# STORIES OF MOTHERS EXPOSED TO BIOPSYCHOSOCIAL FASD SERVICES IN THE LANGEBERG MUNICIPAL AREA

by

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# DECLARATION

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own original work, that I am the authorship owner thereof (unless to the extent explicitly otherwise stated), and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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# ABSTRACT

Fetal alcohol spectrum disorders (FASD) are a range of detrimental physical, psychological, behavioural, and social effects caused by prenatal alcohol exposure. South Africa, with the highest recorded prevalence of FASD worldwide, has no formal policies for FASD prevention, intervention, and support services. Although FASD research worldwide has benefitted from research done in SA, little is done to address the individual and societal factors contributing to the prevalence of FASD in SA. Social workers have an important role in the prevention of FASD, interventions with and support to high-risk drinking women. From a biopsychosocial perspective, it is important to address the biological, psychological as well as social factors contributing to FASD as well as its consequences for the affected individual.

This study aimed to gain an in-depth understanding of the lives, realities and needs of women with a high risk of having a child with FASD. A qualitative study employing a combination of the exploratory and descriptive case study designs was utilised. To select study participants, purposive sampling was done. File content of women who previously participated in a case management study with high-risk drinking pregnant women in the Langeberg Municipal area was studied before interviews were conducted. A semi-structured interview guide was used in the in-depth, face-to-face interviews with six women.

The seven themes identified from the data collected were: childhood, intergenerational patterns, level of education and work circumstances, the role of partners, pregnancies and children, psychological factors and the availability of services and a need for more services. Findings from this study indicated that several childhood factors can be linked to high-risk drinking, that there is intergenerational transfer of embedded drinking patterns, such as weekend binge-drinking and that mothers and grandmothers influence young women's drinking patterns and attitudes. It was found that none of the study participants completed their schooling and, as a result, were financially vulnerable. The role of partners in the drinking habits of pregnant women were found to be substantial. It was found that partner support or a lack thereof, partners having affairs or leaving pregnant women, and domestic violence affect women's physical and mental health contributing to high-risk drinking. Findings showed that none of the

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women participating in this study planned their pregnancies, leading to late pregnancy recognition and continued drinking throughout at least the first trimester. It was shown that psychological factors such as depression, feelings of hopelessness and defaulting on psychological treatment, were common. The findings also showed that there is a need for practical interventions, social work and counselling services, physical and mental health services, and a need for the coordination of these services. The lack of collaboration and policies to guide FASD prevention on all three levels of prevention, to deliver intervention services addressing the biological, psychological, social, and educational complexities of FASD and the need to put such policies and strategies in place to construct and implement a plan of action, was clearly shown.

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# ABSTRAK

Fetale alkohol spektrum afwykings (FASA) is ’n reeks nadelige fisiese, psigiese, gedrags- en sosiale effekte wat deur voorgeboortelike alkoholblootstelling veroorsaak word. Suid-Afrika, die land waar navorsers die hoogste voorkoms van FASA wêreldwyd gevind het, het geen formele beleid vir FASA voorkoming, intervensies of ondersteuningsdienste nie. Alhoewel FASA navorsing wêreldwyd voordeel getrek het uit navorsing wat in SA gedoen word, word min in SA gedoen om die individuele en gemeenskapsfaktore wat bydra tot die hoë voorkoms van FASA, aan te spreek. Maatskaplike werkers het ’n belangrike rol in die voorkoming van FASA, intervensies met en ondersteuning aan vroue met hoë risiko drinkgewoontes. Uit ’n biopsigososiale perspektief is dit belangrik om die biologiese, psigologiese en sosiale faktore wat bydra tot die voorkoms van FASA, sowel as die gevolge daarvan vir die geaffekteerde individu, aan te spreek.

Hierdie studie het ten doel gehad om ’n diepgaande begrip te ontwikkel van die lewens, realiteite en behoeftes van vroue met ’n hoë risiko om ’n kind met FASA te hê. ’n Kwalitatiewe studie wat ’n kombinasie van verkennende en beskrywende-gevallestudie-ontwerpe gebruik het, is gedoen. Om die studiedeelnemers te kies, is van doelgerigte steekproefneming gebruik gemaak. Voordat onderhoude gevoer is, is die lêers van vroue wat voorheen aan ’n gevallebestuurstudie waaraan swanger vroue met hoë risiko drinkgewoontes deelgeneem het, bestudeer. ’n Semi-gestruktureerde onderhoudskedule is gebruik om onderhoude met ses vroue in die Langeberg munisipale area te voer.

Die sewe temas wat uit die ingesamelde data geïdentifiseer is, is kinderjare, die oordra van gedragspatrone tussen generasies, vlak van opvoeding en werksomstandighede, die rol van lewensmaats, swangerskappe en kinders, sielkundige faktore, die beskikbaarheid van dienste en ’n behoefte aan meer dienste. Bevindinge van die studie dui aan dat verskeie faktore uit hul kinderjare verbind kan word met hoë risiko drinkgewoontes, dat daar ’n oordrag van vasgelegde drinkgewoontes soos fuifdrinkery tussen generasies is, en dat moeders en grootmoeders jong vroue se drinkpatrone en houdings teenoor alkoholgebruik beïnvloed. Dit is bevind dat nie een van die studiedeelnemers hul skoolloopbane voltooi het nie en gevolglik finansieel kwesbaar

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is. Dit is verder gevind dat lewensmaats 'n groot rol speel in swanger vroue se drinkgewoontes. Dit is bevind dat die ondersteuning van lewensmaats of 'n gebrek daaraan, lewensmaats wat swanger vroue verlaat of ander verhoudings het, asook gesinsgeweld, vroue se fisiese en psigiese gesondheid affekteer en bydra tot hoë risiko drankgebruik. Daar is bevind dat nie een van die vroue wat aan hierdie studie deelgeneem het, hul swangerskappe beplan het nie. Dit het daartoe gelei dat hulle laat bewus geword het van hul swangerskappe en ten minste in die eerste trimester van swangerskap gedrink het. Daar is getoon dat sielkundige faktore soos depressie, gevoelens van hopeloosheid en die onderbreking van sielkundige behandeling algemeen is. Die bevinding het 'n behoefte aan praktiese ingrypings, maatskaplike werk dienslewering, berading, fisiese en geestesgesondheidsdienste en 'n behoefte aan die koördinering van hierdie dienste getoon. Die gebrek aan samewerking en beleid om FASA-voorkoming op al drie vlakke van voorkoming te lei, 'n behoefte aan intervensies wat die komplekse biologiese, psigiese, sosiale en opvoedingsaspekte van FASA aanspreek en die behoefte om sodanige beleid en strategieë in plek te stel en 'n plan van aksie te implementeer, is aangedui.

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# LIST OF ABBREVIATIONS

| | | |
|---|---|---|
| ARBD | - | Alcohol Related Birth Disorders |
| ARND | - | Alcohol Related Neurodevelopmental Disorders |
| AUD | - | Alcohol Use Disorders |
| AUDIT | - | Alcohol Use Disorder Identification Test |
| BAC | - | Blood Alcohol Concentration |
| BMI | - | Body Mass Index |
| CanFASD | - | Canadian FASD research network |
| CDC | - | Centre for Disease Control and Prevention |
| CHOICES | - | Changing High-risk Alcohol use and Improving Contraception Effectiveness Study |
| CM | - | Case Management |
| CNS | - | Central Nervous System |
| CRA | - | Community Reinforcement Approach |
| DESC | - | Department of Social Work Ethical Screening Committee |
| DVA | - | Domestic Violence Act, no 116 of 1998 |
| EUFASD | - | European FASD Alliance |
| FAE | - | Fetal Alcohol Effects |
| FARR | - | Foundation for Alcohol Related Research |
| FAS | - | Fetal Alcohol Syndrome |
| FASD | - | Fetal Alcohol Spectrum Disorders |
| FASER | - | Fetal Alcohol Sydrome Epidemiological Research |
| FC | - | File Content |
| HCET | - | Hantam Community Education Trust |
| IOM | - | Institute of Medicine |
| ISDM | - | Integrated Service Delivery Model |
| MEC | - | Member of the Executive Council |
| MI | - | Motivational Interviewing |
| MRI | - | Magnetic Resonance Imaging |
| NIAAA | - | National Institute of Alcohol and Alcohol Abuse |
| PAE | - | Prenatal Alcohol Exposure |
| PFASD | - | Partial Fetal Alcohol Syndrome |

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| | | |
|---|---|---|
| RDP | - | Reconstruction and Development Programme |
| REC | - | Research Ethics Committee |
| SA | - | South Africa |
| SACSSP | - | South African Council for Social Service Professions |
| SBIRT | - | Screening, Brief Intervention and Treatment |
| SIDS | - | Sudden Infant Death Syndrome |
| USA | - | United States of America |
| WCP | - | Western Cape Province |
| WHO | - | World Health Organisation |

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# CHAPTER 1
# INTRODUCTION AND BACKGROUND TO THE STUDY

## 1.1 INTRODUCTION AND RATIONALE

Fetal alcohol spectrum disorders (FASD) are a range of possible deleterious effects caused by prenatal alcohol exposure (Nguyen, Coppens & Riley, 2011; Hoyme, Kalberg, Elliot, Blankenship, Buckley, Marais, Manning, Robinson, Adam, Abdul-Rahman, Jewett, Coles, Chambers, Jones, Adnams, Shah, Riley, Charness, Warren & May, 2016). Maternal alcohol use during pregnancy can result in a variety of physical, behavioural, social, and psychological detriments affecting not only the exposed individual, but also their families and communities (Nguyen et al., 2011; May, Gossage, Marais, Adnams, Hoyme, Jones, Robinson, Khaole, Snell, Kalberg, Hendricks, Brooke, Stellavato & Viljoen, 2007).

FASD forms a continuum of possible effects on the exposed individual with full-blown Fetal Alcohol Syndrome (FAS) on the one end of the spectrum, followed by Partial Fetal Alcohol Syndrome (PFAS), Alcohol Related Neurological Disorders (ARND) and no FASD on the other end of the spectrum (Carpenter, 2011; May, De Vries, Marais, Kalberg, Buckley, Adnams, Hasken, Tabachnick, Robinson, Manning, Bezuidenhout, Adam, Jones, Seedat, Parry & Hoyme, 2017). The consequences of FASD on the exposed individual, though highly variable, are irreversible and have lifelong effects (Osterman, 2011).

Despite FASD being a preventable condition, South Africa (SA) and especially the wine growing areas of the Western Cape Province (WCP), has the highest recorded prevalence of FASD in the general population worldwide (May et al., 2007). A prevalence study using active case ascertainment methods with first grade learners in the Langeberg Municipal area in 2011, found that between 20% and 28% of first grade learners in this area, were on the FASD spectrum. Compared to international prevalence figures of 4.3% in Croatia, 3.7% in Italy, 3% in Canada, 0.1 % in Australia (Roozen, Peters, Kok, Townend, Nijhuis & Curfs, 2016) and, using a weighted approach, between 3 and 9.9% in the USA (May, Chambers, Kalberg, Zellner, Feldman, Buckley, Kopald, Hasken, Xu, Honerkamp-Smith, Taras, Manning,

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Robinson, Adam, Abdul-Rahman, Vaux, Jewett, Elliot, Kable, Akshoornoff, Falk, Arroyo, Hereld, Riley, Charness, Coles, Warren, Jones & Hoyme, 2018), the severity of the problem in SA is clear.

Although the high prevalence of FASD in SA is partly attributed to high-risk drinking behaviour, the adverse effects of alcohol use in pregnancy is the result of a wide range of factors, including social, behavioural, environmental, and genetic factors (Chudley, 2011). Various other studies (May, Gossage, Marais, Hendricks, Snell, Tabachnick, Stellavato, Buckley, Brooke & Viljoen, 2008; May, 2011; May, Blankenship, Marais, Gossage, Kalberg, Joubert, Cloete, Barnard, De Vries, Hasken, Robinson, Adnams, Buckley, Manning, Parry, Hoyme, Tabachnick & Seedat, 2013; Olivier, 2017) have attributed co-risk factors such as socio-economic factors, demographics, cultural factors, lifestyle, psychosocial factors, maternal age, gravidity, maternal body mass index, religiosity, unstable relationships and drinking patterns to having a child with FASD.

The combination of these multi-faceted factors clearly indicates that FASD is a complex problem consisting of biological, social, and psychological factors. Addressing FASD in all its complexity will, therefore, require a holistic approach, which recognises that the risk factors are connected and cannot be treated in isolation. This resonates with the work of George Engel, who developed the biopsychosocial model. This model promotes a more integrative view, which recognises that there is complex interaction between biological, psychological, and social factors (Borrell-Curriò, Suchman & Epstein, 2004).

