware... and that’s where it ends... People want to know about... they ask what it’s about.*

*The poster can’t explain everything. Uh, you can only put so much on a poster. You can put alcohol on pamphlets for instance [inaudible]... but a lot of people don’t read; a lot of people are illiterate. So what type of people... one should have a collective process. If you decide to go with print media then you also have to have the type of contact... direct contact with the people you’re trying to reach.”)*

A few other participants made suggestions of others ways of disseminating information on FASD prevention. Dan was excited when he suggested ways in which the existing prevention strategies could be supplemented:

*“I will make use of the media. I would distribute pamphlets with all the information about FAS. People like to read pamphlets. If somebody cannot read there is always a close family member or neighbor who will read to them. People also spend a lot of time watching TV... Sewende Laan (an Afrikaans soap). Not many may listen to live radio programmes... they will only listen to music from a tape recorder or CD’s.”*

Mark, a development worker from The Department of Social Development, suggested communication that focuses on community development:

*“as ons praat van ontwikkelingsgerigte kommunikasie... Dat jy nie net vir iemand 'n pamphlet gee of 'n poster posit en dan gaan jy nie. Uhm, ek sien as jy rondom die boodskap gaan en jy kan deur jou vennote : die kliniek uhm die Badisa, ACVV almal die organisasies, jy kan gesamentlik kan identifiseer wie is die mense wat swanger is en jy kry al daai mense en jy vorm 'n groep., 'n support groep dan kan jy 'n workshop aanbied binne in die gemeenskap sê elke maand...het jy 'n tipe van 'n workshop en dan vat jy veral die gevaar van swangerskap.”*

*(“if we talk about communication that focuses on development.... That you don’t just give someone a pamphlet or put up a poster and then leave. Uhm, you can talk about issues surrounding the message and with the help of your partners: the clinic, uhm Badisa, ACVV, all of these organizations; together you can identify those who are pregnant and you can get those people to form a group... a support group and then you can run a workshop in the community,*

*say every month... you can have a type of workshop where you especially talk about the dangers of pregnancy.”)*

Dan echoed the need to focus on development of individual capacity and more specifically with people who are currently struggling with diminished intellectual and social capacity as a result of the lifelong effects of alcohol:

*“Ek voel altyd ‘n groot social responsibility so ook ‘n economic responsibility, so ek sou wou daai persoon met sy strengths, wat nou weaknesses is, sy, sy hiperaktiwiteit en daai goed, sal ek in strengths probeer omsit en kyk hoe daai ou economically kan survive. En vir hulle in sulke rigtings stuur, because as ons in Suid-Afrika nie gaan fokus nou op kinders wat gebore word met Fetale Alkohol Sindroom nie, of wat Fetal Alcohol exposure het nie, dan oor tien, twintig jaar is daar ‘n redelike persentasie grootmense in die land in wat [sonder werk gaan sit]”.*

*(“I always feel I have a great social responsibility as well as an economic responsibility, so I would like that person with his strengths, that are weaknesses now... his hyperactivity and things like that, I’d like to convert it to strengths and see how that guy can survive economically. And send them in such directions because if we don’t focus on children with Fetal Alcohol Syndrome in South Africa or those who had Fetal Alcohol exposure then we’ll have a reasonably high percentage of adults in the country [without work] in ten or twenty years.”)*

Dan believed that a real turning point could only be reached if alcohol affected people were assisted towards becoming economically active:

*“So ek sou graag wou daai ouens na ‘n sekere punt toe wou vat, man. En, en vir hulle help om selfstandig te raak in ekonomiese gebied.”*

*(“I would like to take those guys to a certain point, man. And I’d like to help them become self-sufficient on the economic front.”)*

After raising her first alcohol-affected baby Wilma promised herself not to consume alcohol during her second pregnancy. She realized that excessive alcohol use destroyed her future. She argued that if she had not used alcohol excessively she would not have been pregnant and that she might have reached more goals in life:

*“ Hulle moet ophou drink terw... al is hulle nie swanger nie vir hulle toekoms, want wyn vernietig jou toekoms. Ek gee nie wyn die skuld nie, maar ek meen nou maar. Was dit nie vir die wyn nie sal ek nie vandag 'n kind gehad het nie, swanger gewees het nie. Want uit daai...hoe die kêrels en ...verstaan?...Jy't 'n toekoms voor jou, jy kan skool toe gaan vir geleerdheid. Maar nou begin drink jy, jy wil ook nie meer skool gaan nie en jy't nie 'n toekoms eintlik nie...Verstaan? ...jy gooi jou lewe weg ter wille van drank. Dat jy miskien nou nie drink nie, waar jy's meer gefokus op jou goed en jy kom ver. Dis nou my punt as jy ophou drink...”*

*(“They have to stop drinking while... even if they’re not pregnant, for the sake of their future because alcohol destroys your future. I’m not blaming the alcohol but I just mean... If it weren’t for the alcohol, I would not have had a child today. I would not have become pregnant. Because of that... how the boyfriends and... understand?... You have a future ahead of you, you can go to school to get an education. But then you start to drink and you don’t want to go to school anymore and you end up not having a future... Understand?... You throw your life away for the sake of alcohol. If you don’t drink, you’re more focused on your things and you get far. And that’s my point, if you stop drinking...”)*

She also realized that alcohol cannot solve problems:

*“drank kan nie help nie, want die drank is 'n tydelike ding. Jy drink dan raak jy nugter dan kry jy maar net weer dieselfde gedagte.”*

*(“alcohol can’t help you because alcohol is a temporary thing. You drink, you get sober and then you have the same thoughts again.”)*

The above quotes highlight the importance of teaching the appropriate use of alcohol to children from an early age. Comments within this category related to changes that need to be made to the infrastructure and existing services. These suggestions were made in addition to the contributions from mothers articulated in 3.1.1. When developing information on FASD prevention the contextual background and the personal life stories of mothers as well as their suggestions for creating safer environments should be considered. All prevention initiatives should be tailored to address specific individual needs as well as addressing institutional, societal and contextual barriers.

## CHAPTER FIVE

### DISCUSSION

#### 5.1 Introduction

The findings illustrated how alcohol consumption among women before, during and after pregnancy is a practice that is integrally part of the occupations in Pikeville community. Women, their partners, friends and service providers alike acknowledged excessive alcohol use as a normalized practice in their community. This chapter will explain how alcohol abuse in Pikeville community is an expression of domestic violence, abuse and colonialism. These types of structural oppression will be discussed in relation to the values, beliefs, norms and practices of people who live in Pikeville. Illustrations of the structural factors as main contributing influences to prenatal alcohol consumption (as explored in Chapter Four) will be used to suggest a different approach to health promotion in FASD prevention among women of childbearing age in contexts similar to the research study context. Literature will be used to explain how generational trauma can be expressed in different ways in different populations across the globe.

#### 5.2 Alcohol consumption among women as an expression of oppression

Zeldenryk and Yalmambirra (2006) stated that occupational therapists should know and understand the history of oppressed indigenous groups if they want to fully appreciate the impact of occupational deprivation. In similar terms it is crucial to fully understand that the residents of Pikeville as an equally oppressed group were deprived of certain social, economic and political rights. Traditional cultures were lost and with it the knowledge of indigenous occupations. Communities who lost their sense and meaning from not participating in culturally significant occupations thus fail to develop a “genuine identity within their community” (Zeldenryk and Yalmambirra, 2006:45). This lost sense of identity was passed down through the generations. Disenfranchised groups were forced to find a new sense of identity in superficial familial and social relations. Ross (2010:23) emphasizes this predicament in the following quote:

“Under apartheid, racial classification for Colored people rested partly on whom one associated with, and family relations were stretched and torn by the requisites of

‘passing’ in class and race terms. Apartheid’s legacies remain powerful. Fine gradations such as association, comportment, place of residence, manners – continues to mark people’s social standing”

It is at this juncture that current contextual factors in addition to the historical background of families who are current residents of Pikeville become a starting point of understanding alcohol consumption during pregnancy and FASD. The existing literature on women at risk of having children with FASD tends to be reductionist in identifying and addressing FASD. In an attempt to address gender violence on farms in the Western Cape, Women on Farms (a South African non-governmental organization) trained farm worker women in self-assertiveness and is setting up advice office services to support women who are victims of gender violence (Women on Farms, 2011). Yet, more has to be done to address the poor state of the housing and basic infrastructure available in settlements such as Pikeville, the low wages (and often no wages) these women and their families receive, (R1 189 per month according to 2001 census) and the extent of displacement experienced as a result of lawful or illegal evictions (SA Wine Council, 2007).

The literature is devoid of any descriptions that give recognition to the rich and positive attributes of this group of marginalized people. Therefore, instead of exclusively focusing on deficits or risk factors, this study encourages the use of positive attributes as a way of presenting the residents as human beings. By including positive values of research participants a more balanced picture is provided. The final reason for including positive attributes of residents is to attempt to recognize and build the human dignity of this group that had been eroded over time because of human injustices. This process of recognizing marginalized groups as agents in promoting their own health and the health of their families and other community members will actively involve them in transforming their own occupational engagement. This process will facilitate actions that will encourage individuals to ‘do with each other’ rather than being ‘done to’ by health professionals and service providers.

### 5.2.1 Excessive alcohol consumption as a normalized practice

Theme 1 centers on the subculture of abusing alcohol within a context where excessive alcohol consumption is normalized. The drinking mothers and service providers alike confirmed that the phenomenon of drunken adults and parents is a common one in this community. The adults from this community are therefore 'known' for drinking excessively across the generations. The claim of excessive drinking would also not be untrue for most. However, when the individual is being defined by a practice only and not by all the other aspects that have an influence on his/her life it becomes a problem. The action of taking a complex multi-faceted phenomenon, such as excessive alcohol use by large groups of people and all the practices, beliefs and values that such a group of people have acquired and reducing this phenomenon to a few basic and inherent 'essences' (that often present a false account of the situation) to explain this group in totality is termed essentializing (Masselink, 2008). Descriptions that essentialize are often ahistorical and they have the capacity to distort realities in a way that maintains the very conditions that caused the problematic practices, beliefs, and values in the first place (Ibid). Unfortunately, perceptions of society become internalized as individuals, groups and communities are being treated accordingly. Individual perceptions are reinforced by the way family service providers, people outside of the immediate community and the media depict affected persons (e.g. mothers who consume alcohol during pregnancy who are being depicted as uncaring, irresponsible or lazy). By essentializing such characteristics of women who live in communities similar to Pikeville and with similar historical backgrounds as these women it is impossible to identify and address the structural factors that contribute to alcohol consumption during pregnancy. By focusing on how to address only some of these characteristics identified in women who are at risk of alcohol exposed pregnancy, existing research on FASD prevention runs the risk of reinforcing essentialized perceptions of black mothers.

All the participants lived in Pikeville and some of them even grew up in this community. Yet, none of them identified any underlying causes. Addressing the issue of why people (and mothers) consume alcohol to the extent that their health and the health of their offspring are being compromised, will begin to highlight structural issues, such as unequal distribution of resources and socio-economic status, contributing to this problem. It is possible that service providers may not be aware of such causes or that

they do not understand the link between the underlying causes and alcohol consumption during pregnancy. The lack of awareness among service providers in health care, educational services, and social services may aggravate the marginalization of persons with FASD. The functional limitations caused by FASD affect a number of neurological, cognitive and behavioral capacities in those who are affected. These limitations require special consideration and these individuals often need an 'external brain' (Andrew, 2011) to negotiate their school careers, their work careers and their social lives. For example, there might be learners with undiagnosed FASD in special schools or mainstream schools, who may experience learning difficulties or struggle with behavioral problems. However, with the underlying problems not being identified such children may be viewed by teachers and peers as ill-disciplined. Such learners may feel ostracized and misunderstood and might not be getting the necessary support needed to progress through their school careers. Within the health system, service providers may find it challenging to work with undiagnosed individuals with FASD (May, 2005). Service providers may perceive them as non-compliant with health interventions. It is important, however, that other risk factors, such as alcohol dependency and other mental health concerns of mothers should not be ignored. An argument is made for a more balanced approach that will move the focus away from the characteristics of mothers and towards the root causes of alcohol consumption during pregnancy and the supports that need to be put in place to ensure healthy pregnancies. Taking an occupational determinant perspective (Scaffa et al., 2010) on FASD prevention will encourage health practitioners to ask 'but-why'-questions (Hope and Timmel, 2007).

It is not enough to know about FASD and its functional implications. Ideally service providers should actively contribute to identifying and addressing barriers that might prevent persons with FASD to fully access and participate in obligatory occupations and other occupations of meaning and development. Stadnyk et al. (2010:332) argue that "when people experience justice or injustice they are not fully aware of the invisible decisions about policy, professions, health, economics, social welfare, education, transportation and industry that determine possibilities for participating or not in various occupations or the function of the state in regulating or otherwise influencing what they

do". Without the process of critical conscientization<sup>46</sup> (Freire, 1972) service providers as well as drinking mothers will constantly face the challenges that are caused by macro influences on the context without identifying the root problems and addressing these. Service providers and drinking mothers alike will therefore remain part of a marginalized group in Pikeville.

It is at this point that the traditional approach to health promotion and prevention of FASD is challenged. The traditional focus of health promotion initiatives is on encouraging the individual to make the needed behavioral and habitual changes that could improve health and well-being. The emphasis is placed on the individual's beliefs about health practices (Becker, 1974; Glanz et al., 2002) and self-efficacy (Wood & Bandura, 1989). Very little emphasis is placed on communal support; communal engagement in occupations of meaning; and the nature, content and appropriateness of prevention material.

The findings showed that alcohol consumption during pregnancy was viewed by residents as a symptom of underlying problems (domestic violence, sexual violence, poverty, unemployment, poor maternal mental health, generational trauma). What was initially viewed as an individual problem of the mother should rather be viewed as a combination of alcohol dependence as the expression of prolonged socio-political and economic conditions. While some forms of public health recognize social determinants and politics in the promotion of health (Cook, 2005), more should be done to implement initiatives that address the socio-political and economic aspects of this issue. This approach will highlight the structural issues that contribute to excessive alcohol use among the wider community and women of childbearing age. By viewing excessive alcohol use within Pikeville as an individual problem the tendency has been and will continue to be an individualized problem followed by an attempt to 'fix' the individual. However, the approach of the latest FASD clinical guidelines remains very individual-oriented. One of the limitations of this FASD Guideline Summary is that structural factors are not considered as part of the intervention. The main objective in the latest FASD clinical guidelines for alcohol use and pregnancy is to establish national standards of care for

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<sup>46</sup> Critical conscientization is process whereby critical awareness is raised regarding underlying social, economic and political factors that maintain and perpetuate oppression and marginalization.

the screening and recording of alcohol use and counseling on alcohol use of women of child-bearing age and pregnant women. Regular maternal alcohol screening and periodic screening of women of child-bearing age will include the following:

- a) Single question method – this is the most brief screening tool that consists of a question related to alcohol intake: How many times in the past year have you had...
  - **5 or more** drinks in a day? (for men)
  - **4 or more** drinks in a day? (for women)
- b) Motivational interviewing - is a directive, client-centered counselling style for eliciting behaviour change by helping clients to explore and resolve ambivalence (Miller and Rose, 2009). Intensive cultural-, gender-, and family-appropriate interventions need to be available and accessible for women with problematic drinking and/or alcohol dependence. If a woman continues to use alcohol during pregnancy, harm reduction/treatment strategies should be encouraged.
- c) Supportive dialogue – dialogue is used to foster scaffolded instruction to women **of** childbearing age. This technique should be explored further as a tool for teaching comprehension strategies on the dangers of drinking during pregnancy among second generation FASD mothers. Health care providers should create a safe environment for women to report alcohol consumption. Health care providers should be aware of the risk factors associated with alcohol use in women of reproductive age.
- d) Structured questionnaires could be used for maternal screening purposes. Maternal alcohol screening and recording by health care providers could lead to a reduction of primary disabilities associated with FASD as well as a reduction of secondary disabilities often related to FASD in the absence of diagnosis and appropriate interventions. Universal screening for alcohol consumption should be done periodically for all pregnant women and women of child-bearing age. The public should be informed that alcohol screening and support for women at risk is part of routine women's health care.
- e) Laboratory-based screening tools - Toxicology tests are costly and are associated with laboratory analysis to determine blood alcohol concentration levels of

pregnant mothers. Accessibility to these tests may be a problem if services are not subsidized by the government or private agencies.

- f) Clinical preventive action was found to be successful according to expert opinion. Health care providers should advise women that low-level consumption of alcohol in early pregnancy is not an indication for termination of pregnancy (Carson, et al., 2010).

This approach taken in these guidelines goes against the principle of empowerment and overall community development as the expert remains in the position of power to devise solutions to this problem. Working towards empowerment of women and community development requires a shift in focus from the individual women to the communal and structural factors, without excluding the person. This means that women and service providers should be equally empowered to name their realities and voice solutions. Spivak (1988:24) stated that the processes of colonization in the eighteenth century obliterated the “textual ingredients with which ...a subject could cathect, could occupy or invest its itinerary, not only by biological and scientific production, but also by institution of the law”. The effects of colonization were obviously most intense on the indigenous nations. Spivak refers to Guha’s proposition for a dynamic stratification grid describing colonial social production as a useful one (Guha,1982). Guha represented different strata of people in a colonized country in sequence from top to bottom as: the dominant foreign groups; the dominant indigenous groups at national level; dominant indigenous groups at the regional and local levels; and the subaltern classes. The subaltern classes refer to those people whose voices have been previously silenced by dominant ideologies. Spivak (1988) recognized the representation of a subaltern voice<sup>47</sup> as a problem because of the possibility that such representation would essentialize its message and negate the heterogeneity of the subaltern ‘masses’. This was illustrated by the fact that Rony had strong opinions that he shared confidently. The listener had to distinguish carefully between whose voice was represented when Rony came across as if he was providing a represented account from service providers and drinking mothers who live in Pikeville. When referring to crime in Pikeville, Rony stated the following:

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<sup>47</sup> Subaltern group is a group of people who have been oppressed for generations. They have lost the ability to speak their reality and have no consciousness of their own culture because they have lost connection with their culture. As a result they lack individual and social identity.

*“wat vir my positief is dat [die dorp] nie so hoë misdaad syfer nie...oor die algemeen is [dit] 'n rustige dorp. Jy kan saans laat buite loop jy kan saans buite op die stoep nog slaap wat vir my sê dis rustig daar's nie daai skollie element...ons sit nie eens met bendes op [die dorp] ....”*

*(“What’s positive for me is that [the town] doesn’t have such a high crime rate... in general, [this] is a quiet town. You can walk around late at night. You can still sleep on the stoep at night, which tells me that it’s peaceful. There’s not that gangster element... we don’t even have gangsters in [town]...”)*

When compared to the mothers’ stories on gender violence Rony’s view is clearly not representing the women’s experience and views on the matter. A compromised alternative would serve the purpose in the form of strategic essentialism whereby the person who represents the subaltern class uses a clear image of identity to fight opposition (Spivak, 1990). A problem arises however, when the group who is being represented lost individual and cultural identity centuries back and has very little or nothing upon which to draw. Only two service providers (Rony and Amanda), one mother (Martha) and Rob (the only male partner who participated) confirmed that excessive alcohol use was an endemic and problematic practice. Martha (one of the mothers) confirmed this by stating that her parents drank excessively for as long as she could remember. Rony, who grew up in Pikeville claimed that excessive alcohol use was not such a general problem in the 1980’s. Unfortunately, South African systems to record substance use before the 1900’s had not been reliable in the sense that the only available information comes from ad-hoc cross-sectional research studies that collected data from certain locations (Parry, 1998). Specific alcohol consumption rates for informal settlements and townships are therefore not available. A WHO Report states high levels of drinking in low and middle income countries like Argentina, Costa Rica, Mexico, Brazil, Sri Lanka, India, Uganda and Nigeria (Obot & Room, 2005). Although South Africa was not listed in this report a population growth of 50% was recorded during the period between 1978 and 1994 with an increase of 150% in alcohol consumption per capita (Crisp and Ntuli, 1999).

In traditional African societies, alcoholic beverages were highly regulated and only taken in a communal fashion during ceremonial festivities. However, during British Imperialism

alcohol was prohibited and restricted as a way of economic and social control of Black people (London, 1999a). Without attempting to make a linear link between resistance to oppression and alcohol abuse it is noteworthy how South African Black communities in particular responded to the control on the production and distribution of alcohol. The establishment of unregistered or illegal shebeens is still taking place long after the Apartheid – rule. Although it offers livelihoods to shebeen owners it continues to make alcohol easily accessible within townships.

Thus, in addition to the impact of the *Dop System* on local farming communities, this surge of excessive alcohol use was being spurred on in local townships as well. The burden of alcohol dependency for some and the norm of excessive alcohol use for others created a unique culture of alcohol abuse within farming communities. The real impact of these historical processes could only be determined with studies that were done after the drastic social, economic and political changes made since 1994. Whereas South African marginalized generations were paid with wine, current generations work for money and spend most or all their money on alcohol purchases. This practice illustrates how the occupation of excessive alcohol use across generations changed in process, but remained constant in form<sup>48</sup>.

With wine as a “historical currency” in the Pikeville community, residents were forced into practices that maintained the micro economy in the community. With alcohol as part remuneration, wine became an intricate part of the work life of farm workers. Within Pikeville many of the parents lived in the village and worked as seasonal workers on farms. This involved working away from home for extended periods and children had very little to no adult supervision back at home. Alcohol abuse and binge drinking became integrated into the socialization of people and how they spent their free time with heavy drinking in groups on weekends and in the holiday as a common form of recreation (May et al., 2005). With alcohol abuse as normalized practice and very little structure on farms to encourage a healthy lifestyle, conditions did not allow for much constructive occupational engagement.