Davidson and Strauss (1995) agree with this view when they state that the biopsychosocial model adds together biological, psychological, and social factors in different levels of organisation interacting with each other in varying degrees. The biopsychosocial model makes it possible to examine the conditions that contribute to the individual’s situation, as well as how these conditions relate to each other (Babalda, Noel & White, 2017). It can thus be said that the biopsychosocial model is in search of the factors underlying the conditions affecting and influencing an individual’s situation.

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In the search to find and understand some of these underlying risk factors in mothers with children on the FASD spectrum, May et al. (2008) utilised data from population-based studies in SA to compile a profile of the women who gave birth to children with the most severe diagnosis on the FASD spectrum. This study found that mothers of children with FAS and PFAS were from even lower socio-economic status (SES) groups than mothers of control group children who were from low socio-economic circumstances themselves. In addition, the mothers of children with FAS and PFAS had fewer social resources, and had extended families, cohabitating partners and friends who were heavy drinkers. Rather than having a circle of family, friends and partners as support, these mothers experience that their social circles and partners add to their challenges and stressful life events.

May et al. (2008) confirm this with their finding that mothers of children with FAS and PFAS more often reported physical assault, acutely stressful life events and severe circumstances that contributed to their problem drinking during pregnancy. Moreover, an elevated risk of violence between pregnant women and their partners was shown in a study by Eaton, Kalichman, Sikkema, Skinner, Watt, Pieterse and Pipiman (2012). Despite these findings highlighting the effect poor inter-partner relationships can have on pregnancy outcomes, FASD prevention services are mostly focused on women and the role of the father in pregnancy is seldom acknowledged or brought to light (De Vries, 2012; Olivier, 2017).

La Raya (2020) adds to these findings by stating that alcohol use is often regarded as individual behaviour, while contributing factors such as the context, purpose and location of the behaviour are ignored. The embeddedness of alcohol use in social settings in the WCP with its lifestyle of weekend binge drinking in some communities is part of the problem and contributes to the complexity of FASD prevention and support services.

Considering effects of prenatal alcohol use such as damage to the developing brain, physical malformations, general health and behaviour problems in the affected individual, Osterman (2011) emphasises the importance of interventions for women who are at risk to use alcohol during pregnancy, even for those women who do not have alcohol use disorders (AUD). Past alcohol use is seen as a strong predictor of a woman’s drinking behaviour during pregnancy. For this reason, Osterman (2011) is of

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the opinion that antenatal screening for alcohol use is essential to identify women at risk for using alcohol during pregnancy in order to provide timely interventions to decrease their alcohol use.

A study by May et al. (May, Marais, Gossage, Barnard, Joubert, Cloete, Hendricks, Roux, Blom, Steenekamp, Alexander, Andreas, Human, Snell, Seedat, Parry, Kalberg, Buckley & Blankenship, 2013) enrolled pregnant women from antenatal clinics for an intervention, in which case management (CM), using the techniques of motivational interviewing (MI) and the principles of the community reinforcement approach (CRA), was introduced as a means of targeted intervention to reduce drinking in pregnancy. In CM, pregnant women with high-risk drinking behaviour were supported to set their own goals and identify the resources they needed to stop or reduce their drinking (De Vries, Joubert, Cloete, Roux, Baca, Hasken, Barnard, Buckley, Kalberg, Snell, Marais, Seedat, Parry & May, 2015).

Although CM proved to be a successful means of FASD prevention for heavy drinking women, it also provided the opportunity for these women to share their day to day lives and realities with their case workers. CM sessions became the rare instance where somebody really listened to them, supported them, believed in them, and gave recognition to their pain about broken relationships and constant losses. Being heard, seen, and recognised brought back a sense of worthiness, which made it possible for many women to change their drinking behaviour in pregnancy (De Vries et al., 2015).

A factor that adds to women's sense of unworthiness is the fact that women who drink in pregnancy are often judged and even brought to shame by their communities, families and even health care workers and social workers (Olivier, 2017). This study explored the hardships, realities and needs of women who were exposed to prevention and support services and tells their stories of change or inability to overcome the obstacles preventing change. By telling their stories, the study provides insight into the biological, psychological, and social factors that must be considered in rendering services to high risk drinking pregnant women.

Social workers are regularly confronted and challenged with the consequences of drinking during pregnancy in the offspring of high-risk drinking women without recognising the possibility of FASD. One study (Kambeitz, Klug, Greenmeyer, Popova

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& Burd, 2019) showed that children with FASD have a 9-fold increased risk for placement in foster care, a 6.7-fold increased risk for residential care placement and a 19-fold increased risk for placement in juvenile correctional centres. Behavioural problems, problems with social adaption and even failure to thrive in children can be linked to prenatal alcohol exposure. However, despite the demands this places on social services, the connection with FASD is seldom made. A lack of knowledge about FASD and its effects on the individual amongst social workers limit the contributions social workers as part of the multi-disciplinary team can make regarding intervention, prevention, and support services. This study views FASD and the prevention thereof from a social work perspective to add to the existing body of knowledge about FASD in social work.

## 1.2 PROBLEM STATEMENT

Since 1997, various epidemiological research studies on the prevalence of FASD were undertaken in SA (May et al., 2007; May et al., 2013; May, De Vries, Marais, Kalberg, Adnams, Hasken, Tabachnick, Robinson, Manning, Jones, Hoyme, Seedat, Parry & Hoyme, 2016; May, De Vries, Marais, Kalberg, Buckley, Adnams, Hasken, Tabachnick, Robinson, Manning, Bezuidenhout, Adam, Jones, Seedat, Parry & Hoyme, 2017; Viljoen, Gossage, Brooke, Adnams, Jones, Robinson, Hoyme, Snell, Khaole, Kodituwakku, Asante, Findley, Quinton, Marais, Kalberg & May, 2005; Olivier, Urban, Chersich, Temmerman & Viljoen, 2013). All of these studies found an extremely high prevalence of FASD in SA compared to other parts of the world where similar research was done.

The above-mentioned studies and the recognition it gave to the extent of the problems with FASD in SA, opened the way for many national and international researchers to study related topics, such as the educational needs of children with FASD, behaviours related to FASD, the experiences of parents and foster parents taking care of children with FASD and many similar studies. The maternal risk factors for having a child with FASD, prevention efforts on all levels of prevention (primary, secondary, and tertiary) and interventions that can benefit affected children are frequently studied and described in literature (De Vries & Green, 2013; De Vries et al., 2015; May et al., 2013; Kalberg, Marais, De Vries, Seedat, Parry & May, 2017). These studies indicated, amongst other things, that maternal risk factors include biological, psychological, and

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social components. Many women had adverse life experiences, suffered from depression, or had stressful lives influencing their functioning and decision-making, especially regarding their drinking.

Search results from the National ETD portal showed only one case study about the occupations of women with a high risk for having a child with FASD on farms, done by an occupational therapist (Cloete, 2005). Despite extensive research about FASD and all of its components, there is a gap in literature where the voices of mothers with drinking behaviour putting them at high risk for having a child with FASD, can be heard telling their stories from their own biological, psychological, and social realities. This study will consider these realities from a social work perspective, adding to the existing body of knowledge in social work.

## 1.3 RESEARCH QUESTION

The primary research question was: 'What are the lived realities and experiences (stories) of high risk drinking pregnant women from a biopsychosocial perspective and how may these realities and experiences influence their choices during pregnancy?"

This question was researched by reflecting on the following secondary questions:

1. What are the life experiences and realities of a high risk drinking pregnant women?
2. How do these experiences and realities influence their choices, especially during pregnancy?
3. Why do some women succeed in changing their drinking behaviour whilst others continue their lifestyle despite interventions to support changes to their drinking behaviour during pregnancy?

These questions were explored with a sample of women who were not pregnant at the time but participated in a case management programme during a previous pregnancy and contributes to the body of knowledge regarding FASD prevention and support services to high-risk women in social work.

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## 1.4 AIM AND OBJECTIVES OF THE STUDY

The aim of this research was to gain an in-depth understanding of the lives, realities and needs of women with a high risk of having a child with FASD to add to the existing body of knowledge in social work and to contribute to a better understanding of how to structure prevention and support services to high-risk women.

In order to reach the aim of this study and to answer the research question satisfactory, the following objectives were pursued:

- To give a detailed description of the effects of prenatal alcohol exposure on the developing fetus as well as on the long-term functioning and health of the affected individual.
- Based on the biopsychosocial model, to analyse:
  - a) The maternal risk factors for FASD,
  - b) The prevention of FASD,
  - c) Rendering support services to high risk drinking pregnant women, as well as
  - d) The structuring and management of policy and legislation that can lead to a more comprehensive, inter-sectoral and holistic approach to FASD prevention and support services.
- To describe FASD prevention and support services.
- To empirically investigate the realities and needs of women with high-risk drinking behaviour in pregnancy.
- To draw conclusions and make recommendations regarding the effective prevention of FASD and support services to pregnant women to health care providers, social service professionals, communities, organisations, and policy makers.

## 1.5 THEORETICAL POINT OF DEPARTURE

This study utilised the biopsychosocial model as its theoretical point of departure. The biopsychosocial model, developed by George Engel in 1977, is a scientific model based on the systems approach. This model was constructed to address the dualistic Western understanding of mind and body which, Engel believed, missed the

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psychological and social dimensions as important determinants of health (Engel, 1980; Babalda et al., 2017).

The most important texts focussed on the description of the complex relationship between the biological, psychological, and social factors and the interactions between these factors in order to provide a conceptual framework capable of accommodating humanness and human phenomena, were those of Engel (1980, 1990, 1997), Davidson & Strauss (1995), Highland, Herschl, Klanecky & McChargue (2013) and Borrel-Cariò, Suchman and Epstein (2004).

The application of the biopsychosocial model in social work where there is, in contrast with the biomedical model, a history of underestimating the need to include the biological and psychological dimensions in favour of an almost exclusively social perspective, also served as a crucial point of departure. Whilst the biopsychosocial model often refers to “social determinants of health”, this study also focussed on the importance of the “health determinants of social well-being”. Vital texts in this regard were those of Barkley (2009), Burns, Dannecker and Austin (2019), May et al. (2007), May, Hamrick, Corbin, Hasken, Marais, Brooke, Blankenship, Hoyme and Gossage (2014) and May, Hamrick, Corbin, Hasken, Marais, Blankenship, Hoyme and Gossage (2016).

Adding the concepts “social determinants of health” and “health determinants of social well-being” to Engel’s view that a person is essentially within a social context, which includes cultural, social, and psychological factors, provided a platform for this study to get an insider’s perspective into the “network of interlocking pathways” (Garland, Boettiger & Howard, 2011:746) influencing high risk drinking behaviours during pregnancy.

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## 1.6 RESEARCH METHODOLOGY

This section briefly describes the research methodology regarding the research approach, research design, sampling methods, the nature of data management and data analyses used in this study.

### 1.6.1 Research Approach

This study employed a qualitative research approach to attain the research objectives. The qualitative research approach, which aims to understand rather than to explain (Schurink, Schurink & Fouché, 2021) is also described as a means of "getting inside the participant's skin" and capturing information from the perspective of the participant (Greeff, 2011:351). Miles and Huberman (1994) describe data collected via qualitative research as rich and holistic, providing the opportunity for thick, vivid descriptions nested in reality and with the potential to reveal complexity. This view is confirmed by Daniel (2012) who is of the opinion that qualitative studies require from the researcher to immerse herself into the social setting being studied and to comprehensively describe the study topic. This approach befitted this study that was interested in gaining an in-depth understanding of the lives, realities and lived experiences of women at high risk for having a child with FASD.

The study was pursued as a descriptive case study aiming at an ideographic explanation for each case. According to Schurink et al. (2021), the distinguishing characteristic of a case study is that it is a means to examine a contemporary phenomenon in the context of real life. To achieve this, the researcher mostly made use of deductive reasoning, but moved between deductive and inductive reasoning to ensure a more powerful and comprehensive understanding of the phenomenon (Babbie, 2014). The researcher, therefore, started with a research question, followed by a literature study, the collection of empirical data and, finally, analyses of the data. The research approach is described in more detail in chapter five.

### 1.6.2 Research design

In this study, a combination of the exploratory and descriptive case study designs was utilised. Exploratory study designs are typically used to gain a basic understanding of a specific phenomenon, situation or individual in circumstances where a lack of

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information in a particular field exists, producing new insights into that field (Babbie, 2014; Fouché, 2021). The need to explore the stories about the hardships, realities and needs of women at high risk of having a child with FASD, was recognised, and described in the motivation for this study. Alternatively, the description of situations and events is an important purpose of many social science studies and aims to create a clear and full picture of the details pertaining to a situation or phenomenon (Babbie, 2014; Fouché, 2021). Combining the exploratory and descriptive case study designs enabled the researcher to both explore the factors and conditions underlying the individual's situation, whilst also describing the network of interlocking pathways of biological, psychological, and social determinants influencing drinking behaviour during pregnancy.