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<sup>48</sup>Occupation is defined as the relationship between two things: occupational form and occupational performance. Each occupational form has an objective nature independent of the individual engaged in the occupation; sociocultural as well as physical characteristics constitute each occupational form. The individual's interpretation of an occupational form (its meaning) depends on the individual's developmental structure. (Nelson,1988)

### 5.2.2 Excessive alcohol use as imposed occupation

Service providers like Leoni understood the dynamics of alcohol dependence on a physiological level:

*“Ons almal weet drank is verslawend maar nie, nie een van die mense... En dis mos nou maar tipies van mense wat 'n probleem het met alkohol. Voordat jy nie erken dat jy hulp nodig het nie kan jy nie gehelp word nie.”*

*(“All of us know that alcohol is addictive, but not one, not one of these people...and that is typical of people who have a problem with alcohol. If you don't admit that you need help then you will not get the help [you need]”)*

If everyone was aware of the dangers the question can indeed be asked why farmworkers in the past and the residents from Pikeville continued to engage in an occupation like alcohol abuse or binge drinking? Foucauldian theory argues that local people who have been oppressed for generations still do possess the ability to reason about oppressive systems. However, “after years of being conditioned to privilege and defer to the world of experts they lack the resolution and courage to employ their own reason” (Foucault, 1975:188). Spivak (1999) accused Foucault of epistemic violence (projecting a white European epistemology onto the rest of the world, especially third world). She argued that “for the true subaltern group, whose identity is its difference there is no unrepresentable subaltern subject that can know and speak itself...” (Spivak, 1988:24). According to Spivak the identity of the women who have been oppressed is different to other women elsewhere. With their identity being defined by being different these women do not know themselves and can therefore not voice their own preferences. This explains Martha's statement of identifying herself as a drinker. Martha stated this without acknowledging the other roles she holds as a woman, mother, daughter, worker and community member. She defined herself by the fact that she engaged in binge drinking during her pregnancy and her continuation of alcohol abuse. The 'differentness' of the mothers in this study is not only reflected in their roles as mothers, daughters, sisters, spouses/partners, members of Pikeville community, but also as powerless and voiceless citizens of South Africa. In an era where gender differences are globally being evened out, Martha and women like her remain caught in their pseudo identities (Freire, 2002). Freire describes a pseudo identity as the way in

which a person names him or herself in relation to the dominant forces in society, what society expects from them and how they are expected to act upon their world. The pseudo identity held by a woman like Martha relates to being a drinker and an inadequate mother and may therefore render her unable to critically explore systems, structures and practices that perpetuate her oppression. The identity process for Martha is thus a dynamic process and may change depending on the type of support she receives to redevelop and restructure her consciousness. Shifting the focus away from the individual (the drinking mother) and toward exploring the power dynamics (political dynamics) that are embedded in systems and structures that maintain excessive alcohol use and binge drinking during pregnancy may initiate the process of uncovering alternative occupations. Spivak (1988) highlighted the major challenge that lies ahead in the process of recreating consciousness among oppressed women as altering the consciousness of women as part of a process that explores and develops their ability to voice their concerns. Freire's concept of the oppressed being able to name their own realities (Freire, 2002) resonates with Spivak's suggestion.

In the absence of a distinct identity Spivak suggested that the main goal of a subaltern group such as the women in Pikeville is to rewrite the development of their consciousness. Foucault stated that there is a role for intellectuals in this journey towards the development of a new consciousness. Instead of acting as an adviser the intellectual (or health professional) will act as a resource that provides the "instruments of analysis... in other words, a topological and geological survey of [the issue that needs to be addressed]" (Foucault, 1975: 188). However, caution has to be taken that hegemonic systems and structures do not get maintained and practice repeated. Freire (2002) posits that dialogue can be used as a tool for critically conscientizing individuals to a heightened awareness of individual and political situations. Within a dialogue the focus is not on the people having the dialogue, but on meaningful themes that are generated from the thinking of the people having the dialogue. Within FASD prevention dialogue would therefore create a space where women can reflect on their thinking about (a) alcohol consumption and (b) the practices, systems and structures within the community that perpetuate and maintain excessive alcohol use in Pikeville. Occupational

therapists, who will act as an animators<sup>49</sup> should use their skills to uncover occupational potential and to inquire further about different choices of occupations that could be made. This may assist women in considering and trying out different ways of dealing with challenges they experience in Pikeville.

The process of rewriting the development of consciousness is more complicated and challenging than it might appear as the nature of trauma is such that the cognitive processes of the victim are being compromised (Murray, 2009). Women might therefore be unable to recall or even describe what transpired in recent or past traumatic events. When focusing on the redevelopment of consciousness Ramugondo (2009:221) suggested that occupational consciousness is an “on-going awareness of the dynamics of hegemony, an appreciation of the role of personal and collective occupations of daily life in perpetuating hegemonic practices, and an appraisal of resultant consequences for individual and collective well-being”. Occupational therapy is a health profession that is well situated to address power dynamics in the lives and interaction within the personal, social, economic and political development of people in South Africa. Using occupation as a means as well as an end to facilitate such development, occupational therapists are able to identify individual strengths and needs that could be matched with opportunities for individual, group and community development. Occupational therapists are therefore reminded to be aware of how their daily interactions with individuals and the environment perpetuate hegemonies that may prevent development among marginalized populations (Ramugondo and Barry, 2011).

Women who have experienced physical brutality are known to experience disintegration and even loss of language (Vera, 1996; Krog 2003; 2006). With what voice-consciousness can the subaltern speak? Mothers who are abusing alcohol during pregnancy have not had the opportunity to voice their concerns and have these concerns addressed effectively. Even when given the opportunity to express their occupational and developmental needs these concerns have not been effectively addressed as yet. Women in this study could therefore be classified as a subaltern class within Pikeville. Service providers within the study could be classified as dominant indigenous groups at

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<sup>49</sup> A person who does not steer process on behalf of people, but who facilitates and creates spaces in which the community members find themselves comfortable and confident enough to solve their problems and initiate actions.

the regional and local levels. Spivak (1988) noticed that even this group, who serves as a buffer between the macro-structural dominant group and the subalterns, is itself in an in-between social position and in a place where their constructed identity can only be defined as “in – differential” (Guha, 1982). The dominant groups at local and regional levels and the dominant indigenous groups are known to act in the interest of the dominant group and “not in conformity to interests corresponding to their own social being” (Spivak, 1988:27). When applied to Pikeville, this will mean that the service providers will not have developed an identity within themselves that is able to recognize their needs and the needs of the people that they are supposed to represent at a higher level of decision making. In the absence of such consciousness they would not be able to voice their concerns or the concerns of the population which they serve. They too, are therefore silenced by the dominant, oppressive ideologies. In turn the service providers become the new ‘maintainers’ of the historical power dynamics between the black mother (and her questionable moral character) and the health system (Hartouni, 1994). The service providers therefore perpetuate the mass-mediated controlling image of black mothers that elevates racist beliefs about black women and motherhood into an ideological narrative of mythic proportions (Clarke & Olesen, 1999:236).

Viewing alcohol abuse or binge drinking during pregnancy as an occupation may be problematic. Groups of people situated outside of Western and European experience may find ‘occupation’ to be problematically ethnocentric. Iwama suggested that social concepts like occupation do not necessarily transfer universally across cultural boundaries of meaning (Iwama, 2001). Beliefs in the East are rooted in “adapting and adjusting self to attain harmony with them instead of trying to exert control over circumstances (Iwama, 2001:585). Just like Japanese and East Asian social context, the social realities of indigenous South Africans differ markedly in regard to ontology and epistemology. More work is needed, however, to explore this further.

Although authors such as Wilcock (1998a) and Townsend (Townsend and Wilcock 2004a,b) have indicated the traditional nature of occupational therapy’s concern with social and community factors in health and occupational balance, in practice it appears that holism in occupational therapy is often restricted to individualistic and professionally constrained understanding of the clients with whom occupational therapists work. The

philosophy of holism is based on two fundamental concepts namely personality and the law (as in Roman law). The natural process of personality development was the main idea on which holism was founded. A major influence on the work of Smuts (founder of holism) was the Roman law. Beukes (1989:111) suggests that the person is seen as the basis of all law with “emphasis on the supreme worth of every person”. The advantage of holism is that it shifted occupational therapy practice beyond the bio-psycho-social approach towards clients to a model of whole person care (Lorenzo et al., 2006). While this is an adequate approach for interventions that are individually-centered, it fails to identify and address the factors in the meso, exo and macro systems which impact on the individual. The construct of holism thus limits human interactions with the social environment to family and other social relations. An occupational therapy approach to FASD prevention in Pikeville would need to consider the greater social, political economic environment in all its cultural diversity (Iwama 2003).

### **5.2.3 Occupational Therapy in FASD prevention**

The concept of holism in Occupational Therapy refers to “an open process of developing analytical reasoning skills, rather than developing a fixed set of knowledge or competencies.” Holism thus refers to “a disciplined process of knowing how to know that which matters or navigating successfully within complex situations” (Sakellariou and Pollard, 2009:91). Iwama (2003) argues that holism as a concept was appropriate when the role of the occupational therapist was restricted within a biomedical paradigm. In his description, heteroglossia (hierarchically structured multiple discourses that operate within a society) would be a more appropriate concept in the political practice of occupational therapy. The process of developing analytical reasoning skills could therefore be extended to a process of critical thinking about alcohol use in the pregnancy of mothers who live in Pikeville. A critical analysis of the micro factors and the macro influences that impact on alcohol use in pregnancy will thus uncover discourses of social status, language, race and ethnicity in relation to alcohol abuse in Pikeville. The interaction with Martha illustrated how difficult some women find interacting with service providers or people whom they perceive as in a different social class:

*“Daar wat ek werk ook. Ek roep Mevrou, vir die vrou waar ek werk. My ma en my pa het my baie mooi maniere geleer ek sê 'Mevrou' vir iemand wat sulke werke [soos in die kliniek] doen, hou ek daarvan om te eer as hulle my kan reg leer.”*

*[“Even where I work, I say Mrs., to the woman for whom I work. My mother and father taught me good manners I say ‘Mrs.’ to people who do work like you, I like honoring people who can teach me the right things”]*

Service providers, health promoters and occupational therapists should be aware of power dynamics where individuals find it difficult to negotiate their space as an individual with equal standing in the research process. Using the principles of dialogue as part of the assessment phase or intervention phase in Occupational Therapy may facilitate the exchange of valuable information between clients and practitioners. Establishing horizontal relationships between practitioners and clients will contribute to re-instilling respect and dignity as part of the FASD prevention process.

Another clear power dynamic also emerged from the data in the accounts of gender-based violence within Pikeville community. Sandy’s account of how her partner forced her to stop using contraception illustrated how she was denied the opportunity to exercise her own decision or to negotiate on when to fall pregnant:

*“En die inspuiting, in die eerste plek, die inspuiting het nou newe effekte gewerk. [“Mm?”] Toe met die inspuiting, eers was ek op die Nordette [Ja] en na 'n tyd toe sê... want toe sien hy ek gebruik die Pil, toe sê hy, ‘Ja, nou mors jy my tyd’ en die Pil is nou en ek het..., die Pil het ek drie maande gelos. Daarvandaan nie weer die pille gebruik nie, want hy het my so ge-monitor, gemonitor. Dan gebruik ek sy suster se pille..ons het een en dieselfde (voorbehoedpille) [Ja] Dan sê hy vir my, ‘Ja, jy gebruik nou alweer die pille en dan sê ek vir hom ‘Nee ek gebruik nie die pille nie!’”*

*(“And the injection, in the first place, the injection had negative effects. [“Mm?”] Then with the injection, first I was on Nordette [Yes]... and after some time he said... because he saw I was on the Pill, so he said: ‘Yes, you are wasting my time’ and the Pill [is the culprit] and I... I stopped taking the Pill for three months... I never used the pills again after that because he would monitor me, he monitored me. Then I used his sister’s pills... we used the same [contraceptives] [Yes] so he said to me: ‘Yes, you’re using the pills again.’ And then I said to him: ‘No, I’m not using the pills!’”)*

Social status and gender are only two of many discourses within Pikeville that created a unique cultural discourse that informs the interactions between children and parents, spouses and partners, friends, workers and employers, health care service consumers and health care service providers over the past two centuries. It is only when the hierarchy and power dynamics between these different actors are understood that the context can really be viewed as an active and vital component in determining the health of women who live in such contexts. The focus is therefore not on the women who consume alcohol during pregnancy and the interaction between her needs and potential (biological, psychological, and contextual), but it shifts to a situation where the individual is situated in relation to the different discourses that are operating in Pikeville community. Heteroglossia thus lends itself to a perspective of alcohol abuse and binge drinking by women and their families (as occupation) informed and shaped by the different discourses within the Pikeville community. The Pikeville community in turn is being informed and shaped by the excessive alcohol use of the women of their families.

Critical thinkers, such as Marx, Gramsci, Foucault, Basaglia and Paulo Freire provided theoretical elements for reflecting on the risks of producing conformity, instead of emancipation. Although Western occupational therapy theory has also been criticized for non-responsiveness to different cosmologies and worldviews (Iwama, 2005, Watson, 2006) a body of research is slowly developing to advocate for occupational therapists as agents of social transformation (Galheigo, 2011). Emancipatory development in the field of FASD prevention would comprise the enablement of women toward selecting alternative occupations that would lead to participation in social, economic and political activities of choice. When advocating for a different perspective on FASD prevention, this research is encouraging occupational therapists, health professionals, public health practitioners and policy makers to tackle issues that hamper inclusive development in South Africa. Occupational therapists certainly have the skills to critically evaluate their interventions and interactions with individuals affected by FASD. Occupational therapists also have the skills to assess impairments and participation restrictions experienced by mothers who abuse alcohol during pregnancy. Finally, occupational therapists are experts on occupational engagement of persons with disability and will be able to facilitate a process whereby alcohol abuse as occupation could be replaced by different constructive occupations. Occupational therapists also have to be aware of other

negative imposed occupations within contexts that might hinder individual and communal development. Changing occupational engagement patterns for mothers who abuse alcohol during pregnancy would result in a dynamic transformation (Freire, 1972) for generations to come.

An educational strategy such as peer education to reduce binge drinking among adolescents during weekends (Planken and Boer, 2010) is one example of how occupational therapy can be effectively applied in the field of FASD prevention. In addition to this the exploration of alternative occupational possibilities would facilitate new and different trends in occupational engagement. The profession's knowledge in the areas of psychology (Padilla, 2002; Lubin et al., 1998), human biology, and diversity in contexts, in occupation (Yerxa et al., 1990) and a variety of cognitive and physical disabilities (Francisco and Carlson, 2002; Kielhofner, 2005) render it ideal for making a major contribution in the development of appropriate FASD prevention approaches in particular and the development of healthy individuals and communities.

Galheigo (2011) posits that the poor, migrants, ethnical minorities, women and people with disabilities or mental disorders are prone to suffering the most of the effects of social exclusion. She acknowledges Freire's work (1981) on using education as a tool to enhance political literacy. This approach should combat social invisibility as "one of the most successful political strategies of oppression, varying across time, place and culture" (Galheigo, 2011: 64). Social invisibility is produced by the following:

- economic and political interests
- cultural differences and ethnic conflicts
- The lack of awareness on social issues or by approaching human affairs in a reductionist manner.

Another type of visibility identified by Galheigo is negative visibility. This is "when people are seen negatively based on what they are or represent...people may be seen and referred to by the current political plan, or the present research protocol and even so be treated as mere objects." The commonality between social invisibility and negative visibility is that people are not addressed as human beings "with needs, desires and rights" (Galheigo 2011:64). Women in Pikeville are both socially invisible and negatively visible. Their lack of political literacy also prevents them from identifying the forces that

maintain their position in society. It is therefore imperative that education and awareness raising campaigns make the link between the occupations in which individuals and groups currently engage in and possible future occupations that might facilitate healing, restoration and development.

#### **5.2.4 Situating Pikeville as a traumatized society**

The experience of humaneness and interpersonal generosity within the Pikeville community could be likened to Ubuntu. This term is derived from the Zulu proverb 'ubuntu ungamntu abantu'. It can be translated as "a person depends on other people to be a person" (Battle 1997:39). The philosophy of Ubuntu holds that "community is essential to subjectivity: a person is incomplete unless he or she maintains an active connection with the society or culture of which he or she is a part" (Libin 2003, 126). This connection between person and community and its culture was evident in the Pikeville community. Within African communities it is difficult and almost impossible to separate the individual from the collective. There is a parallel between the characteristics that were described of the Pikeville community (see Contextual background) and the concept of Ubuntu. People in the Pikeville community also share the trait of interdependence and the beliefs, values and practices of individuals are not easily separated from that of the larger community. This active connection between Pikeville residents is illustrated in the way Eve accommodated a stranger in her already cramped house. It is also evident in how neighbors would share the little food they have with each other.

Unfortunately, the same holds true for negative practices like alcohol abuse and binge drinking, where people would organize their drinking together with family and friends. The blurred boundaries between the individual and the collective thus hold the possibility for the positive as well as the negative. I will first discuss the impact of collective trauma on the occupational engagement of the Pikeville community before I explore collective agency as a positive possibility for FASD prevention in this community.

Murray (2009) compared the impact of colonialism with that of apartheid in South Africa when she referred to "traumatized societies" (Murray 2009:13). Pikeville is thus located within a traumatized society. Furthermore, based on the individual and collective trauma

experienced by the people who live in Pikeville, this small community of people can be viewed as a traumatized society in itself. An argument is made for cultural genocide as a form of genocide of historical generations of the Pikeville community. The ability of the subaltern to express and address their conditions is critically explored.

Laub (1992, 85) argues that a traumatic event is constituted through a process of 'historical retroaction' when someone listens to it. The trauma of colonialism can be said to work in a similar way. In the same way as individual trauma overflows the individual victim's frame of reference, the trauma of colonialism 'disrupts the colonized culture's frame of reference' (Durrant 2004, 69). In this view, the trauma of colonialism is "not so much a historical occurrence as a collapsing of history, a process in which the tribe's own world-historical view is displaced". Theorists believe that the trauma of colonialism can be said to work in a similar way (Murray, 2009). Individual trauma and the trauma of colonialism are similar in effect. With individuals the trauma overflows the individual victim's frame of reference and during the trauma of colonialism the colonized culture's frame of reference is disrupted (Durrant 2004). Dan alluded to this displacement of world-historical view of many South Africans when he said:

*"...hier [in Suid-Afrika] het soveel klomp ander sensitiewe goed gebeur in Suid-Afrika... want wat het veroorsaak dat die stigma kom dat die plaaswerker 'n swak person is, of dat iemand wat drink 'n swak person is?"*

*("... so many other sensitive things happened here in South Africa...Because what caused this stigma that lead to a farm worker being considered as a weak person or that someone who drinks is a weak person?")*

Although alternative legislation has been passed since 1994 in an attempt to address negative stereotyping of marginalized groups, many of the descendants of farm workers still live in oppressive conditions in Pikeville. The displacement of farm worker families and their reaction to the trauma is mimicked and expressed in the everyday occupations of people who live in Pikeville. Negative stereotyping of marginalized groups in the country found expression in what people do. Martha, who is a second generation FASD individual, explained how she preferred to drink with friends or family members as a way of forgetting about the challenges her life presents:

*“Maar ten minste is daar dan company om saam te drink en jy voel beter want jy' s saam met ander mense. Jy vergeet van jou sorges tot daar wat jy weer nugter raak (lag)”*

*(“But at least there’s some company to drink with and you feel better because you are with other people. You forget your troubles until you sober up [laughs loudly]”)*

According to Martha, you feel better when you share a drink with other people. Excessive drinking in Pikeville community and binge drinking in motherhood should therefore be viewed as responses to living in a traumatized community.

### **5.2.5 Excessive alcohol use as a response to trauma**

Trauma theory from the field of Psychology could be used in attempt to identify and address the issues that relate to historical generational hardship in Pikeville. By using trauma theory one may even be able to explain why excessive alcohol use is so prominent in Pikeville. The only problem with using trauma theory in this context is that the cultural values related to Ubuntu do not resonate with the ontological foundations of trauma theory. Trauma theory has originated from Freudian analysis. This means that this theory was framed in psychoanalytic terms and psychoanalysis is necessarily an individualizing practice. The same applies to cognitive psychology, neuropsychology and social psychology which all adopted this framework and views the individual as a distinct entity (Edkins, 2003). In her analysis of African writers on the topic of trauma experienced by women on the African continent Murray (2009) states that the expression and understanding of trauma is not only an individual phenomenon, as commonly understood within trauma theory. It is also a cultural and social phenomenon. Issues that surface in private lives are therefore not easily extricated from the political issues of the day (Coetzee, 1997). Within the stories of the women trauma presents itself at two levels: the individual level (the everyday live stories which cannot be separated from the trauma the whole community is experiencing); collective trauma and the communal level (not easily noticeable and not apparent without an understanding of the historical trauma). Durrant (2004:3) noted that “[colonialism] produced difficulties of memorialization”. He argued that “the impact of [colonialism] exceeds the moment of its historical occurrence, acquiring the disturbed, belated chronology of trauma”. The occurrence of the event may be significant, but of more importance are the after-effects

experienced by its victims. If the current traumatic state experienced by women of Pikeville is not acknowledged and understood by the system (service providers, politicians and other dominant indigenous groups) similar or different events caused by those in power it may cause repetitious trauma. This will ostracize women even further. The disproportionate levels of violence against women and children in South African society cannot be understood without considering the trauma that people have been exposed to historically. By claiming and dealing with history the repetition of generational trauma can be avoided. European countries that are in denial of the extent of the trauma caused by colonialism (Murray, 2009) would not be able to comprehend the impact of this kind of trauma. It is only those who have emerged from the trauma of this historical condition who would know what they have been exposed to and what the current effects are on their cultures.

The stories of Girty and Jenna illustrated how victims of sexual abuse continue to be silent for different reasons. Although these two women formed a small group of the participants there are many women in Pikeville who are experiencing similar acts of abuse. Whereas Girty remained silent because of fear of a scolding from her older brother, other women might fear the physical danger involved in exposing perpetrators or even because they know that people will not be empathic listeners (Murray, 2009). The silence caused by trauma does not only have the capacity to silence, but also to isolate. Forming new relationships can reduce isolation (CanFASD, 2010). Adverse outcomes and risks associated with prenatal alcohol exposure can be reduced if women are successfully engaged when they are pregnant, (Best Start, 2005). This would require victims of sexual abuse to get the necessary support before they become pregnant and during their pregnancy.

According to Whitehead (2004) trauma has the capacity to disrupt the consciousness of an individual and can confuse the victim's sense of being in the world and being part of oneself. Durant (2004) argues that colonialism and apartheid constitute "collective or cultural trauma not simply by aggregating the traumatic experiences of individual victims, but because they disrupt the 'consciousness' of the entire community, destroying the possibility of a common frame of reference and calling into question our sense of being-in-common" (Durant, 2004:4). Mothers who abuse alcohol or binge drink as well as the entire community should therefore be viewed as individuals with a disrupted

consciousness. Taking this perspective allows an outsider to view alcohol abuse and binge drinking during pregnancy as a response to trauma rather than as a callous act of a mother towards her unborn child. This perspective also moves away from portraying black mothers as incompetent and bad and points away from individual character to underlying determinants that are situated in past and present systems, structures and discourses. When viewed from this perspective it is clear that the chances of the individual mother who lives in Pikeville ridding herself from alcohol abuse or binge drinking during pregnancy is highly unlikely.

A critical theoretical approach is therefore well-placed to enable individuals to regain their courage and confidence in their own solutions. Approaches to working with the Pikeville community therefore have to consider the impact of current and historical individual and communal trauma. The impact of poverty, mental ill-health, malnutrition, housing difficulties and physical health problems (Cory et al., 2010) should be taken into account when dealing with mothers who consume alcohol during pregnancy and who live in Pikeville. O'Connor and Whaley (2006) suggest that support systems that offer assistance with basic needs such as food, nutritional supplements, a safe place to live, transport around the community and childcare should be established. Tait (2003) also found that easy access to services should be ensured. Empathetic service providers are pivotal in building trusting relationships with mothers. All interactions should ensure that mothers get the message that they are deserving of support and care (Can FASD, 2010). This would call for a developmental approach that offers the necessary emotional and counseling support. Since Pikeville comprises of many individuals, this approach implies an empowerment approach at the level of the individual as well as at community level.