## 1.7 INSTRUMENT FOR DATA COLLECTION

In this section, the population, and sampling, as well as the method of data collection is discussed.

### 1.7.1 Population and sampling

This study employed purposive sampling and more specifically case control sampling, to select participants for the study. According to Daniel (2012), the qualitative researcher is mainly interested in those elements in the population that will be most effective in providing rich information about the topic studied. Strydom (2021:382) adds that purposive sampling enables the researcher to compile the sample in such a way that it contains "the most typical attributes of the population being studied."

In this study, with its focus on a particular segment of the population, Daniel's (2012) argument confirms the fact that purposive sampling not only provided control over the selection of the cases, but also enabled the researcher to select the participants who were most likely able to provide the thick descriptions leading to a better understanding of the "network of interlocking pathways" (Garland et al., 2011:746) influencing drinking behaviour during pregnancy.

The researcher recruited women from a group of women in the Langeberg municipal area who completed a case management programme for women with high-risk drinking during pregnancy. This group of women were recruited for the case

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management programme between 2014 and 2016. This programme was part of the research activities of the Fetal Alcohol Syndrome Research study funded by the National Institute of Health in the United States of America. The criteria for participation in case management included the following:

- Heavy drinking women with an Alcohol Use Disorder Identification Test (AUDIT) score of eight or more. (The AUDIT, a 10-item questionnaire developed by the World Health Organisation [WHO], is used as an assessment tool for alcohol consumption, drinking behaviours and alcohol related problems. Each item is scored on a scale of 0 – 4 and a total score of eight or more is considered hazardous or harmful drinking) (Osterman, 2011; National Institute on Alcohol Abuse and Alcoholism: Alcohol Use Disorders Identification Test [AUDIT], 2000).
- Gestational age of 20 weeks or less,
- Gravidity of more than two, and
- Age of 25 years or older.

When participants in the case management programme signed their informed consent forms for participation in case management, they had the opportunity to indicate whether they would be willing to participate in any future studies. The researcher started out by selecting all the women who gave permission to be contacted again. The sample of participants for this study was chosen from the group who consented to be contacted for follow-up studies.

The number of participants recruited for this sample was relatively limited and “based on saturation” (Strydom, 2021:380). A sample size of five to seven women, which included a number of women who positively reacted to the case management process and stopped drinking in pregnancy, as well as women who were not able to change their drinking behaviour sufficiently to prevent damage to their unborn babies, was envisaged to reach data saturation. Since all the above-mentioned information was available in the case management files, it was possible to make this distinction between participants. In this way, both typical and divergent data were obtained (Strydom, 2021). Data saturation was reached after the fifth interview, but the researcher still conducted another interview to ensure that no new information emerged.

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### 1.7.2 Data collection

Consent was obtained from the principal investigator of the Fetal Alcohol Syndrome Epidemiological Study (FASER), Prof. Phil May, to approach previous participants in the case management programme of the said study, to participate in the proposed research before the onset of data collection (See Annexure F). Study participants who gave permission to be contacted again in their original consent to participate in the case management study, were contacted by a research assistant to determine their interest to participate in the proposed study. Participants who indicated that they were interested to participate in this study were then approached by the researcher. Although the researcher is involved with the research activities of the FASER study, she was not one of the case managers involved in interviewing or rendering any services to the participants in the CM study.

For this study, data were collected from two sources to obtain thick descriptions from the perspective of the participants (Schurink et al., 2021). This is in keeping with what Cresswell and Poth (2018) describe as building an in-depth case or storied experience using multiple forms of data.

Firstly, existing file content with data starting at an antenatal screening for risky drinking behaviour shortly after the participant's pregnancies were confirmed, up to a year after the participants were recruited, served as a point of departure to provide background information on demographics, socio-economic circumstances, drinking behaviour at different times during pregnancy, relationship with family and partners, health, as well as information on their nutrition during pregnancy. The file content provided the foundation for the information about the study participant during her pregnancy, upon which information gathered in this study built to sketch a more comprehensive picture of her experiences and circumstances as seen during her pregnancy, as well as in hindsight.

Gathering information from the file content was followed by semi-structured face-to-face interviews in order to gain in-depth understanding and knowledge of the participant's beliefs, perceptions and accounts of the factors that had an influence on their drinking behaviour during pregnancy (Geyer, 2021). Semi-structured interviews allowed the researcher the flexibility needed to follow avenues of particular interest

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due to its complexity or the controversial or personal nature thereof (Geyer, 2021). More than one interview with some study participants was needed to complete the interview schedule and obtain all relevant information.

Due to the COVID-19 pandemic and the resulting health and safety regulations, all the necessary precautionary measures such as wearing of masks, maintaining a social distance of 1.5 metres or more, hand sanitizing and sanitizing of surfaces before and after interviews, were taken to conduct face-to-face interviews. All interviews were conducted in a space with good ventilation.

However, would it because of COVID-19 restrictions and/or precautions, not be possible to conduct face-to-face interviews, telephonic interviews as an alternative were envisaged. Other computer-based technologies were not considered for these interviews since the participants were unlikely to have either access to or previous exposure to such technologies. According to a study by Farooq and De Villiers (2017), researchers making use of telephonic interviews had no difficulties building rapport with participants. These authors indicate that some participants were more comfortable discussing personal matters due to the feelings of greater anonymity a telephonic interview provided. Telephonic interviews may, therefore, contribute to open discussions where the study participant is the centre of the interview. Pre-interview telephonic conversations to put study participants at ease about the content of the interview schedule, arrange the time and duration of the interview and start building rapport for the interview itself, were planned. It was, however, due to limited Covid-19 restrictions, possible to conduct face-to-face interviews following all Covid-19 regulations.

The interview schedule was prepared and was based on a literature study to determine possible themes and consisted of open-ended questions allowing the participants to speak for themselves and tell their own stories (Schurink et al., 2021). The design of the interview was iterative, meaning that questions were remodelled during the course of the study (Babbie, 2014).

The researcher conducted all the interviews in Afrikaans and captured the data by means of audio-recordings and transcribed the data after each interview.

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### 1.7.3 Data analyses

According to Schurink et al. (2021) in qualitative data analysis there is an inseparable relationship between data collection and data analyses. Lester, Cho and Lochmiller (2020:98), describe the process of qualitative data analyses as a “non-linear, iterative process” while Babbie (2014:382) is of the opinion that qualitative data analyses involve interpreting observations in order to discover the “meanings and patterns underlying relationships”.

For this study, thematic analysis was utilised to organise and describe the data in rich detail. This method of analysis was chosen for its flexibility in analysing and reporting themes within the data (Schurink et al., 2021). The details of each of the cases were scrutinised to order, structure and find meaning in the available data with respect to the meanings the study participants intended (Braun & Clarke, 2006; Leech & Onwuegbuzie, 2007; Schurink et al., 2021). The content of the data was analysed by direct coding, and finding themes and patterns according to the aim of the study. The themes and patterns generated from the analysis were described, interpreted, and presented in the research report.

### 1.7.4 Data verification

According to Babbie (2014) the quality of a qualitative study is, although elusive, still important. Schurink et al. (2021) add to this viewpoint by stating that the strength of a qualitative study is found in its credibility. In this study credibility was achieved by describing the complex interactions between variables within the parameters of the study and its theoretical framework.

Although Schurink et al. (2021) are of the opinion that transferability in a qualitative study can be problematic, they also indicate that triangulation, where different methods of data collection are used, strengthens the transferability of a study. In this study, data were collected via face-to-face interviews, as well as by studying existing documents in the form of file content created in the case management programme, thus adding to the transferability of the study.

Although the researcher is involved in a research study on FASD, she was not the case worker of any of the participants in this study and, therefore, had no personal

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opinions or bias towards any of the possible study participants. The researcher's extensive experience in interviewing further enabled her to be attentive to reflexivity (Annexure J) and the impact it had on her understanding of what she observed as well as the impact she had on the study participants (Babbie, 2014).

Dependability was strengthened by following a logical, well-documented research process in order to ensure an understanding of the detail of the data collection process (Schurink et al., 2021). Transcription of the semi-structured face-to-face interviews were comprehensive to add to the completeness of the process and provided further evidence validating the findings of this study and adding to the conformability as well as the trustworthiness of this study (Babbie, 2014; Schurink et al., 2021). Member checking (Annexure I) was done to confirm that the transcriptions of the interviews are a true reflection of the interviews conducted.

## 1.8 ETHICAL CONSIDERATIONS

Research in the social sciences with its unique set of ethical dilemmas, should fundamentally be based on norms broadly agreed on such as mutual trust, acceptance, cooperation, and a widely accepted set of moral principles to guide the behaviour, the rules of conduct and the responsibilities of the researcher (Strydom & Roestenburg, 2021; Babbie, 2014).

The South African Council for Social Service Professions (SACSSP) binds registered social workers, amongst which this researcher, to its general ethical code of conduct. In addition to this general code of conduct, the researcher has completed the Good Clinical Practice (GCP) course online in 2019.

Ethical issues that received consideration in this study were:

- Avoidance of harm. Since the focus of the study was on past behaviour and social circumstances that might have included issues of sensitivity to the participants, avoidance of harm on an emotional level was important. In order to do this and in the light of this study being a medium risk study, participants were informed about the potential impact on their emotional well-being.
- Voluntary participation. The researcher recruited participants from a case management study they had previously participated in. As part of their informed

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consent in the previous case management study, participants indicated whether they would be willing to participate in future follow-up studies. The researcher, therefore, started by determining which participants indicated that they would be willing to participate in follow-up studies and selected the cohort for this study from the participants who already consented to be contacted for follow-up studies.

- Informed consent. According to Babbie (2014), participants' voluntary participation in a study must be based on understanding the study and the risks it implies for them. This study made use of informed consent forms enlightening the participants about the nature of the research, their roles and what were expected from them, the voluntary nature of their participation, their right to withdraw at any time during the course of the research and their right to refuse to answer any question should they choose to (See Annexures A and B). The informed consent forms were read to and discussed with every study participant. Participants got signed copies of the informed consent forms.
- Confidentiality was ensured by protecting the privacy of participants regarding their identity and protecting the security of the data collected. The anonymity of the participants was ensured. Data are stored on a password protected computer and on OneDrive. Field notes and hard copies of any form of data are stored in a locked filing cabinet.
- Compensation in the form of gift vouchers for a grocery store to the value of R100 per participant was given as an incentive to thank participants for their time and participation after completion of their interviews. Participants were not paid or compensated in order to influence their decision to take part in the study or not.
- Debriefing. Since the collection of data for this study was done from a biopsychosocial perspective, it included emotional content. The study was, therefore, considered a medium risk study. The researcher addressed this by debriefing participants after the interviews. An arrangement was also made with a counsellor in private practice for further debriefing of participants if needed.

An online application for ethical clearance for the proposed study was made to the Department of Social Work Ethical Screening Committee (DESC) and the Research Ethics Committee (REC) before the commencement of the study. Approval to

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commence with the study as a medium risk study was given on 27 July 2021 (Annexure G).

In chapter two, the first literature chapter, fetal alcohol spectrum disorder as a phenomenon will be discussed.

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# CHAPTER 2
# AN OVERVIEW OF FETAL ALCOHOL SPECTRUM DISORDERS

## 2.1 INTRODUCTION

This chapter will address the first objective of this study, which aims to provide a detailed description of the effects of prenatal alcohol exposure on the developing fetus. It further aims to provide information about the long-term effects of prenatal alcohol exposure on the health and development of the exposed individual as discussed in chapter one.

The adverse effects of alcohol use during pregnancy were raised and debated for many years before the term Fetal Alcohol Syndrome was formalised and published as a medical diagnosis by Doctors Kenneth Jones and David Smith in 1973 (May et al., 2007). In the years since the realisation that alcohol has a teratogenic effect on the developing fetus and the initial description of the clinical features associated with a FAS diagnosis was made (May et al., 2009), giant strides have been made in FASD research. Specific guidelines for the diagnosis of FASD were developed and is still evolving (Hoyme et al., 2016; Hoyme, May, Kalberg, Kodituwakku, Gossage, Trujillo, Buckley, Miller, Aragon, Khaole, Viljoen, Jones & Robinson, 2005; Kalberg, May, Buckley, Hasken, Marais, De Vries, Bezuidenhout, Manning, Robinson, Adam, Hoyme, Parry, Seedat, Elliot & Hoyme, 2019).

These guidelines led to a better understanding of the varied influence alcohol use during pregnancy may have on human development, especially on the developing brain. Hoyme et al. (2005:40) refer to the effects caused by prenatal alcohol exposure (PAE) as “a spectrum of structural anomalies and behavioural and neurocognitive disabilities”. This spectrum, known as the FASD spectrum, forms a continuum of effects with full-blown FAS, as the most severe phenotype, displaying growth restriction, a distinct pattern of minor facial anomalies and neurocognitive deficiencies combined with an established history of prenatal drinking (Hoyme et al., 2005). Because the severely affected children in the FAS phenotype were recognised and

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described first, it is still the most familiar diagnosis on the FASD spectrum (Hoyme et al., 2016).

Since the first epidemiological study on FASD was done in South Africa (SA) in 1997, ongoing research in SA has made important contributions to the existing body of knowledge about FASD. Not only did the fact that SA has the highest recorded prevalence of FASD in the world add to an increased awareness of the extent of the problem in SA as well as worldwide, but significant contributions have also been made to refine the ability to diagnose and distinguish between the diagnostic groups, to diagnose at an earlier age than previously thought possible, to find interventions applicable to the different levels of prevention as well as to study and describe the development of FASD across the lifespan.

This chapter aims to give a better understanding of the history of FASD, to provide insights into the criteria for and the process followed to assign a diagnosis on the FASD spectrum and to describe the effects of PAE on the individual.

## 2.2 THE HISTORY OF FASD

Alcohol use during pregnancy and the adverse effects thereof is not only a modern-day controversy. References in this regard date back to ancient times, making mention of Aristotle and even a Biblical reference to Judges 13:4. In the 1700s and again in the late 1800s mention was made of the weakness and disadvantages in terms of health and productivity later in the lives of children born to alcoholic mothers by physicians and researchers such as Sullivan in 1899 (Catterick & Curran, 2014; Hoyme et al., 2005).

In 1968 a French researcher, Lemoine, reported on the harmful effects of alcohol use in pregnancy and described several of the distinctive characteristics now associated with FAS. However, he did not provide any formal criteria for a diagnosis or draw a conclusion about the true meaning of this findings. It was only in 1973 that the term FAS was assigned to the distinct constellation of physical malformations found in children prenatally exposed to alcohol by the dysmorphologists Kenneth Jones and David Smith. The result of this was the development of the diagnostic criteria for FAS

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as a formal diagnosis for the genetic syndrome caused by prenatal alcohol exposure (Catterick & Curran, 2014; Hoyme et al., 2005; May et al., 2007).

Although the initial description and diagnostic criteria only made provision for the diagnosis of full-blown FAS, it was soon realised that some alcohol-exposed children had less dysmorphic features and that prenatal alcohol use could lead to a range of potential detrimental effects on the individual, which might not include all the criteria needed for a diagnosis of FAS (Aase, Jones & Clarren, 1995). This led to the use of the term Fetal Alcohol Effects (FAE), a term initially intended for use to refer to the fact that children of alcoholic women more often displayed genetic abnormalities and developmental delays than found in the general population (Hoyme et al., 2005). Unfortunately, the term FAE was gradually used by some medical professionals as a diagnosis and eventually became widely accepted for use as a diagnosis. Since the term FAE lent itself to be broadly interpreted and did not make provision for any specific diagnostic criteria, it was often used indiscriminately to diagnose children with any kind of developmental problems, solely on the basis of suspected maternal alcohol use (Aase et al., 1995; Hoyme et al., 2005). As a result of these problems, Aase et al. recommended in 1995 that the use of the term FAE is abandoned.

Despite several attempts to define lesser phenotypes, the first description of the FASD spectrum as a continuum consisting of four distinctive diagnoses namely FAS, Partial Fetal Alcohol Syndrome (PFAS), Alcohol-Related Neurodevelopmental Disorders (ARND) and Alcohol Related Birth Defects (ARBD), was done by the Institute of Medicine (IOM) in the United States of America (USA) in 1996 (Hoyme et al., 2005; Hoyme et al., 2016). At that time, the clinical procedure for assigning an individual's diagnosis to any of the groups was not set out in detail, familial and genetic traits were not properly accounted for and the diagnoses of ARND and ARBD were not defined clearly enough to be used in a clinical setting (Hoyme et al., 2005; Hoyme et al., 2016). Due to these shortcomings in the description and definition of the diagnostic groups, several systems were developed over the years to provide explicit clinical guidelines for the assignment of a diagnosis to each of the diagnostic groups, each with its own shortcomings and impracticalities, for use in clinical settings.

In 2005, Hoyme et al. proposed a revision of the 1996 IOM diagnostic criteria with the aim of defining more specific criteria for each diagnostic category outlined by the IOM,

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which would, simultaneously, be more practical for use in general paediatric as well as research settings. In a collaboration with several researchers from multi-disciplinary teams and with the support of the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CiFASD) and the Collaboration on FASD prevalence (CoFASP) in the USA, these diagnostic criteria were updated in 2016, further refining guidelines for the parameters of each category and thereby improving the likelihood of an accurate diagnosis (Hoyme et al., 2016).

Since 1997, FASD research in SA has played an important role in the development of diagnostic criteria, knowledge about the true prevalence of FASD worldwide, as well as in creating a more comprehensive understanding of the true impact of FASD on the individual and the community. In the next section, the history of FASD in SA, the developments FASD research in SA has brought about, as well as the prevalence of FASD in SA will be discussed.

## 2.3 FASD IN SOUTH AFRICA

The high prevalence of FASD in SA has received much attention since the first FASD prevalence study was done in 1997. The possibility that FASD is a problem in SA was, however, suspected much earlier. In this section a detailed history of FASD research in SA, the process followed to assign a diagnosis on the FASD spectrum and the prevalence of FASD found by researchers between 1997 and 2016, will be discussed.

### 2.3.1 The history of FASD research in SA

The occurrence of FAS in SA was first mentioned by Beyers (Beyers & Moosa, 1978) who reported on four cases of FAS they encountered over a period of three months in the Somerset Hospital in Cape Town. This was followed by an article by Palmer who described examining 14 children born over a 12-month period in the Heideveld Mobile Obstetric Unit, displaying the facies and dysmorphological traits associated with FAS (Palmer, 1985). These 14 children described by Palmer were part of a group of 281 infants born over the same period in the same facility, giving an incidence of FAS in 1/281 or 3.6% of children born in that specific obstetric unit.

In 1995 Dr Dennis Viljoen, a South African geneticist currently involved with the Foundation for Alcohol Related Research (FARR), contacted several

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dysmorphologists across the USA to discuss his notion of a high prevalence of FAS in SA, based on his observation that a large number of children visiting paediatric genetics clinics in SA had FAS. Prof. Viljoen also met with officials at the National Institute of Alcohol and Alcohol Abuse (NIAAA) to bring this matter to their attention and to convince them to conduct a prevalence study of FAS in SA (Kalberg, Marais, De Vries, Seedat, Parry & May, 2017; May, 2020). At that time, Prof. Kenneth Jones, one of the dysmorphologists who described FAS as a genetic syndrome, was the scientific director of the NIAAA (May, 2020).

After Prof. Viljoen's meeting with the NIAAA, he also visited the highly respected dysmorphologist Dr Jon Aase at the University of New Mexico in Albuquerque to further his quest for FAS research in SA. Dr Aase involved Prof. Phil May who, at that time, was the director of the Centre on Alcohol, Substance Abuse and Addiction (CASAA) and had conducted several epidemiological studies on FAS in the USA, in this discussion. During their meeting, Prof. Viljoen mentioned his estimate that up to 10% of children visiting paediatric genetics clinics in SA had FAS (May, 2020). Since prevalence studies in the USA at that time showed prevalence figures of 0.1 to 1% in certain communities, a prevalence figure of 10% was thought impossible (Warren, Calhoun, May, Viljoen, Li, Tanaka, Marinicheva, Robinson & Mundle, 2001). Due to Prof. Viljoen's persistence in advocating the need for FAS research in SA, and as part of a binational agreement between the vice-presidents of the USA and SA, the NIAAA funded a fact-finding mission to SA (Kalberg et al., 2017; May, Brooke, Gossage, Croxford, Adnams, Jones, Robinson & Viljoen, 2000; Riley, Mattson, Li, Jacobson, Coles, Kodituwakku, Adnams & Korkman, 2003).

In September 1996, a group of 13 scientists visited SA to lecture, share their knowledge on a variety of subjects and assess opportunities for future research (Kalberg et al., 2017; May, 2020; May et al., 2000). As a result of this visit, the decision was made to conduct a first epidemiological research study on FAS in SA (May, 2020). At that time Prof. May was the only researcher funded with RO1-funding by the NIAAA to study the epidemiology of FAS amongst Native Americans. The NIAAA supplemented his existing funding and the first epidemiological study on FAS in SA, was conducted in 1997 in Wellington in collaboration with Prof. Viljoen and on invitation of the then mayor of Wellington, Mr Herman Bailey (May, 2020).

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Two more collaborative epidemiological studies between Prof. May, principal investigator of the Fetal Alcohol Syndrome Epidemiological Study (FASER) group and Prof. Viljoen, principal investigator, and chairperson of the board of directors of the non-governmental organisation, FARR, followed in 1999 and 2001 (Olivier, 2017). The results of this research focussed the attention of researchers worldwide on the high prevalence of FAS and the numerous opportunities for FASD research in SA. This has led to a variety of ongoing studies, including epidemiology, prevention studies, brain imaging and many more, enriching the FASD knowledge base worldwide. Studies about the effects of FASD on behaviour, the increased population of children with FASD in alternative care and the role of the social worker in the multi-disciplinary team providing services for affected individuals, also confirmed the role of social workers in providing services for both the prevention of FASD and the support of affected individuals.

### 2.3.2 The prevalence of FASD in South Africa

When the first large epidemiological study with grade 1 learners was done in 1997, the focus was on diagnosing FAS. This was due to the fact that the criteria for diagnosing PFAS, ARND and ARBD were not yet developed. It was only after the clarification of the 1996 IOM criteria by Hoyme et al. (2005), that there was a clear enough description of the specific criteria for each of the four diagnostic categories, for diagnoses of ARND and ARBD to be made.

The first epidemiological study in Wellington in 1997 was, as far as could be established, the first active case ascertainment study in a developing nation. This study showed the highest prevalence rates of FAS ever recorded. It also indicated that 61% of the children with FAS were from rural schools (May et al., 2000), emphasising rural residence as a risk factor for FASD.

Over the 20 years following the first epidemiological study on FASD in SA, various similar studies were done in different parts of the country. The results of these studies all confirmed the extremely high incidence of FASD in SA. Table 2.1 presents a summary of prevalence studies conducted between 1997 and 2017 and the prevalence figures found in the specific area where each study was conducted.

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**Table 2.1: FASD prevalence figures in SA**

| Year | Place | Prevalence rate per 1000 children | Percentage children affected | Reference |
|---|---|---|---|---|
| 1997 | Wellington, Western Cape Province (WCP) | 41 - 46 (FAS only) | 4.1 – 4.6% | May, Brooke, Gossage, Croxford, Adnams, Jones, Robinson & Viljoen (2000). |
| 1999 | Wellington (WCP) | 65 - 74 (FAS only) | 6.5 – 7.4% | Viljoen, Gossage, Brooke, Adnams, Jones, Robinson, Hoyme, Snell, Khaole, Kodituwakku, Asantè, Findlay, Ouinton, Marais, Kalberg & May (2005) |
| | Soweto, Diepsloot, Lenasia (Gauteng) | 26 (FAS only) | 2.6% | Olivier, Curfs & Viljoen (2016) |
| 2001 | De Aar (Northern Cape Province) | 119.4 (FAS and PFAS) | 11.9% | Urban, Chersich, Fourie, Chetty, Olivier & Viljoen (2008) |
| 2002 | Wellington (WCP) | 68 to 89 (FAS and PFAS) | 6.8 – 8.9% | May, Gossage, Marais, Adnams, Hoyme, Jones, Robinson, Khaole, Snell, Kalberg, Hendricks, Brooke, Stellavato & Viljoen (2007) |
| 2002 | Upington (Northern Cape Province) | 74.7 (FAS and PFAS) | 7.5% | Urban, Chersich, Fourie, Chetty, Olivier & Viljoen (2008) |
| 2003 - 2006 | De Aar (Northern Cape Province) | 112.8 (FAS and PFAS) | 11.3% | Chersich, Urban, Olivier, Davies, Chetty & Viljoen (2012) |
| 2008 | Wellington (WCP) | 135.1 to 207. (Total FASD) | 13.5 - 20.7% | May, Blankenship, Marais, Gossage, Kalberg, Joubert, Cloete, Barnard, De Vries, Hasken, Robinson, Adnams, Buckley, Manning, Parry, Hoyme, Tabachnick & Seedat (2013) |
| 2008 | Aurora (WCP) | 100 (FAS and PFAS) | 10% | Olivier, Urban, Ursich, Temmerman & Viljoen (2013) |
| | Saldanha (WCP) | 6.7 (FAS only) | 0.7% | Olivier, Curfs & Viljoen (2016) |
| | Witzenberg (WCP) | 9.8 (FAS only) | 1% | Olivier, Curfs & Viljoen (2016) |
| 2009 | Robertson, Ashton, Montagu, Bonnievale area (WCP) | 179.9 – 248 (Total FASD) | 17.9 – 24.8 % | May, De Vries, Marais, Kalberg, Adnams, Hasken, Tabachnick, Robinson, Manning, Jones, Hoyme, Seedat, Parry & Hoyme (2016) |
| 2005 - 2010 | Upington (Northern Cape Province) | 65.9 (FAS and PFAS) | 6.6% | Chersich, Urban, Olivier, Davies, Chetty & Viljoen (2012) |