Kaseje (1991) defined empowerment as the process by which disadvantaged people come together to increase their control over events that control their lives. The goal of this process is to enable families, communities and individuals to read and transform their reality. The success of empowerment processes, democracy and community participation should therefore be judged by the extent to which community members are able to participate in activities they have to determine for themselves. This definition of empowerment resonates with Windley's description of community development as a process that focuses on "empowering people to gain control over the conditions in which they live." (Windley, 2011:123) The core values of community development include

social justice, self-determination, working collectively, equality and justice, reflection, participation, political awareness and sustainable change (Department of Communities and Local Government's Community Empowerment Division, 2006). Women like Wilma showed a good understanding of what it will require to address FASD effectively in Pikeville. Her suggestions of providing women with the needed and appropriate resources and support indicated a need for women to get assistance until they are in a position to look beyond their immediate needs and focus on addressing and taking control over their own health. It is only when women are able to care for their own health that they will be able to consider the health of their unborn babies. Once this stage had been reached women would be in a position to actively become involved in economic activities and other activities that would allow them to make decisions about the provision of services. By gradually learning to know what their needs are and exercising their right to voice these needs women can gain control over their immediate life circumstances as well as over conditions within the community.

Introducing alcohol in bulk as payment to farm workers certainly did not entail the physical killing of people, but it would alter the neurological, psychological, physical and physiological function of affected children and disable them for the rest of their lives. Excessive alcohol use was induced on a large scale, which resulted in alcohol dependence across many demographic fields (gender, age and stage of life). The largest impact of alcohol abuse is seen in its generational extend. Although this phenomenon could be likened to cultural genocide, this term could not encompass the full extent of what actually took place. Not only was the culture of indigenous people destroyed, but other beliefs, norms and practices were enforced. Macro factors within the context of Pikeville maintain and perpetuate the enforced beliefs, norms and practices that still have an impact on some of the descendants of the original indigene groups. In my argument that colonial oppression, and thus cultural genocide, should be held to account, it is also important to consider the individual pathology of alcoholism.

Alcohol dependence is defined by some as a way of life, a moral weakness, a mental illness or a disease. It is said that alcohol dependence is inherited or that it can be an environmental or drug-induced disorder (CNS Productions, 1999). The major debate is between hereditary susceptibility and environment susceptibility. The following three aspects should be considered when entering this nature-nurture debate. The first

consideration is that second generation FASD women such as Wanda, are smaller in height, weight, head circumference and body mass index. The nutritional status of these women is also poorer, which already places them at risk for general poorer health. Due to their impaired judgment (due to brain damage as a result of prenatal alcohol exposure) and the constant pressure from within the community to use alcohol excessively these women may be most vulnerable to problematic alcohol use and dependency without the necessary support. Women who live in Pikeville do not have any support to maintain sobriety during pregnancy and will thus find it challenging to manage a healthy pregnancy on their own.

Secondly, lower education levels, poor literacy and impaired comprehension compromise the individual's ability to understand the physiological process and developmental stages of the fetus and how the health status of the pregnant mother and baby are interlinked. In addition, intellectual impairment in mothers as a result of brain damage due to prenatal alcohol exposure may compound this problem. Having an intellectual disability in a context like Pikeville establishes the conditions that ensure a high FASD prevalence in current and future generations. If mothers who live in Pikeville are unable to link the consequences of prenatal alcohol consumption to their immediate situation and the conditions in which they live, they may fail to understand the full impact of their alcohol consumption. It is only when links are made between a healthy pregnancy, the ability of the child to learn in school and the possibilities of good education in ameliorating current conditions and these are explained in a manner that mothers can understand and be enabled to explain this link to other mothers, that the fundamental importance of abstinence in pregnancy is translated. In the case of Pikeville, mothers are faced with a multiple burden of poverty, poor literacy, and intellectual impairment, normalized alcohol abuse practices and, for some, even alcohol dependency. Prevention initiatives therefore have to be developed with all of these conditions in mind.

Thirdly, there are currently very few, if any, services and technologies available for individuals with FASD in South Africa. The only available service to mothers is the local health clinic. As in clinics across the country, the staff at the Pikeville clinic are not trained to work with individuals with FASD. Participants like Wanda (who was under the influence of alcohol during the delivery of her second child) thus had a difficult time convincing the nurses that she was in labor. This discouraged her from going for prenatal check-ups during her third pregnancy. Wanda's dependency on alcohol resulted in her

third child also being born with a FASD. Tracking back into Wanda's history her children would be the fourth generation of children who will have been prenatally exposed to alcohol.

Alcohol dependence is a disease which needs to be treated by professionals. Mothers who are dependent on alcohol need lots of support from family and friends if they would like to recover from this dependency (CNS Production – Roots of Addiction). Similarly, mothers who are abusing alcohol in a context like Pikeville need support from friends and family as well as from sources that are external to Pikeville community. Resources such as alcohol cessation services, legislation, opportunities for engaging in alternative occupations will introduce alternative occupations in which mothers can engage as a way of establishing healthier lifestyles and maintaining healthier pregnancies. With the use of alcohol being normalized in Pikeville the conditions are not supportive of women who may be willing to maintain sobriety during pregnancy. Furthermore, the participants who were dependent on alcohol failed to recognize their dependence and act upon this to ensure healthy pregnancies. Under these circumstances there is a strong likelihood that young girls and women of childbearing age may continue to abuse alcohol. As illustrated by Wanda's scenario, alcohol abuse practices are likely to be maintained and transferred to their children and the generations to follow if the context remains unchanged or if participants remain under the same conditions in Pikeville. In addition to the mental, physical and social effects of alcohol dependence, the effects of collective, historical trauma (Bussey and Bula Wise, 2007) may have resulted in generations of women who do not only struggle under the weight of political and cultural forces, but also that of alcohol dependence. Being a woman under these circumstances and having to take sole responsibility for a healthy pregnancy not only qualifies as an act of oppression. It also becomes a process of giving birth to children who might never have a quality of life that will enable them to engage in activities that lead to health, well-being and development towards becoming an active South African citizen. Spivak argues that "the subaltern has no history and cannot speak, the subaltern as female is even more deeply in shadow..." (Spivak, 1988:28).

In his response to why people from this community drink, Rony suggested that people attach certain values to alcohol consumption. Although Rony could not elaborate on what these values were, he admitted that they had a negative influence on the community

members who are abusing alcohol as well as on the public image this community holds. A useful question to ask would be: where did they learn this attitude towards/value linked to alcohol? The process of learning an imposed communal practice (that has a negative impact on personal and social health as well as on development) certainly cannot be seen as an action of occupational choice or preference. As much as the participants struggled to explain this phenomenon, sustainable answers cannot be generated when the cause is located within the individual. A more helpful approach may be in seeking answers at a macro level.

According to Duncan, Stevens & Bowman (2004) colonialism was a form of structural oppression. Duncan suggested that alcohol consumption amongst women, before during and after pregnancy could be an expression of the effects of domestic violence, abuse and collective trauma as a result of colonialism. Introducing and maintaining excessive alcohol use practices were effective tools to eliminate any possibility of the residents of Pikeville partaking in meaningful economic, social and political development. Their overall development across generations was therefore compromised, violated and completely obliterated.

The fact that younger women in Pikeville select local women as role models for different reasons merits further discussion. While service providers might be of the opinion that role models are lacking, it is clear that the criteria held by service providers for individuals who would qualify as role models differ from that of mothers. While the criteria held by mothers, centers around an individual's ability to provide the basic needs of neighbors and friends, the mothers never mentioned sobriety as a particular requirement. Service providers, on the other hand, do not deem a person who provides basic needs and who abuses alcohol as a role model. This disjuncture in the meaning of what constitutes a role model is crucial when planning and developing FASD prevention messages. The collective nature of the hardships as well as the achievements made by the Pikeville mothers requires an approach that draws on the collective agency of the group rather than only from the individual agency of mothers to maintain healthy pregnancies.

Based on the conceptualization of memory as an element that accounts for human behavior (Eyerman, 2001), excessive drinking may be viewed as an expression of collective trauma that is ingrained in the collective memory of the Pikeville community.

In this way the past becomes present through the embodied reactions of individuals as they carry out their daily lives. These individual reactions are reinforced by and re-enacted through interactions with peer groups (friends and families) as well as the broader community. Pikeville as a community in which 'Ubuntu' is clearly a unique, but pertinent characteristic, could surely benefit from an approach that draws on collective agency (Erwer, 2003) of the community. An approach that considers individual and collective needs and combines individual and collective agencies in the attempt to maintain healthy pregnancies will match the unique contextual demands of Pikeville.

#### **5.2.6 Excessive alcohol consumption as occupation in motherhood**

The incidents described by Girty, Sandy, Martha, Wanda and Wilma are discussed against the background information that was provided on Pikeville in the first section of the Findings chapter. The stories of these five participants' echoed incidents of teenage pregnancies, excessive alcohol use, binge drinking, alcohol dependence, domestic violence and shattered dreams. Girty concluded her story by suggesting that only people who are "bekeer" (converted or religious) do not use alcohol excessively. Sandy's story highlighted the fact that contraceptives are not effective if the partner is not supportive of the woman using family planning. This story also highlighted the submissive role of women in this community and illustrates how some women are unable to make independent decisions on reproductive health. Both Girty and Sandy's stories share a common theme of sexual violence. Murray (2009), who described the use of literary fiction as a way of expressing trauma for women, suggested that women deal with the consequences of trauma by abusing alcohol. Martha's stories started with experimentation with alcohol as a learner in grade 7. Her story ended in a painful confession of how her alcohol dependence affected her children. Martha is the image of the isolated, marginalized mother who is blamed and ostracized because of her dependence on alcohol. She had no family or community members to support her in maintaining a healthy pregnancy. Similar to Martha, Wanda and Wilma also started to experiment with alcohol while they were still at school. This started out as a fun activity with friends and boyfriends. After her third pregnancy Wanda was binge drinking whenever she could find the opportunity. She was willing to change her life, but was

caught in a circle of friends and family (brothers, sister, mother and grandmother) who frequently engaged in binge drinking. Wilma wanted to become a doctor before she fell pregnant and ended her story with a new dream of wanting to support and care for young mothers who were on the way of establishing healthy habits in motherhood. The summary of the above stories may be as diverse as one would expect to hear from mothers in other societies across the globe. The only difference here is that the mothers who abused alcohol and those who were dependent on alcohol lived in an environment that not only supported their alcohol use practices, but initiated and maintained alcohol abuse and alcohol dependence in prior generations as a willful act of those in power.

Life is a struggle in Pikeville, unemployment is rife and livelihoods unsustainable. The housing structures built through the Reconstruction and Development programme provides shelter. However, large groups of people (in many cases three generations or more than one family) live in limited space in these housing structures and privacy is out of the question. These situations could be likened to Ross's description of shack dwelling when she states that this kind of living "makes a mockery of public-private distinctions. The neighbors' sounds impinge on the attempts of others to create privacy and the crowding and the walls of shacks rendered privacy vulnerable. Anger, enjoyment, arguments, conversation and lovemaking were easily audible, making precarious people's attempts to establish 'private lives' – forced intimacies of close living" (Ross, 2010:25). This state of knowing the finer details of neighbor's lives results in the "erosion of human dignity" (Ross 2010:26).