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| Year | Place | Prevalence rate per 1000 children | Percentage children affected | Reference |
|---|---|---|---|---|
| 2010 | Wellington (WCP) | 170 – 230 (Total FASD) | 17 – 23% | May, Marais, De Vries, Kalberg, Buckley, Hasken, Adnams, Barnard, Joubert, Cloete, Tabachnick, Robinson, Manning, Jones, Bezuidenhout, Seedat, Parry & Hoyme (2016) |
| 2011 | Robertson, Ashton (WCP) | 200 – 280 (Total FASD) | 20 - 28% | May, De Vries, Marais, Kalberg, Buckley, Adnams, Hasken, Tabachnick, Robinson, Manning, Bezuidenhout, Adam, Jones, Seedat, Parry & Hoyme (2017) |
| 2012 - 2013 | Kimberley (Northern Cape Province) | 64 (Total FASD) | 6.4% | Urban, Olivier, Viljoen, Lombard, Louw, Drotsky, Temmerman & Chersich (2015) |
| | Renosterberg Municipality (Northern Cape Province) | 282 | 28.2% | Olivier (2017) |
| | Bethelsdorp, Port Elizabeth, Eastern Cape Province | 130 | 13% | Olivier (2017) |
| 2014 | Wellington (WCP) | 305.9 (Total FASD) | 30.6% | May, Marais, De Vries, Buckley, Kalberg, Hasken, Stegall, Hedrick, Robinson, Manning, Tabachnick, Seedat, Parry & Hoyme (2021). |
| 2016 | Robertson, Ashton (WCP) | 310 (Total FASD) | 31% | May, De Vries, Marais, Kalberg, Buckley, Hasken, Rahman, Robinson, Manning, Seedat, Parry & Hoyme (2022). |

From the above-mentioned information it is clear that FASD is not a problem confined to the WCP but, although most studies to date have been conducted in the Western Cape, it is evident that FASD is a reality in other provinces in SA too. In the following section information will be provided on how a diagnosis of FASD is made.

### 2.3.3 Diagnosing FASD

The importance of a correct diagnosis is connected with the huge societal cost in terms of the financial implications for treatment and care of persons with FASD, unproductivity due to the physical, behavioural, and learning restraints caused by the

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syndrome and the physical, social, and often mental suffering that goes hand in hand with FASD (Catterick & Curran, 2014; Hoyme et al., 2016). Despite FASD having lifelong effects on an individual, early interventions with young children can have a positive effect on their development and overall functioning (Eagan, Combs-Orme & Neely-Barnes, 2011; Kalberg et al., 2019). Due to the ability of the young brain to adapt and react to experiences and the environmental setting by reorganising existing connections and creating new connections (neural plasticity of the young brain), the importance of early diagnosis is emphasised (Kalberg et al., 2019).

According to Hoyme et al. (2016:139) the "assignment of an FASD diagnosis is a complex medical diagnostic process best accomplished through a structured multidisciplinary approach by a clinical team comprising members with varied but complementary experience, qualifications, and skills. The assessment of individuals prenatally exposed to alcohol requires a medical assessment and team leadership by a paediatrician or clinical geneticist/dysmorphologist with expertise in the full range of human malformation syndromes and the dysmorphology evaluation of children with FASD."

For a diagnosis of FAS, a specific combination of defects, including growth deficiency, a distinctive group of minor facial anomalies and neurocognitive deficits combined with confirmed maternal alcohol use in pregnancy, are needed (Hoyme et al., 2005). This confirms the view of Aase et al. (1995) who stressed the fact that each of the physical characteristics needed for a diagnosis of FAS, is non-specific and only has meaning when these characteristics are found in combination with one another. Furthermore, Aase et al. pointed out that the facial characteristics associated with FAS only has significance when it is found in combination with pre- or postnatal growth restriction and cognitive deficiencies to form the full range of effects needed for a diagnosis of FAS.

Hoyme et al. (2005:46) state that a diagnosis on the FASD spectrum must always be a "diagnosis of exclusion". This refers to the fact that many characteristics of FASD are also displayed in other genetic syndromes such as Williams syndrome, Dubowitz syndrome and Cornelia de Lange syndrome. Therefore, the importance of a clear description of the diagnostic criteria for each of the categories on the FASD spectrum in order to accurately diagnose not only FASD as a whole, but each of the four

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diagnostic groups on the continuum of FASD, is emphasised. The specific criteria needed include exact measurements of the head circumference, height, weight, palpebral fissure length (width of the eye openings) and philtrum length (distance between the vertical column of the nose and the upper lip). A small head circumference, which is indicative of deficient brain growth, is seen as a significant risk indicator for problems with cognition and behaviour (May et al., 2016).

In addition to a thorough medical examination to determine if physical determinants for a diagnosis on the FASD spectrum are present, extensive neurocognitive developmental testing is needed. One of the primary indicators of the teratogenic effects of alcohol on the developing fetus is the damage it causes to the central nervous system (CNS), which can result in damage to the structure, neurology, or functions of the brain (Catterick & Curran, 2011; Hoyme et al., 2016). It is, therefore, generally advised that standardised neurocognitive tests assessing a variety of complex tasks are used. There is broad consensus that even children on the lower end of the FASD spectrum have significant impairment in executive functioning. However, it is important to be able to distinguish these delays to more than environmental influences or the typical neurocognitive abilities of members of the same family not prenatally exposed to alcohol (Hoyme et al., 2005).

The influence of PAE on the brain not only affects neurocognitive ability, but has a profound effect on behaviour, leaving affected individuals at risk for mental problems, conflict with the legal system and limited potential for independent living (Riley, Infante & Warren 2011). Riley et al. (2011:78) also refer to these effects on the brain as the “neurofunctional consequences” of alcohol exposure.

Neither the 1995 IOM diagnostic guidelines nor the 2005 Hoyme criteria required evidence of neurobehavioural impairment for a diagnosis on the FASD spectrum. Although it was recognised that PAE adversely affects the neurobehavioural profile of the individual, the original guidelines permitted a diagnosis on the FASD spectrum in the absence of confirmed neurobehavioural impairment (Hoyme et al., 2016). Recognition of the fact that neurocognitive disabilities and behavioural deficits are the main causes of disability in individuals with FASD, led to a shift of the focus on the physical outcomes of PAE to a more prominent focus on neurofunctional outcomes including behavioural outcomes (Hoyme et al., 2016; Riley et al., 2011).

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For a diagnosis on the FASD spectrum it is now necessary to show that the domains of the brain controlling adaptive skills as well as behaviour and self-regulation, which include mood, attention, the ability to control behaviour and impulse control, are affected by prenatal alcohol exposure (Hoyme et al., 2016). Keeping in mind that the purpose of an FASD diagnosis should be to provide the interventions an individual needs, it is important that the focus of the diagnosis is more often thought of as providing the means to improve the neurofunctional behaviour of the affected individual (Hoyme et al., 2016; Riley et al., 2011), a goal which can be better attained by early diagnosis and interventions. Kalberg et al. (2019) state that, although the diagnosis of infants on the FASD spectrum are seldom attempted, it is possible to correctly identify children with FASD as early as at 9 to 18 months of age. However, children with FASD are often only identified once they start formal schooling and learning, and behavioural difficulties become evident (Carpenter, 2011). This poses its own challenges to social workers, from whom it often is expected to address behaviour and adaption problems in children and youth without the background knowledge of possible PAE and the influence that might have on a child's behaviour. In SA where FASD is mainly diagnosed by research groups and a diagnosis of FASD is hardly ever available, this places a responsibility, which should have been shared by a multi-disciplinary team, squarely on the shoulders of the social worker to find solutions for all the problems that an individual might present with.

A description of the effects of PAE and the detrimental consequences thereof for the individual with FASD will be deliberated hereafter.

## 2.4 THE EFFECTS OF ALCOHOL EXPOSURE ON THE INDIVIDUAL

Despite the emphasis that has been placed on the physical traits of FASD in some communities and even professions, the teratogenic effects of alcohol are predominantly revealed in the structure and functions of the brain. For this reason, FASD is often described as "the leading cause of preventable developmental disabilities in the world" (Hoyme et al., 2016:139). Kalberg et al. (2019) state that assessing an individual's physical growth and features combined with neurobehavioural characteristics create the opportunity for identifying FASD even at an early age.

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This statement confirms the earlier opinion of Hoyme et al. (2005) that the effect of alcohol on the developing fetus constitutes a spectrum of physical anomalies, neurocognitive impairment, and behavioural deficits. The behavioural deficits associated with FASD are often accompanied by emotional disturbances and problems with mood regulation. These deficits extend into adulthood, often with increasing severity and with serious consequences to “social interaction and adaptive living skills” (Dörrie, Föcker, Freunscht & Hebebrand, 2014:869; Mattson, Crocker & Nguyen, 2011). This indicates that the effects of PAE on the individual are physical (biological), psychological as well as social. Taking a biopsychosocial approach will, therefore, be beneficial in attempting to gain a broad understanding of the effects of PAE on the individual.

In this section, the effects of PAE on the individual will be discussed under these three categories of possible effects, namely biological, psychological, and social.

### 2.4.1 Biological effects

The biological effects of PAE on the individual include physical effects. These effects are not static but develop over time. The physical effects of PAE, early life predictors of FASD and the development of FASD over the lifespan, will be discussed next.

#### *2.4.1.1 Physical effects*

PAE has a wide variety of physical effects on an individual. These effects include effects on the brain, the development of facial features, growth, the heart and internal organs, hearing and vison, skeletal and other physical effects. These effects will be discussed in more detail next.

##### *2.4.1.1.a Effects on the brain*

Despite much focus on the observable physical phenotype of FASD in the past, there has recently been a shift towards recognising that structural deficiencies to the brain are the most devastating physical characteristics of FASD (Hoyme et al., 2016; Mattson, Schoenfeld & Riley, 2001; Suttie, Wozniak, Pamell, Wetherill, Mattson, Sowell, Kan, Riley, Jones, Coles, Foroud, Hammond & CIFASD, 2018; Riley et al., 2011). According to Costa, Aschner, Vitalone, Syversen and Solden (2004) the central

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nervous system of the developing embryo is more susceptible to harm than that of an adult. These authors emphasise that chemicals, such as alcohol, cause morphological changes in the development of the central nervous system, causing severe and extensive damage to the brain.

PAE has a multitude of effects on the structure of the brain. One of the possible effects is a reduction in the volume of the entire brain or in specific regions of the brain (Dörrie et al., 2014). A decrease in the size or volume of the brain is reflected by a reduced head circumference, a trait that is one of the indicators of FASD. A head circumference of less than the 10$^{th}$ centile is considered small and one of the criteria for a diagnosis of FAS (Hoyme et al., 2016).

The areas of the brain most often affected by PAE are the corpus callosum, cerebellum and basal ganglia. Variability in shape, as well as underdevelopment and/or incomplete development of the corpus callosum, cerebellum and basal ganglia are possible. This may result in an inadequate or below-normal number of cells in these areas (Wozniak, Riley & Charness, 2019). Deviations in the development of the corpus callosum cause changes in the communication pathways between the different regions and hemispheres of the brain, leading to functional impairment in the communication pathways of the brain (Dörrie et al., 2014). In addition, changes to the density of the grey matter in the brain, as well as abnormal cell migration and distortion of brain tissue is possible (Costa et al., 2004; Hoyme et al., 2016; Mattson, Schoenfeld & Riley, 2001; Riley et al., 2011; Suttie, Wozniak, Pamell, Wetherill, Mattson, Sowell, Kan, Riley, Jones, Coles, Foroud, Hammond & CIFASD, 2018). However, the structural deviations in the development of the brain are often subtle and it is more often the effect of these deviations that can be observed as functional deficits in the affected individual (Dörrie et al., 2014). In addition, a frequent incidence of recurrent nonfebrile seizures has been established in children with FASD (Andrew, 2011; Hoyme et al., 2016).

There is a growing notion about the existence of a relationship between facial features, brain growth and behaviour. This relationship is attributed to alcohol exposure in the third to fourth week of pregnancy when the tissues, which will develop into the face and brain are still growing as one structure and can influence the development of facial dysmorphology as well as the development of brain structure (Suttie et al., 2018).

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Other than the visible physical characteristics of FASD, which diminish over time, the physical impact of PAE on the brain permanently alters the individual's neurocognitive ability and in doing so, their potential for normal, independent living.

*2.4.1.1.b Facial features*

The revised IOM criteria focussed on specific facial anomalies in children prenatally exposed to alcohol (Hoyme et al., 2005). The three facial features considered cardinal for a diagnosis of FASD are palpebral fissure length (the width of the eye opening), a smooth philtrum (the prominence, or lack thereof, of the vertical ridges between the nose and upper lip) and a thin vermillion border (thin upper lip). Hoyme et al. (2016) state that these features must be examined live and evaluated objectively by a paediatrician or geneticist using published norms.

The three cardinal facial features associated with FASD are accompanied by a range of possible minor facial anomalies including epicanthal folds (skinfolds covering the inner corners of the eyes), ptosis (drooping eyelids), strabismus (crossed eyes), a short inter-pupillary distance (short distance between the pupils), short intercanthal distance (short distance between the inner corners of the eyes), anteverted (upturned) nares, a flat midface with a flat nasal bridge and minor ear anomalies such as railroad track ears (May, Gossage, Smith, Tabachnick, Robinson, Manning, Cecanti, Jones, Khaole, Buckley, Kalberg, Trujillo & Hoyme, 2010; Wozniak et al., 2019). In railroad track ears, "the upper part of the ear is underdeveloped, folded over and parallel to the curve beneath it", creating "the impression of a railroad track" (De Vries, 2012:55). In addition to these features, a relationship between PAE and cleft palate was described by Sek, Cybulski, Olejnik & Krajevska-Kulak (2017), who also mentioned oral cavity defects and dental deformities in children prenatally exposed to alcohol.

A study by Feldman, Jones, Lindsay, Slymen, Klonoff-Cohen, Koa, Rao & Chambers (2012) found that early gestational alcohol exposure in the second six weeks of the first trimester is the critical period for the development of the facial features associated with FAS. This study also indicated that a higher number of binges and a higher number of drinks per day during this critical period in development, exacerbate alcohol-related facial features. These authors state that an increase of one drink in the

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number of drinks consumed daily, is responsible for a 25% increase in the risk for having a smooth philtrum and a 22% increase in the risk for having a thin vermillion.

Since the facial characteristics associated with FASD is only meaningful in combination with growth restriction for a diagnosis of FASD, the influence of PAE on growth will be discussed hereafter.

*2.4.1.1.c Growth*

Pre- and postnatal growth retardation and microcephaly are considered crucial characteristics for a diagnosis of FASD (Hoyme et al., 2005; Hoyme et al., 2016; Jones, Hoyme, Robinson, Del Campo, Manning, Prewitt & Chambers, 2010; May et al., 2009). Infants prenatally exposed to alcohol have low birth weight and stay smaller in height, weight, and head circumference than their unexposed peers. One study (Carter, Jacobsen, Molteno, Dodge, Meintjes & Jacobsen, 2016) found that PAE affects prenatal growth more than it does postnatal growth. This study also showed that more than 50% of children who were heavily exposed to alcohol prenatally were small for gestational age at birth compared to less than 20% of children with light exposure. These authors further demonstrated that children born small for gestational age had higher levels of PAE than those born appropriate for gestational age.

A study by Kalberg et al. (2018) established that at age five years children with FASD weighed less and had significantly smaller head circumferences than unexposed children of the same age. Several epidemiological in-school studies with grade 1 learners had similar findings regarding height, weight, and head circumference at the age of seven years (May, Beate, Russo, Elliot, Blankenship, Kalberg, Buckley, Brooks, Hasken, Abdul-Rahman, Adam, Robinson, Manning & Hoyme, 2014; May et al., 2007, May et al., 2017). Furthermore, Carter et al. (2016) indicated that children prenatally heavily exposed to alcohol and small for gestational age at birth, did not catch up in growth to unexposed children by the age of thirteen years. Additionally, a Swedish study with adopted children with FASD showed that, although there was a steady rise in the body mass index (BMI) of affected children from adolescence, stunted growth for height and head circumference was still evident in adulthood (Landgren, Svensson, Gyllencreutz, Aren, Grönlund & Landgren, 2019). According to these authors their findings demonstrate an altered growth trajectory in individuals with FASD.

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Children born small for gestational age who catch up in growth postnatally, usually do so by the age of 12 months (Carter et al., 2016). This leads these authors to suggest that an altered growth trajectory could be a physical expression of the severity of FASD at as early as 12 months of age. Carter et al. (2016) further indicate that children displaying both pre- and postnatal growth stunting are more at risk to be intellectually impaired than children with PAE born small for gestational age but with catch-up growth. Additionally, both these groups are more at risk to be intellectually impaired than children with normal fetal as well as postnatal growth.

Discussions about a correlation between altered patterns of fetal growth and permanent changes to normal developmental trajectories and physiological functioning, refer to research by Barker (2004; 2006; 2012) who developed the "Barker Hypothesis", which was built on his notion termed "Developmental Origins of Adult Health and Disease" (Lunde, Washburn, Golding, Bake, Miranda & Ramadoss, 2016). In 2004, Wilcoxon and Redei stated that adversity in the environment of the fetus, which results in low birthweight, "programme" permanent physical changes, causing a predisposition for early onset of chronic disease in adulthood. Barker (2006) reasoned that babies who are small at birth are vulnerable for disease later in life, partly because they have decreased functionality in vital organs such as the kidneys, but also because they are more vulnerable to adverse environmental events during their lifetime. Barker, therefore, concludes that birthweight provides a base to assess the extent of the adversity caused by disruption of the fetal environment on the development of disease later on in life. This agrees with the concept of fetal imprinting, which refers to the fact that early environmental factors, such as prenatal exposure to alcohol, can permanently imprint physical and behavioural organisation and elevate susceptibility to disease or disorders during the life course (Urban, Bodnar, Butts, Sliwowska, Comeau & Weinberg, 2011).

In the light of this information, the next section investigates and describes the effect of PAE on the development and functioning of the heart and internal organs.

*2.4.1.1.d Effects on the heart and internal organs*

According to Popova, Lange, Shield, Mihik, Chudley, Mukherjee, Bekmuradov & Rehm (2016:985), FASD is "a multi-faceted spectrum of disorders, affecting multiple organs

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and systems". These authors further add that the teratogenic effect of alcohol on the developing fetus can "alter the growth and normal development of most organs and tissues in the embryo" (Popova et al., 2016:985). This argument confirms the earlier work of Manning and Hoyme (2007), who stated that malformations of organs such as the heart and kidneys are found in individuals with PAE. Furthermore, O'Neill (2011) adds that PAE affects "the developmental stage of heart foundation" and, consequently, leads to various aberrations in the developing heart. This author confirms the connection Manning and Hoyme (2007) made between anomalies of the heart such as septal defects (commonly known as "a hole in the heart"), heart murmurs, malformations of the heart, anomalies of the pulmonary arteries (the arteries carrying blood from the heart to the lungs), enlargement of the left ventricle of the heart, as well as problems with the development of valves, and PAE. Since fetal heart development already begins in the third week of pregnancy and the heart starts beating in the fourth week of pregnancy, alcohol exposure early on in pregnancy can have a devastating effect on the development of the heart and even result in miscarriage (O'Neill, 2011).

Animal studies have confirmed the occurrence of different forms of congenital heart defects, amongst which are structural defects of the heart in the presence of alcohol exposure (Sarmah & Marrs, 2017). Congenital heart defects are defined as "structural anomalies of the heart and great vessels that are present at birth and can disrupt the normal flow of blood through the heart and great vessels near it" (Yang, Qiu, Qu, Zhang, Zeng & Yan, 2015:2).

A study by Sek et al. (2017) found heart defects to be the most common comorbidity in children with PAE in their cohort in Polish care centres. This study also found a statistically significant correlation between maternal alcohol use throughout pregnancy and the occurrence of heart defects in their offspring. An earlier study by Parkington, Coleman, Wintour & Tare (2010) described the influence of alcohol on the developing cardiovascular system of the fetus as complex and having a severe, direct influence with permanent effects on this system.

Other research (Barker, 2006) indicates that cardiovascular functioning in adulthood is affected by the pattern of fetal growth. This research shows that a low birthweight

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has a strong correlation with cardiovascular disease developing in adulthood, including problems with blood pressure.

Barker (2012) further states that, in the development of the human fetus, there is a hierarchy of priorities for development with brain development at the top of this hierarchy and the development of organs not needed to function in the womb, at the bottom of the hierarchy. The organs that are "traded off" to protect the development of vital organs are, amongst others, the kidneys, and lungs (Barker, 2012:186). Manning and Hoyme (2007) describe the underdevelopment or incomplete development of one or both kidneys, malformation of kidneys such as "horseshoe" shaped kidneys, inflammation in the kidneys and swelling of the kidneys caused by insufficient draining of urine due to obstructions in the urinary tract, as possible effects of PAE on the development of these organs. However, although the emphasis is often on the damage alcohol use in pregnancy can cause to the heart and kidneys, Lunde et al. (2016:1 403) emphasise that "alcohol can target virtually any fetal organ system".

##### *2.4.1.1.e Hearing and vision*

Over the years, researchers have studied a variety of teratogenic effects of alcohol on the development of the fetus. Already in 1988 Church and Gherkin referred to damage to the eyes and problems with ears including recurrent otitis media (middle-ear infection) and hearing loss resulting from prenatal alcohol use. According to Popova et al. (2016), chronic serious otitis media is one of the five most common comorbid conditions in children with PAE. Wozniak et al. (2019) confirmed this finding and stated that recurrent otitis media is seven times more common in individuals prenatally exposed to alcohol than in the general population.

Church and Abel (1998) describe four types of hearing loss related to FASD, namely delayed auditory maturation, conductive hearing loss because of recurrent otitis media, sensorineural and central hearing loss. These authors state that hearing loss in children with FAS is so common that up to 77% of children with FAS have some form of hearing loss. The severity of the effect of PAE on hearing is underscored by Popova et al. (2016) and Wozniak et al. (2019) who state that a range of moderate to severe hearing loss in individuals with PAE is 126 – 129 times more common than hearing loss in the general population of the USA.

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Wozniak et al. (2019:761) further reported “atypical auditory processing” in individuals with PAE. These authors state that such processing disorders not only have the potential to influence speech and language but can also contribute to problems in the development of reading and writing.

In addition to hearing problems, eye problems occur in children with PAE. Eye problems are not only limited to physical problems such as strabismus and ptosis but also include visual problems and blindness. Sek et al. (2017) refer to the presence of squints and short-sightedness in children with PAE in care facilities in Poland and state that 11% of the children affected by PAE in these facilities had visual impairment. Prior to this finding, Popova et al. (2016) described low vision as 31 times more prevalent in children with PAE than in the general population of the USA and blindness as 71 times more prevalent.

In addition to the damage to the brain, face, growth, internal organs, eyes, and ears, PAE also causes skeletal problems in exposed individuals.

*2.4.1.1.f Skeletal problems*

Various researchers (Manning & Hoyme, 2007; Popova et al., 2016; Wozniak et al., 2019) refer to skeletal problems especially in individuals with ARBD. The tenth revision of the International Classification of Diseases and Related Health Problems (ICD-10) of the World Health Organisation (WHO) lists various deficits in the skeletal structure of individuals with FASD. These deficits include dislocated hips, hand deformities, deformities of the upper limbs such as the shoulder girdle as well as malformations of the spine, ribs, skull, and facial bones.

Minor anomalies of the hands are often found in children with PAE. Altered palmar creases such as hockey stick creases and underdeveloped nails, also called hypoplastic nails, are amongst the most common anomalies (Manning & Hoyme, 2007; Wozniak et al., 2019). Other deficits include abnormal growth of the fifth fingers on one or both hands resulting in curved fingers with an abnormal inward bent, known as clinodactyly. This unusual shape of the fingers can lead to changes in the position of the joints in the fingers (Boston Children’s Hospital: Clinodactyly, 2021). Additionally, camptodactyly, a condition where one or more fingers are bent at the middle joint preventing the finger or fingers to straighten completely, can be found in

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one or both hands (Children's Hospital of Philadelphia: Camptodactyly*,* 2022; Manning & Hoyme, 2007; Wozniak et al., 2019). A decrease in joint movement, especially of the elbows, may also be found in affected individuals (Manning & Hoyme, 2007; Wozniak et al., 2019).