Although a number of organizations that can address socio-economic issues in Pikeville exist, they are not accessible to everyone. The mothers who participated in the research therefore did not have access to such organizations. Awareness of FASD was minimal and was expressed with partial accuracy by service providers as a symptom of other underlying socio-political problems. Stadnyk, Townsend and Wilcock (2010:332) suggest that "when people experience justice or injustice they are not fully aware of the invisible decisions about policy, professions, health, economics, social welfare, education, transportation and industry that determine possibilities for participating or not in various occupations or the function of the state in regulating or otherwise influencing what they do". Thus, considering the impact of underlying factors in addition to the effects of

occupational injustice would bring us a step closer in understanding alcohol abuse and binge drinking during pregnancy of women who belong to traumatized societies.

### **5.2.7 Occupational identity of the mother who drinks**

If the agenda of the development processes in South Africa is to navigate from a place of oppression then it should be acknowledged that the identity, class and culture of women in Pikeville are strongly rooted in the South African history. This history includes the remnant and legacies of slavery, colonization, apartheid, forced removals, migrant labor, urbanization and religion (James et al., 1996; Mountain, 2003). While it is important to recognize the origins of the 'colored identity'<sup>50</sup>, the focus should now begin to move away from ethnicity and towards communities that have been affected by decades of exclusion and rootlessness.

With this in mind the identities by which drinking mothers are portrayed is of particular interest within this debate about identity making of marginalized groups in South Africa. Should alcohol abuse during pregnancy be linked with a certain identity in South Africa? This has certainly been the case in FASD. With the high incidence of FASD that was found in Black Afrikaans speaking communities this misconception was firmly established in research circles. Mothers like Martha and Wanda who are second generation FASD individuals have to live with the challenges posed by their disability as well as their alcohol dependency in the context of Pikeville. FASD and alcohol dependency each has its limitations on the person. Combined with limitations situated in Pikeville these women's understanding of who they are and thus their identities are shaped around what they cannot do instead of what they can do. These mothers' understanding of their responsibilities in motherhood is maimed primarily by their own perception and experiences of what is possible in this context. For this reason mothers may acknowledge their accountability for a healthy pregnancy, but continue to fail to care for their children in the best way.

Service providers know who the drinking mothers are. Staffmembers at the clinic perform prenatal checks on the pregnant women and some of these women are often under the

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<sup>50</sup> 'Colored identity' was a result of a legacy of racial relations of power and privilege. The colored race was only created in the twentieth century (Goldin, 1987).

influence of alcohol. As in Wanda's case, some mothers are under the influence of alcohol when they have to deliver their babies. It was clear that there were no services available for mothers with drinking problems and all these mothers were referred to the research project. This calls for a closer look at the type and scope of services offered at Pikeville clinic. When one considers what is being offered, how people are being treated and what the outcomes are of such interactions it takes us to a new dimension of these women's 'being' in Pikeville. In a country like South Africa answers to a few critical questions will locate women like Martha. The following questions need to be answered first:

1. What does a woman like Martha represent in the South African context?
2. Which social group does she belong to?

Madison (2008) refers to "race in the moment" when she speaks of the phenomenon where the reconstruction of who a person is tied to their ethnicity and to where they live. This reconstruction is also shaped by the politicized perspectives on wealth, opportunity, and technology by people from developed countries who impose their perceptions on people living in the developing world. Within the South African context mothers like Martha are likely to be viewed as being black first (thus judged by race) and then their locality (where she lives). Due to historical and current unequal distribution of wealth and access to quality services as well as to socio-economic status South African Black women remain the most vulnerable to contracting diseases (Western Cape Government, 2005). Martha is the image of many South African black mothers who engage in alcohol abuse drinking during pregnancy. Taking a closer look at the challenges these mothers have to face brings a new perspective to the problem.

Martha lives in Pikeville which means that she has to make use of the health services at the local clinic. The primary health care clinics in South Africa offer basic health services. Primary health care clinics in South Africa have long waiting times and clients often have to queue from four 'clock in the morning (personal communication – staff member at Pikeville clinic). The focus is on medical care and medical specialists visit Pikeville clinic once a month. There were no rehabilitation services or programmes available at the clinic or within Pikeville community during the time of the research. Patients who needed rehabilitation services had to travel 120 kilometers to the nearest town. Being known as a drinker and often being misunderstood and mistreated by staff at the clinic Martha was

pointed away from the clinic and failed to get support from the only accessible point of health provision. Negative stereotypes about women's commitment to their own health could easily be upheld by health care providers if they do not know how to deal with women who are dependent on alcohol. Under these circumstances women are not functioning from a position where they can make informed choices about their health. Instead they are being steered by their alcohol dependency. It is therefore important to distinguish between individual beliefs, norms and values and actions that are spurred on by alcohol dependency and those that are being reinforced by the context.

As stated in literature on FAS and FASD Martha represents the low socio-economic circumstances and less formal education of people who live in an environment where heavy drinking was the norm (Viljoen et al., 2002). Women like Martha also represent the individuals who come from alcohol abusing families in which heavy drinking was common. Martha and Wanda also symbolize some South African mothers who binge drink over weekends. Based on the stories shared during the interviews, both Martha and Wanda are second generation FASD individuals. According to May et al. (2005), poor nutrition and second generation fetal alcohol exposure (height, weight and head circumference, and body mass index) is one of the less emphasized indicators for FAS. Reality also increases the likelihood of having an alcohol-exposed pregnancy by three times more than women living in urban areas (Moroejele et al., 2010). Both Martha and Wanda fit both of the criteria mentioned by May et al. (2005) and Moroejele, et al. (2010). It is thus important to note that women like Martha and Wanda may have different identities to what is represented by researchers, epidemiologists and health promoters. In the view of medical and research personnel, Martha is thus not perceived as a woman who has to face multiple challenges while mothering three children, but as a statistical probability which presumes her blackness and other risk factors to reflect inadequacy as a mother. She is perceived as someone who needs to take accountability for the conditions in which she lives and someone who should know better in the choices she makes.

The identity that Martha holds thus determines with which groups she identifies. Hence her statement: "I am a drinker, and that's it!" Although the group of drinkers is not the only group with which Martha could be identified, this is the only identity that Martha is representing in her statement. The meaning of Martha's representation was constructed

away from being a woman and a mother, but around being a drinker. Madison (2008:249) states that “one of the things that culture is based on is the production and exchange of meanings, and one of the ways we give things meaning is by how we produce them or how we represent them or how they appear to us”. The culture of excessive drinking in Pikeville is therefore represented in the way Martha presents herself: a culture of drinking is represented by the members of the culture represented or appearing as excessive drinkers. It follows that drunkards would drink and that drunken mothers would drink – irrespective of their health status. This takes us a step closer to the beliefs held about excessive alcohol use in the general community of Pikeville and the practices surrounding alcohol consumption of mothers in Pikeville. With an internalized identity as a drinker the beliefs and values of a mother like Martha will revolve around the activities that are in line with being a drinker. In addition to other occupations alcohol abuse and binge drinking during pregnancy may then become one of the central occupations in the life of this mother. These beliefs and values may remain for as long as Martha stays a member of Pikeville community and forms part of this culture. The odds are against mothers like Martha for as long as the system, structures and discourses that maintain excessive alcohol use in Pikeville are not challenged.

Within FAS research the identity of woman is consistently denied and that of an inadequate, black mother is constantly reinforced. Within this instance “race is constructed, reconstructed and deconstructed depending on locale, history and power” Madison (2008:249). We have to be reminded, though, that the experiences of mothers like Martha penetrate much deeper than a socially constructed concept.

The finality with which Martha makes this statement is as if nothing can be done to change this state. However, Krefling (1991b), Fitzgerald, Mullavey-O’Byrne and Clemson (1997) and McGruder (1998) suggested that culture itself is not static nor fixed. Culture can change in response to politics and economics and there are many individual differences within any cultural group. In a national address Kader Asmal said that “None of us have a fixed and frozen...identity, because we live in a complex and changing process of cultural creativity” (Asmal, 2008). Identity formation is thus not a stagnant point in history, but an elusive and dynamic phenomenon (Gordon, 2003). Creating a new cultural identity would mean having to “shift the focus of the identity and race debate from “what I look like/what I represent” to “who I am” (a mother, sister, daughter,

human being!) (Gordon, 2003:143). The “who I am” will be followed by “which family group and organizational/institutional group I belong to” as illustrated by Iwama’s statement: “Belonging is more important than ‘doing’ in a collectivist society...Human agency is determined and modified through the social” (Iwama, 2003:585). Pikeville is one of the many collectivist societies in South Africa. If social ills such as alcohol abuse and binge drinking in pregnancy are addressed in appropriate ways then people’s sense of individual identities and cultural identities may begin to develop separate from the contextual pressures of excessive alcohol use. Provision of appropriate opportunities, services and meaningful interactions with service providers may reinforce dignity and encourage individuals to participate in developing initiatives that may enhance individual, family and community development. This is in contrast to the dominant discourse on occupation and the emphasis on ‘doing’ in occupational therapy. This view strongly resonates with the notion of occupational identity and belonging to a certain group as constructs of culture.

Consuming alcohol may inextricably be a part of the culture of the Pikeville community and ‘being drunkards’ may have become part of personal and communal identities of women who live in Pikeville. Christiansen (1999) and Wilcock (1998b) explain how doing (an activity) shapes being (identity). If excessive alcohol use within the context of Pikeville is understood as an imposed activity that became an inherent activity for people who live in this community, then Martha’s statement shows how doing an activity can become an intricate part of who you are (I am a drunkard, and that’s it!). This is in contrast to Christiansen and Wilcock’s view of the activity as not being a part of identity. In Martha’s case being a drunkard is not only her way of expressing her current personal identity, she is also a representation of the community of drunkards to which she belongs. There is thus an important interface that needs to be considered between the following aspects

- women’s personal identities,
- their cultural identity and experience of belonging
- their occupations (including alcohol abuse and binge drinking)
- their perceptions of alcohol abuse and binge drinking during pregnancy
- how they relate to and interact with others within this context that supports this practice

- how they relate to and interact with others outside of this context as a way of exploring different opportunities for participation in society

A multi-faceted approach is therefore needed to address alcohol consumption during pregnancy and hence FASD in Pikeville.

### 5.2.8 Having local role models

This category highlights the preference of the women who live in Pikeville when it comes to role models. The introduction of this theme highlighted the dilemma with the identity that these women hold and how they are being perceived by others. Knowing this the service providers of Pikeville argue that there are no positive role models for young girls in the Pikeville community. The statements of young mothers like Jenna and Lisa are in disagreement with the service providers' views. They respect and look up to local women in their village for, among other things, their ability to care for others in need. This respect revolved around their assistance in obtaining basic amenities like food and shelter and did not consider alcohol abuse, binge drinking or its related problems. While this could be an advantage, it is important to mention that there are a few older women in Pikeville who used to consume alcohol during their pregnancies as young mothers, but who stopped drinking later in their lives. Both Evora and Jane are currently looking after their grandchildren and both their daughters were abusing alcohol during their pregnancies. Women like Evora and Jane know what it was like to be a drinking mother and their positions render them perfect for providing support to current young mothers. So, while drunken mothers should not be selected as role models, older mothers who have been through a similar experience to Wilma, Wanda and Martha should be assisted in assuming positions of positive role models in Pikeville.