It is of the utmost importance to keep in mind that minor anomalies in physical appearance alone are not enough for a diagnosis of FASD, but that a distinct pattern of minor anomalies in combination with deficits in growth and other dysmorphic facial features are needed for a diagnosis of FASD (May et al., 2010). Wozniak et al. (2019), however, is convinced that there is a correlation between the number of minor anomalies and the magnitude of PAE. More possible physical effects that can manifest in an individual with FASD are discussed below.

##### *2.4.1.1.g Other physical effects*

The teratogenic effects of alcohol use in pregnancy can result in multiple physical complications for the developing fetus. In addition to the more serious damage to organs, the brain and central nervous system, other physical effects found in individuals with PAE include chronic respiratory disorders, allergies, upper or lower limb tremors, sucking or swallowing dysfunction, abnormal oral cavities, aberrant dental formation, urinary infections and disorders and disturbances in the immune and endocrine systems, as well as thyroid deficiency in adults (Sek et al., Wozniak et al., 2019). A study (Roozen, Olivier, Niemczyk, Von Gontard, Peters, Kok, Viljoen & Curfs, 2017) also pointed out that incontinence was documented amongst affected children.

Although FASD is mostly diagnosed between the ages of five and 10 years, there is increasing evidence of denominators of damage caused by PAE early on in life. A discussion of some of these predictors follows.

#### ***2.4.1.2 Early life predictors of FASD***

Despite the bleak picture often painted for children prenatally exposed to alcohol, the neuroplastic quality of the brains of young children offer ample opportunity for interventions to improve their development. Although the damage caused by PAE can never be undone, therapeutic interventions can contribute to the prevention of secondary disabilities (Sek et al., 2017). However, to provide these interventions, early

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diagnosis of FASD is needed. This is seldom attempted in infants because the facial characteristics associated with FASD are better developed at school-going age when more reliable developmental assessments are also possible (Kalberg et al., 2019).

Young children with FASD often have complex and distressing backgrounds including neglect and parental alcohol or drug abuse, increasing their risk for placement in alternative care. The many challenges these children pose in alternative care places a huge burden on social workers who have to see that the children's complex needs are met whilst simultaneously providing support and guidance to foster parents (Pelech, Badry & Daoust, 2013).

Researchers studied various possible early predictors of FASD to find ways to identify children at risk for developmental and other delays as early as possible. One animal study found that magnetic resonance imaging (MRI) can detect deficient brain development in the third trimester of pregnancy even if alcohol exposure only occurred in the first trimester (Wang, Cuson Carlson, Studholme, Newman, Ford, Grant & Kroenke, 2020). It is also well known that there is a strong link between intrauterine growth restriction and alcohol exposure. One recent South African study showed that the mean birth weight of new-born babies unexposed to alcohol was 3 132 grams while the birth weight of new-born babies prenatally heavily exposed to alcohol was 2 709 grams (Odendaal, Kruger & Botha, 2020). The strong association between low birth weight and PAE is also evident in continued growth restriction postnatally (Carter et al., 2016). These authors further indicated that prenatal growth is more sensitive to alcohol exposure than postnatal growth and could "demonstrate that a child's growth trajectory provides a biological indicator of [the] severity of FASD" (Carter et al., 2016:8).

Findings by Kalberg et al. (2019) show that, except for the clear differences in growth, it is possible to distinguish the dysmorphological (facial) features of children affected by PAE from those of unexposed infants successfully as early as the age of 9 months. The heavier the exposure and the more significant the effect of PAE, the clearer the distinction in growth and facial features by 9 months of age.

Several characteristics associated with PAE are often experienced in infants. In some cases where mothers continued drinking in the third trimester of pregnancy, new-born

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infants may display signs of alcohol withdrawal that can manifest as hypersensitivity to sound, convulsions and/or general anxiety (Sek et al., 2019).

Already in the first weeks after birth, tell-tale signs of central nervous system damage such as jitteriness, infant irritability, higher than normal levels of activity, problems with feeding, problems with sleeping, problems with crying and even emotional withdrawal, are noticeable (Lemola et al., 2009; Molteno, Jacobsen, Carter, Dodge & Jacobsen, 2014; O'Connor & Paley, 2009; Sek et al., 2017). The study by Molteno et al. (2014) clearly indicates that infant emotional withdrawal is a strong early predictor of alcohol-induced emotional instabilities and is particularly noticeable in severely damaged infants. Infant emotional withdrawal is, therefore, regarded as an early sign of the widespread socio-emotional problems associated with FASD. In the researcher's experience, these early signs of FASD are seldom the reason for the referral of infants to social services. At this early stage of life, children are usually referred to social workers due to neglect, parental behaviour that puts the child at risk and failure to thrive. It is thus important for social workers to recognise and further investigate these early signs to be able to make a connection between the reasons for referral and the possibility of PAE.

As the infant grows and develops, the signs and effects of PAE manifest in different ways and developmental domains. This expression of FASD over the lifespan will be discussed below.

#### *2.4.1.3 FASD from childhood to adulthood*

The expression of FASD not only varies between individuals, but also over the lifespan of individuals. In addition, the domains damaged by PAE also change over the course of the lifetime (Popova, Dozet & Burd, 2020). The influence of PAE and the way it is expressed in the individual does not only start to show at birth, but is already present and visible in the developing fetus. Growth restriction and damage to the developing brain are effects visible on ultrasound and MRI scans. Because alcohol has an influence on the female's capacity to sustain a successful pregnancy, miscarriage and pre-term births are common occurrences in alcohol exposed pregnancies (Sek et al., 2017; Urban et al., 2011). Information about prior miscarriages and stillbirths in women are, therefore, important factors for social workers to consider when they are collecting

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background information about new referrals. This information, coupled with maternal drinking information and early signs in behaviour and physical growth in young children, can be indicators of possible PAE. In their 2004 study Burd and Wilson showed a 530% increase in the mortality rate of the siblings of children with a FAS diagnosis when compared to the mortality rate of a control group. Cousins and Wells (2005) state that this finding should be considered an indicator of risk in the siblings of children with FAS.

In infancy, several signs of central nervous system damage such as increased irritability, problems with sleeping, sucking disorder, feeding problems, increased activity, and crying are experienced in infants with PAE (Lemola et al., 2009; O'Connor & Paley, 2009; Sek et al., 2017). Infant irritability is often a result of structural damage permanently altering the areas of the brain associated with mood regulation. The neurological damage associated with infant irritability causes changes in the individual's sensitivity to stressors and can result in mood disorders later on in life (Lemola et al., 2009; Urban et al., 2011). Signs of mood disorders can already be displayed in infancy as emotional withdrawal, which in turn is indicative of affective disorders and associated with infant depression (Molteno et al., 2014).

As children age, the effects of PAE on development are displayed in more areas of development. At six weeks of age prenatally alcohol exposed children exhibit difficulty sustaining a state of attention. These difficulties may present as shallow or uneven breathing, fatigue and collapse into sleep, jerky movements, crying, yawning or even hiccups (Kalberg et al., 2019). This is followed by delays in reaching milestones for sitting, walking, and use of language at the appropriate ages. Difficulties with balance and motor coordination, which might affect gait and the length of steps taken, may also be experienced (Sek et al., 2017; Wozniak et al., 2019).

Kalberg et al. (2019) showed that a difference in the cognitive abilities of children with and without PAE can already be seen between the ages of nine and 18 months and that a significant decline in overall cognitive abilities is noticeable between the ages of 18 and 42 months compared to children without alcohol exposure. Poorer everyday memory functioning is established in pre-schoolers with FASD, making it more difficult for them to learn self-care, social skills, and adaptive behaviour (Agnihotri, Subramaniapillai, Keightley, Rasmussen, Cameron, Ryan & Rovet, 2018). By the time

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alcohol-exposed children reach the age of five years, they show a marked difference in especially visual processing and overall cognitive functioning. Already in early childhood the beginnings of behavioural difficulties are displayed as increased levels of activity, irritability, problems with emotional responsiveness and problems to sustain attention. These characteristics enhance the vulnerability of children with FASD, adding to the level of support the children and their caregivers demand from social workers (Pelech et al., 2013).

By the time children reach school-going age, problems with learning, socialising, hyperactivity, inattention, and emotional immaturity are often recognised and addressed for the first time. However, once a child reaches school-going age, a certain level of development is needed to be able to learn, progress and keep up with their peers. A study (Adnams, Kodituwakku, Hay, Molteno, Viljoen & May, 2001) showed that at the age of seven years, children with FAS are already significantly behind in the development of higher order cognitive motor abilities such as speech and hearing abilities, hand-eye coordination, performance (which includes pattern construction) and practical reasoning. Andrew (2011) states that between the ages of six and eight years of age children should be able to think more individualistically, solve problems, do their own planning and organising and have a grip on abstract concepts.

Learners with FASD face multiple challenges with learning. Carpenter (2011) compiled a list of ten challenges teachers of children on the FASD spectrum identified. These challenges are hyperactivity, a short attention span, emotional dysregulation manifesting as unpredictable mood swings, poor memory, a lack of social skills, problems with hearing and/or verbal processing, visual sequencing difficulties; problems with sensory integration (especially problems with coordination), difficulty holding on to instructions for the completion of tasks and problems with numeracy and mathematics (Carpenter, 2011). Being accepted in their peer group is another major challenge for children with FASD. Although they have an intense desire to have friends, their behaviour, which may include physical or verbal abuse, prevent them from making and sustaining friendships (Carpenter, 2011). Andrew (2011) states that these children have problems understanding social cues and, because of their poor perspective on situations, are easily victimised.

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These difficulties become even more pronounced up to the age of 13 years by exhibiting learning difficulties especially with mathematics, attention deficits, poor planning, difficulties consolidating new information, poor handwriting, and visual-spatial deficits. By the time children with FASD reach adolescence, they struggle with persisting learning disabilities including areas such as mathematics, verbal fluency, problems with planning, slow processing of information, poor judgement, attention deficits, problems in social interaction and with social perception as well as poor memory (Hoyme et al., 2016). According to O'Connor and Paley (2009:231) mental health problems are "hallmark secondary disabilities in adolescents and young adults with FASD". Higher than normal rates of suicide, substance abuse, lifetime experience of trauma, problems with impulse control and conduct disorder, passive-aggressive and anti-social personality disorders such as oppositional-defiant disorder and depression are found in the FASD population (O'Connor & Paley, 2009; Rodger & Gowsell, 2014).

Although the facial features associated with FASD normalise as the individual reaches adulthood the cognitive, social, and behavioural difficulties are persistent. Young children with FASD in a supportive environment may often present as functioning quite normally. However, as they age and are expected to make independent decisions, solve their own problems, judge situations, and have the mental flexibility associated with adulthood, their impaired functioning become more obvious and make them easy targets to be taken advantage of, to involve them in criminal activities or even sexually exploit them (Andrew, 2011). Social workers should keep these signs in mind when children present with behaviour problems, refusal to go to school, poor school attendance and unruly behaviour in the classroom. This is even more important when children are in foster care or alternative placements. A study in the USA have shown that 80% of children with FASD in their foster care system are undiagnosed and another 7% is misdiagnosed (Chasnoff, Wells & King, 2015). An earlier study in the United Kingdom (UK) have found that children in the social care system are at a much higher risk for having FASD than children in the general population (Cousins & Wells, 2005). Chances are that the pattern will be similar in the rest of the world and especially in SA where heavy drinking is institutionalised in many communities.

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Problems with adaption, attention deficits and abstract thinking lead to difficulties functioning in a working environment because they are easily distracted and have problems with motivation and time management (Lutke, 1997). This, combined with the existence of mental health disorders and a high risk for substance abuse themselves, has a serious influence on the ability of an adult with FASD to live independently and be self-sufficient. Often, depending on the degree of damage caused by PAE, adults with FASD may need support or even full-time care (Andrew, 2011; Rodger & Gowsell, 2014). With the lack of support services and full-time care for adults in SA, this causes huge problems for social workers who often find themselves between the expectations of the family and community of such individuals and the harsh reality of no placement options.

PAE has long-term effects on physical health. Adults with FASD may therefore experience a variety of health problems including an increased risk of cardiovascular disease, obesity, type 2 diabetes, hypertension, stroke, skeletal problems, including problems with bone mass and bone mineral content, hypothyroidism, endocrine dysfunction, seizures, and non-alcoholic fatty liver disease (Andrew, 2011; Lunde et al., 2016). Lunde et al. (2016) further state that, in adults, PAE leads to very early onset of chronic adult diseases affecting the cardiovascular, endocrine, neurobiological, as well as metabolic systems.

However, PAE not only results in physical effects on the individual, but also has far-reaching psychological effects on neurocognitive ability, academic achievement, and psychiatric conditions. Table 2.2 (below) describes the effects of FASD on physical development, neurocognitive abilities, self-regulation, and adaption over the lifetime of the exposed individual.