Having local role models bifurcates into two subcategories in which the opinions and suggestions for a way forward between mothers (Subcategory 2.1.1) and service providers (Subcategory 2.1.2) are juxtaposed.

Mothers were keen to make suggestions for the type of support that they thought they might need to assist them through an alcohol free pregnancy. The title of the theme was derived from an interview with Wilma. During this second interview she shared what she

would do to assist pregnant mothers in Pikeville. Early in her interview Wilma started with a very important realization in terms of taking responsibility for her baby and assuming the role of mother. This latter responsibility begins with ensuring that the baby is fed and is safe. Wilma acknowledges that this would require having some kind of income to cover costs for food and shelter. Johanna and Jane echoed Wilma's statement when they add that food security is one of the basic needs in securing the well-being of women in Pikeville. Wanda expressed the need for emotional support and knowing that she can trust her listener. Murray (2009) argues that women who have been traumatized benefit most if the listener shows interest and empathy. The listener then also becomes a witness to the events. Witnessing therefore requires "careful listening" (Laub, 1992:70). Taylor (1997:124) refers to this action as "an involved, informed, caring, yet critical form of spectatorship". A close collaboration between speaker and listener is thus required (Whitehead, 2004).

Gillian was one of the service providers who suggested the creation of alcohol free spaces for workers who received weekly salaries. She argued that weekends should be targeted for creating these spaces:

*"naweke is die mense se groot drink tyd, want hulle kry Vrydae geld... daar word nie iets gerêel om daai mense rîg te akkomodeer om hulle occupied te hou vir daai tyd dat hulle sodoende afskaal totdat hulle op daai stadium kom dat daar niks meer is nie... Al kry jy dit met twee en drie reg, so be it."*

*("Weekends are people's biggest drinking time because they get paid on Fridays... Nothing's really organized to accommodate people, to keep them occupied for a certain time so that they can scale down [on the drinking] before there's nothing left... If you get that right with just two or three people, so be it.")*

The statements from Wilma and Gillian indicate a need for changing the social environment in which individuals spend time. However, this change needs to be coupled with alcohol rehabilitation input that is tailor-made to speak to the needs of men and women alike. Such a programme should foster awareness of factors in the social environment at home that facilitate and maintain excessive alcohol use. It should also allow participants the space to explore alternative occupations that will enhance

participation in other social and economic activities. Alternative occupations ask for alternative occupational therapy practice. Kronenberg, Pollard and Ramugondo (2011:10) state that the purpose of an alternative practice of occupational therapy is to "encourage and remind people and society to understand, build and maintain working relationships through collective occupations". The question is: "How can occupational therapists collaborate with community members from Pikeville to identify, build and maintain occupations that could serve as alternatives or replacements to binge drinking (and related activities). How could this be done in new ways so that social cohesion is created? Following on the principle of Ubuntu the focus should be on people's relations with each other (locally and globally) – identifying destructive interactions and building on positive ones. This will inform culturally appropriate interventions in FASD prevention in South Africa (Kronenberg, Pollard and Ramugondo, 2011).

#### **5.2.9 Sharing the responsibility for healthy pregnancies**

This section captures the input from service providers. All the service providers were in agreement that the fight against FASD is not solely the responsibility of the pregnant women. Partners, family members, friends and service providers all have a role to play. South African villages have been marginalized and excluded from accessing quality health and other services for long enough. While it is important that existing resources within a village or community be utilized better, it often requires an outsider to introduce a perspective that involves drawing from resources outside of the community to enhance prevention and health promotion efforts.

The advertisement by FASed (aired on SABC 2 | December 2011): It takes a village to raise a child – what if the village does not have all the needed resources? More importantly, what if some of the resources are available but the women who are in need of support for abstinence during pregnancy are not able to access such services? Finally, if the attitudes of health professionals and other key service providers remain what they used to be within the bio-medical model of health promotion the village will become an institution that maintains and perpetuates excessive alcohol use as an endemic phenomenon. Thus far, the issue of prenatal alcohol exposure had been mystified (to obscure important causes/contributing factors, or results of a phenomenon by

researchers and journalists alike). This can change if a possibilities-based practice is pursued with community members from Pikeville. A possibilities-based practice of occupational therapy practice enables practitioners “to make things work when they perceive themselves to be in conflict with the hegemony” (Kronenberg, Pollard and Ramugondo, 2011:11)

One suggestion that was made by Monica and was supported by Stanley was to incorporate education regarding alcohol abuse during pregnancy and FASD in the education curriculum of children beginning in primary school. This may increase awareness among children, who may in turn raise awareness among parents, family members and friends. In resonance with Wilma’s suggestion Rony suggested the use of direct contact in addition to written media. Stanley complemented this idea by suggesting the roll-out of development-focused initiatives for FASD prevention.

As indicated earlier in Chapter Four, men were singularly absent from participating in the study as partners. While this may signify the level of involvement of men in parenting issues, it may also suggest the role assumed by males in Pikeville community. Rob, Wanda’s partner, was the only male partner who participated in the first two interviews. He did not have insight into the impact of his drinking patterns on those of Wanda and expected her to abstain during her pregnancy, while he continued drinking. Rob’s views reinforced Wanda’s disempowerment and illustrated the need to include partners and educate them on their role as part of prevention process.

#### **5.2.10 Developing appropriate FASD approaches**

Development-focused initiatives that target the needs of women and their social environment as priority should be more appropriate than only applying medically-focused interventions in this context. Evaluation of programs should acknowledge and facilitate the significant efforts of women as individuals as well as part of a community (Smith et al., 2007). Fetterman, Kaftarian and Wandersman, 1996:323) refer to empowerment evaluation that uses “evaluation concepts, techniques and findings to foster improvement and self-determination”. Such evaluation processes should also illustrate trust in individuals to produce solutions for problems and change their own circumstances. Freire (1972) states that:

[The] prejudices of [the animator] include a lack of confidence in the people's ability to think, to want and to know. So they fall into a type of generosity as harmful as that of the oppressors. Though they truly desire to transform the unjust order, they believe that they must be the executors of the transformation. They talk about the people, but they do not trust them and trusting the people is the indispensable precondition for revolutionary change.

Freire further describes what the approach should be of those who think they may be in a position to collaborate with the oppressed:

A real humanist can be identified more by his [or her] trust in the people, which engages him [or her] in their struggle, than by a thousand actions in their favor, without that trust.

This approach thus contradicts the traditional colonizing approaches that generally view indigenous groups as passive objects and mainly attribute positive changes solely to health service organizations (Smith et al., 2007). This approach should be complemented by a biomedical, behavioral and population health -focus as secondary approaches to care and development in an effort to address the generational impact of colonization.

Smith et al. (2007:323) identified a strength-based approach with Aboriginal women that will allow them to ultimately find their voice by “speaking up” and “speaking out”. This approach may encourage women in Pikeville to break their silence and start to “name their realities” (Freire, 2002:90). Dialogue as a tool would allow women to reflect on their actions (be it alcohol abuse or mothering) in a way that will make them more aware of the conditions that maintain their position of marginalization. The use of critical conscientization in maternal alcohol consumption among women may be a powerful tool in identifying the many ways in which the context reinforces alcohol abuse and binge drinking as one of many imposed occupations in Pikeville. Dialogue would also allow women to share the many positive contributions that they are already making to the community and to society upon which future development initiatives can be built.

### 5.3 Conclusion

A critical, postcolonial stance shaped the focus and methods of this study (Smith et al., 2006). In contrast to the traditional health promotion approach to FASD this study highlights realities related to individual and community realities and expectations (Smith et al., 2007). Identity development of drinking mothers is discussed and distinctions are made between practices, beliefs and values that are reinforced and supported by the context and practices that were the result of alcohol dependency. Dialogue on imposed occupations and its consequences and an empathetic approach to mothers are suggested as tools for initiating dynamic transformation in the lives of mothers who drink during pregnancy.

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## CHAPTER SIX

### CONCLUSIONS AND RECOMMENDATIONS

#### 6.1 Introduction

Promoting occupational engagement among mothers who abuse alcohol requires occupational therapy practitioners to broaden their knowledge base of existing occupations in the living environments of such women as well as of possibilities for alternative occupations that are more in touch with the real world of home and community. This chapter will discuss recommendations for an approach that is culturally relevant in conceptualizing how the long term prevention of FASD should be approached. The suggested model does not only refer to a conceptual process. It proposes particular developmental and empowerment techniques of implementing culturally appropriate methods for its delivery.

#### 6.2 Decolonizing development process against FASD

Although biomedicine has been the dominant health discourse in most developing and developed countries there is a need in South Africa for an alternative discourse in health promotion (Mundel and Chapman, 2010). Such an alternative discourse would consider socio-ecological determinants of health (Robertson, 1998). The WHO defines health promotion as a process for enabling people to increase control over, and to improve, their health (WHO, 1986). The process of increase and improvement of health can however, not take place without a more holistic conceptualization of health. This approach should target the health needs of the person as the social and economic conditions in the living environment. This approach will not only promote health, but the overall well-being of individuals and communities. The “lifestyle approach” to improving health (Mundel and Chapman, 2010:8) is therefore exchanged for a developmental approach in which the individual is viewed in relation to the contextual factors. Whereas the lifestyle approach emphasizes educating individuals to make “healthier” lifestyle choices, for example by eating “right” in order to avoid health problems or to stop drinking during pregnancy to ensure a healthy baby, a development approach focuses on empowerment and critical conscientization of individuals, families and communities.

Canada's Royal Commission on Aboriginal Peoples defined healing as: "Personal and societal recovery from the lasting effects of oppression and systemic racism experienced over generations. Many Aboriginal people are suffering not simply from specific diseases and social problems, but also from a depression of spirit resulting from 200 or more years of damage to their cultures, languages, identities and self-respect" (Report of the Royal Commission on Aboriginal Peoples, 1996, section 3). Sherwood and Edwards (2006) suggest that for healing to happen, a decolonization approach to health is necessary, which will involve a radically different way of promoting health. The Aboriginals from Australia and the indigenous groups from South Africa share similar colonial histories. In both countries these groups are still living marginalized lives. Alcohol abuse in communities as well as among women of childbearing age produces large numbers of children who are affected by prenatal alcohol abuse.

This new approach to the promotion of health, economic, social and political well-being should therefore facilitate a process whereby individuals (identified role models and other community members), their families and the broader community become actively involved in the identification and addressing of barriers (individual, group and communal) to health, well-being and development. Both Jenna and Lisa aspired to be like two of the older women who lived in their own community. In their view, a role model is someone who can offer food and shelter to others when they need it most. This was a valuable discovery and suggests the importance of collaborating with older women from the community to support, educate and inspire young women towards sober pregnancies. The expression by Jenna and Lisa illustrated how individual and collective agency can be combined in the re-creation of self stories that manifest power to instigate change (Polkinghorne, 1996). With careful guidance and the provision of educational initiatives that are pitched at an appropriate level, the resident older women can be involved in establishing new and alternative occupations through establishing trusting relationships that offer opportunities for advice and mentorship. When working with local role models it should be made clear that the focus is shifting from having to make lifestyle choices to conscientizing community members on limiting social, economic and political factors that contribute to and perpetuate health problems. Such a process cannot take place without an encounter where people are able "to name the [ir] world" (Freire, 2002:88). This process of naming includes the naming of people's realities (world they live in; their being in the world; interplaying social, economic and political factors; and the interplay

between their being in the world and the factors that determine who they represent and what position they hold). By naming their world people are able to transform their world. Freire (2002:88-89) describes true dialogue as:

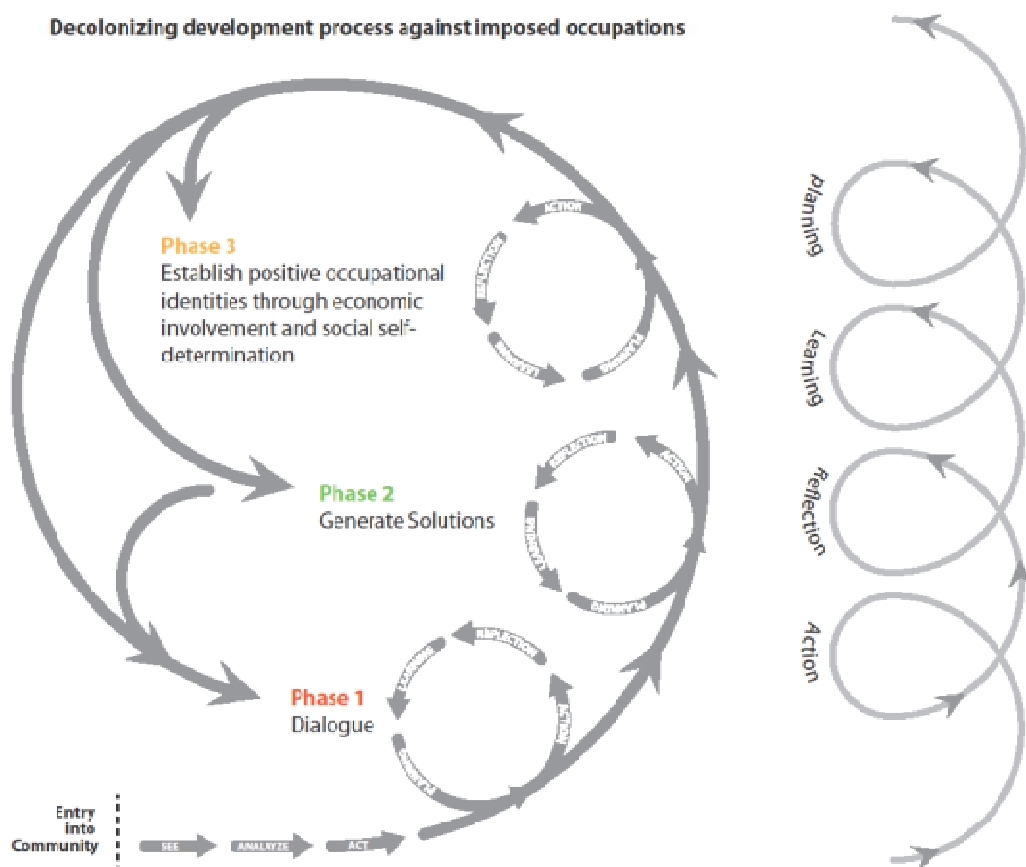
the encounter in which the united reflection and action of the dialoguers are addressed to the world which is to be transformed and humanized, this dialogue cannot be reduced to the act of one person's depositing ideas in another, nor can it become a simple exchange of ideas to be 'consumed' by the discussants.

Using Freirian adult education methods that require full collaboration of those affected means that a drastic change is needed in how health education and promotion among marginalized groups is done. It also suggests that unless mothers are enabled to name their realities in an attempt to identify the underlying determinants that perpetuate prenatal alcohol consumption, health promoters will remain at a loss for addressing and reducing FASD prevalence and ensuring women's health as a critical element of development.

The ability to name their world and identify significant issues relating to health and well-being will allow women who live in limiting social, economic and political conditions to start problem solving around these conditions and generate solutions that will facilitate improved health and participation in health-giving occupations. This will begin the process of increasing individual capacities and strengthening social networks (Mundel and Chapman, 2010). Applying the principles of knowledge translation (Choi, 2005 and Jacobson et.al, 2003) in FASD prevention will ensure that relevant information will be simplified and communicated in a way that can be understood and intergrated into the lives of people involved and/or targeted (Choi, 2003). The basic principles of knowledge translation are integration and simplification. Choi (2005) suggests that methods such as narrative interview, systematic review, meta-analysis, meta-database, inventory of best practices and public health inventory can facilitate integration of new information. Rolling out screening and education programs at primary schools and in community youth programs for adolescents with alcohol abuse tendencies will be a useful strategy for the Pikeville community. Education programs should include information on the development of the female body with particular focus on the developing fetus and the impact of the mother's lifestyle on the normal development of the fetus. Principles of

knowledge translations should be integrated to ensure that the information is accessible and usable in a way that young girls and older women can integrate this into their lifestyles. The next phase of this developmental approach to FASD prevention is to identify and address the structural and historical factors that impact on the identity of individuals, groups and the community. Freire (1967) refers to this process as critical conscientization. Verniest (2006) argues that the key to overall improved health for indigenous groups lies in the establishment of positive identities as well as improving economic and social self-determination in individuals, families, communities and nations. To ensure that animators (individuals who facilitate the process of development) are skilled, such individuals should receive accredited training in development that emphasizes empowerment principles as its foundation. Individuals should receive skills on how to facilitate the process of approaching, interacting, supporting and encouraging women to participate in and contribute to a process that will effectively address FASD. Referral to alcohol dependence rehabilitation programs that reinforce empowerment and individual and communal development as well as follow up, should form part of the comprehensive approach to women who are addicted to alcohol. Fig. 6 on p.233 proposes a process through which individuals with FASD can be supported and involved by naming the issues that prevent them from participating in opportunities that may contribute to individual and communal development. This process also allows such individuals to generate their own solutions to identified barriers and work towards positive occupational identities.

**Figure 6: Decolonizing development process against imposed occupations**



This process consists of three phases that follow an upward cyclical pattern. The starting point is the traditional (current) health promotion practices in FASD prevention that still reinforce the position of Black women of childbearing age as subalterns. At the point of community entry occupational therapists and health promoters should follow the steps of “see”, “analyses” and “act”. “Seeing” involves observing what people do, where they do it and how they do it (See Appendix 8.10). Emphasis is placed on the macro influences of occupational engagement. “Analyzing” involves making sense of what was observed in the first step after entering the community. During this step the occupational therapist should clarify her understanding and interpretations of what was observed (See Appendix 8.9). Throughout these steps the occupational therapist should interrogate her assumptions regarding the people, the context and their occupations. Step three (“act”) comprises of actions that are being taken with occupational therapists working alongside community members to identify, name and address underlying causes of prenatal alcohol consumption (See Appendix 9.9, pg13-14). Step three leads into Phase 1 of the

decolonizing development process against imposed occupations. Phase 1 constitutes the process of dialogue where an enabling environment is created for women to discuss pertinent issues as an equal party to the listener. Among other issues that might be raised it is imperative that community members, health practitioners, development workers, researchers and occupational therapists are cognizant that apartheid's historical legacies endure in the present. It is well known in policy circles and in South African society in general that true development is not possible unless economic benefits accrue to poor people. Occupational therapists should think critically and act drastically to contribute to the improvement of educational outcomes at public schools and particularly black schools. Community members and occupational therapists should collaborate on exploring the possibilities of utilizing social welfare programs to create or develop jobs and other social opportunities. Local skills and assets should be used to address the poor quality of housing initiatives.

Responsibility for material and social maintenance and communal well-being should be shared between poor people, service providers, politicians, government institutions and the business sector. In this way individual, social and material resources that have been eroded by long histories of dispossession, alienation and social aggravation can be restored over time (Ross, 2010).

As part of the dialogue process occupational therapy practitioners need to ensure that they are culturally competent in their practice with indigenous groups (Galheigo, 2011). Galheigo suggested the following strategies if occupational therapists would like to involve marginalized women, such as the mothers from Pikeville, to reinvent occupational therapy along culturally meaningful and relevant lines:

- Increasing therapist's knowledge of indigenous cultures
- Initiating and developing cooperative practice with indigenous leaders and healers
- Adapting therapy to a person's culture and environment (Chiang and Carlson, 2003)

During Phase 2 women are encouraged to generate solutions to the identified problems. During this phase the process can return to Phase 1 (dialogue) or it can proceed to

Phase 3. The solutions generated by the women should be implemented in a way that enables them to partake in occupations that will lead to participation in the economy of the community and of society. The physical and neurological impairments caused by prenatal alcohol exposure create major challenges for those affected and it provides sufficient merit for this condition to be officially classified as a disability. This concept of disability would therefore include the physical and mental impairments as well as participation limitations or restrictions (WHO, 2001) in activities that enhance health, well-being and development. The stance that is taken in this thesis is that the impact of FASD on individuals, families and communities can only be recognized and addressed if FASD is viewed as a disability. This approach to FASD will facilitate an approach that will position the role that the individual (mother) plays towards causing the disability in perspective to the environmental and contextual factors that perpetuate FASD. In doing so, individuals who are unable to find and keep paid employment, for example, could be screened for FASD. Individuals who are diagnosed with effects of prenatal alcohol exposure will then be able to get the needed support or accommodation in the five areas of education, employment, health, livelihood and socializing (WHO, 2010). This support will include, but will go beyond the provision of a disability grant or social grant and should include structured support to facilitate integration and participation in occupations that facilitate physical, emotional, social and economic health and well-being. Women will thus not only receive financial and social support, but will enjoy protection from gender violence as well as violence that occurs in their communities. The occupations that women are involved in will therefore serve as a means to recognized economic participation and social self-determination.

During Phase 3 individual, group and community identity is reconstructed and established. Individuals may learn new skills or improve existing skills in order to enhance their capabilities to participate in social, economic and political occupations. Phase 3 is followed by a return to dialogue (Phase 1) or a return to generation of new solutions (Phase 2). In each of the phases the action-reflection cycle (Taylor, 2005) is followed to allow participants to speak and reflect about what they are doing, to do what they were discussing and to adapt their actions according to the requirements of the process.

To ensure that the decolonizing development process against FASD yields success the preconditions in the form of five cornerstones of social inclusion suggested by the Laidlaw Foundation in Canada (2005) should be met and utilized as guiding principles:

- Valued recognition (individual, group and community)
- Human development (in social, economic and political areas of life)
- Involvement and engagement (in issues identified by community)
- Proximity to resources- ensuring the spaces in which people live is in close proximity to all services
- Material well-being (basic needs are met)

### **6.3 Reflection on the research methodology**

Although critical theory as a paradigm was appropriate to the ethos associated with this study, a feminist approach would lend itself to a deeper, analytical and emancipatory process for drinking mothers. I would suggest that further research be done with drinking mothers while using feminism. Taking a participatory action research approach would allow drinking mothers to engage in alternative occupations while the occupational therapist could record the needed changes in the environment, changes in occupational identity and different types of occupational engagement over a specified period.

### **6.4 Conclusion**

The proposed process follows a retroactive approach. This means that the process would respond to suggestions that will improve access to basic services and the development of personal and collective skills. The goal is to bridge the space between being a traumatized society and becoming a liberated society. This study provides evidence that there is space for alternative methods to the existing health promotion strategies on FASD prevention. Critical conscientization and dialogue as tools in FASD prevention lends itself to active involvement in planning and problem solving of sensitive and personal issues that may hinder collective development as South African communities.

Within occupational therapy, profession specific knowledge, skills and attitudes can be combined with Freirian methodology and knowledge translation principles to enable

mothers who drink during pregnancy to name and transform the underlying factors that impact on their occupational engagement. Taking an occupational perspective to FASD prevention shifts the focus from the individual mother who is caught up in an imposed occupation to a group of mothers who can begin a process of critical conscientization. Occupational therapists and health promoters can draw upon collective agency to establish new occupational identities and create new occupational possibilities.

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## 8. Appendices