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**Table 2.2: The effects of FASD over the lifespan**

| Affected area | New-borns and infancy<br>0 – 2 years | Early childhood<br>3 – 5 years | Middle childhood<br>6 – 12 years | Adolescence<br>13 – 21 years | Adulthood |
|---|---|---|---|---|---|
| Physical | Small for gestational age (height, weight, and head circumference.<br>Range of possible health problems.<br>Possible convulsions. | Small for gestational age (height, weight, and head circumference.<br>Facial features associated with FASD.<br>Range of possible health problems.<br>Possible convulsions. | Small for gestational age (height, weight, and head circumference).<br>Facial features associated with FASD.<br>Range of possible health problems.<br>Possibility of seizures or epilepsy. | Small head circumference.<br>Stunted growth in height.<br>Some adolescents pick up in BMI.<br>Facial features associated with FASD diminish.<br>Range of possible health problems.<br>Possibility of seizures or epilepsy. | Small head circumference.<br>Stunted growth in height.<br>Rise in BMI with some adults becoming obese.<br>Facial features associated with FASD normalise.<br>Range of possible health problems.<br>Early onset of chronic diseases.<br>Possibility of seizures or epilepsy. |
| Neurocognitive | Delayed cognitive development.<br>Delayed global development. | Delayed cognitive development.<br>Delayed global development. | IQ below the normal range.<br>Learning disabilities.<br>Problems with mathematics. | IQ below the normal range.<br>Persistent learning disabilities.<br>Deficient mathematical proficiency. | Impaired intellectual development and functioning.<br>Possible mental retardation. |
| Self-regulation | Jittery.<br>Tremulous.<br>Problems with soothing.<br>Emotional withdrawal.<br>Impaired stress reactions.<br>Irritable. | Attention deficits including:<br>• Maintaining attention,<br>• Shifting, and<br>• Regulating attention.<br>• Visual and auditory attention, | Deficits in memory, especially working memory.<br>Problems with planning and sequencing of tasks.<br>Problems organising tasks. | Deficits in executive functioning:<br>Limited verbal fluency.<br>Problems with planning and sequencing of tasks.<br>Problems organising tasks. | Deficits in executive functioning:<br>Limited verbal fluency.<br>Problems with planning and sequencing of tasks.<br>Problems organising tasks. |

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| Affected area | New-borns and infancy 0 – 2 years | Early childhood 3 – 5 years | Middle childhood 6 – 12 years | Adolescence 13 – 21 years | Adulthood |
|---|---|---|---|---|---|
| | | Hyperactivity,<br>Impulsivity,<br>Problems executing directions with multiple steps.<br>Problems with planning.<br>Difficulty understanding cause and effect.<br>Sleeping problems including:<br>• Short periods of sleep.<br>• Sleep anxiety. | Problems with abstract concepts.<br>Attention deficits.<br>Hyperactivity.<br>Impulsivity. | Problems with abstract concepts.<br>Attention deficits.<br>Problems with judgement.<br>Slow mental processing. | Problems with abstract concepts.<br>Attention deficits.<br>Problems with judgement.<br>Slow mental processing. |
| Adaptive | Sleeping problems.<br>Feeding problems.<br>Tires easily. | Gross motor problems:<br>• Balance,<br>• Coordination,<br>• Appears clumsy.<br>Fine motor difficulties.<br>Arrested development of auditory processing.<br>Speech and language problems:<br>• Delays in language acquisition,<br>• Recognition of words,<br>• Pronunciation of words.<br>Memory problems:<br>• Difficulty remembering steps of self-care. | Language problems, especially language requiring higher order processing.<br>Social functioning including:<br>• Inacceptable interaction,<br>• Improper sexual conduct,<br>• Problems with insight in social situations,<br>Memory problems:<br>• Acquiring and merging new information.<br>Motor problems:<br>• Poor handwriting. | Language problems, especially language requiring higher order processing.<br>Social functioning including:<br>• Inacceptable interaction,<br>• Improper sexual conduct,<br>• Problems with insight in social situations.<br>Memory problems:<br>• Acquiring and merging new information.<br>Motor problems:<br>• Poor handwriting, | Impaired ability to function independently.<br>Problems with adaption.<br>Impaired mental flexibility.<br>Attention deficits.<br>Easily distracted.<br>Problems with motivation and time management.<br>Impaired abstract thinking.<br>Difficulties functioning in a working environment.<br>Social functioning including:<br>• Inacceptable interaction, |

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| Affected area | New-borns and infancy<br>0 – 2 years | Early childhood<br>3 – 5 years | Middle childhood<br>6 – 12 years | Adolescence<br>13 – 21 years | Adulthood |
|---|---|---|---|---|---|
| | | • Difficulty recalling previously learned information. | • Problems with visual-motor integration. | • Problems with visual-motor integration.<br>Mental health disorders:<br>• Depression,<br>• Increased rates of suicide, alcohol-and drug abuse,<br>• Conduct disorder,<br>• Anti- social personality disorders,<br>• Oppositional defiant disorder. | • Improper sexual conduct,<br>• Problems with insight in social situations.<br>Mental health disorders:<br>• Depression,<br>• Increased rates of suicide, alcohol-and drug abuse,<br>• Conduct disorder,<br>• Anti- social personality disorders,<br>• Passive-aggressive disorders.<br>Increased risk of exploitation and involvement in criminal activities. |

Agnihotri et al., 2018; Andrew, 2011; Carpenter, 2011; Hoyme et al., 2016; Kalberg et al., 2019; Lemola et al., 2009; Lunde et al., 2016; Molteno et al., 2014; O'Connor & Paley, 2009; Sek et al., 2017)

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This table clearly shows that the effects of PAE are visible from infancy and lasts throughout the lifespan with the effects of PAE becoming more pronounced in each of these areas as the individual ages. As the effects become more visible and have a bigger influence on the individual's life and functioning, the need for social services, physical and mental health services, and educational support increases. In a developing country such as SA with its huge demand on limited services, social workers are often expected to step in and find solutions to provide in these needs.

The psychological effects of PAE will be discussed in more detail in the next section.

### 2.4.2 Psychological effects

This section will focus on neurocognitive ability, academic achievement, and psychiatric conditions as psychological effects of PAE.

#### *2.4.2.1 Neurocognitive ability*

The teratogenic effects of alcohol on the developing fetus are highly variable, not only in its physical effects on the individual, but also on cognitive and behavioural outcomes (May et al., 2013). Although FASD is often described as the most frequent cause of environmentally induced neurodevelopmental or intellectual disability, the potential effects on the individual are complex, variable and ranges from severe mental disability to "subtle neuronal dysfunctions" (Carpenter, 2011; Carter et al., 2016; Kalberg et al., 2019; Lemola, Stadlmayr & Grob, 2009:60).

Despite the noticeable effect of PAE over several domains of neuropsychological and cognitive functioning, research indicates that the effect of PAE is most recognisable in the higher order cognitive functions such as intellectual ability, attention and information processing, executive functioning, language (including comprehension of grammar), visual perception and visual construction, learning and memory, social cognition and number processing (Kalberg et al., 2013; Kodituwakku, 2009; May et al., 2013; Stevens, Anstice, Cooper, Goodman, Rodgers & Wouldes, 2020). Although each of these cognitive functions are important, executive functioning, which is a reflexion of an individual's ability to strategise and structure behaviour efficiently to accomplish an objective, is generally seen as an important measure of an individual's

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ability to retain attention, memorise information, solve problems and exercise inhibition-control (Kalberg & Buckley, 2006).

Problems with executive functioning fall into two categories, namely cognition-based deficits, and emotion-based deficits (Kodituwakku, Kalberg & May, 2001). Whereas cognition-based actions refer to the ability to solve problems, shift attention and give quick verbal or non-verbal responses, emotion-based actions refer to the ability to change behaviour in response to rewards or punishment. Executive functioning abilities are, therefore, also linked to adaptive deficits, which result in problems with the monitoring and modification of behaviour in different environments (Ware, Crocker, O'Brien, Deweese, Roesch, Coles, Kable, May, Kalberg, Sowell, Jones, Riley, Mattson & the CIFASD, 2012). Inhibition control, working memory and problem-solving have proved to be particularly affected in individuals with FASD (Mattson et al., 2011). Although individuals with FASD experience difficulties with executive control abilities in general, these difficulties become even more pronounced as tasks become more complex (Kodituwakku, 2009).

Several researchers have noted reduced intellectual ability with IQ's ranging between borderline and low average in individuals with FASD (Agnihotri et al., 2018; Kodituwakku, 2009; Mattson et al., 2011). The limitations and general cognitive impairment associated with PAE are widely acknowledged, even though there is no single neurocognitive profile for individuals with FASD (Agnihotri et al., 2018; Dörrie et al., 2014; Kodituwakku, 2009; Ware et al., 2012). Poor performance on more complex intellectual assignments is, however, experienced in all individuals with FASD (Kodituwakku, 2009).

May et al. (2013) state that non-verbal ability, as a measure of fluid intelligence, further differentiates between alcohol-exposed and non-exposed children. Non-verbal ability is described as an indicator of the ability of the brain to analyse and find solutions to complex problems, whereas fluid intelligence refers to the ability to solve novel problems independent of acquired knowledge by finding patterns and using logic and reasoning ability to find solutions to these problems. To be able to problem-solve, different parts of the brain need to work together and rearrange numerous neuron networks to create new networks in reaction to new problems (Eagan et al., 2011). This requires agility of the brain and the capability to concurrently use memory,

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understand cause and effect and transfer information previously gained to solve problems (Lutke, 1997). According to Lutke this is particularly problematic in a brain prenatally exposed to alcohol, since an alcohol-exposed brain lacks communication pathways or connectors essential for higher order cognitive functions. Kodituwakku et al. (2001) hypothesise that individuals with PAE have difficulty employing the brain regions needed to perform specific tasks.

The existence of attention deficits in children with FASD is described well in literature (Agnihotri et al., 2018; Dörrie et al., 2014; Fryer, McGee, Matt, Riley & Mattson, 2007; Kalberg & Buckley, 2006; Mattson et al., 2011). Individuals with FASD often also present with ADHD. Dörrie et al. (2014) describe a difference in individuals with ADHD as primary diagnosis and individuals with FASD and ADHD as a comorbidity. Individuals with FASD more often present as hyperactive, impulsive, and having more difficulty shifting their attention and encoding information whereas individuals with ADHD as a primary diagnosis, more often experience difficulties focussing and keeping attention (Dörrie et al., 2014; Kalberg & Buckley, 2006).

Children with PAE experience trouble holding information in memory for later use in solving problems, planning tasks, and maintaining attention to finish tasks (Kalberg & Buckley, 2006). Agnihotrie et al. (2018:1) found that even everyday memory, which they defined as “the ability to perform real-world tasks that include a memory component, such as self-care” is significantly affected in individuals with PAE. Difficulties with everyday memory has a profound effect on the individual’s daily functioning abilities since it forms the base of many skills needed for independent living.

Whereas the physical effects of PAE diminish over time, the enduring neurocognitive effects are a major lifelong consequence weighing the individual down from the earliest developmental stages throughout adulthood (Kalberg et al., 2019; Riley et al., 2011; Soars & Mann, 1997). These neurocognitive effects also include academic achievement and the ability to complete their education.

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#### *2.4.2.2 Academic achievement*

Children with FASD have special educational needs. Even in developed countries with bountiful resources, classrooms are not always structured to make provision for these needs. This leaves children with FASD in a vulnerable position as far as their education is concerned (Carpenter, 2011).

Learning problems in children with FASD stretch across various aspects of learning. Research has shown that children with FASD have difficulty learning visual as well as verbal materials (Kodituwakku, 2009). Recall of verbal information has proved to be problematic for some, while problems with receptive language have also been noted. Deficits in verbal ability contribute to deficits in reading and spelling, as well as word and grammar comprehension (Mattson et al., 2011). Although some children with FASD may present as talkative and with a decent vocabulary, they might appear more proficient than they really are because they lack the comprehension of the language they are using (Kalberg & Buckley, 2006). Carpenter (2011) states that the child with FASD is predominantly a visual learner and that they have a better understanding of what they see visually than what they only hear.

Problems with mathematics are common in children with FASD. Some researchers are of the opinion that this is due to a specific problem in the areas of the brain involved in number processing, leading to an inability to understand and work with numbers (Dörrie et al., 2014; Mattson et al., 2011). To be able to do mathematics, it is necessary "to understand the relationship between the specific order and function of the numbers, with which one is working to derive a correct answer on a given computation" (Kalberg & Buckley, 2006:60). Solving a mathematical problem requires from the child to hold the steps and the order of the steps in their memory to successfully solve the problem. With the difficulties a child with FASD has with planning tasks, remembering the specific order of steps to complete a task, and holding information in working memory, the challenge mathematics poses to such a child, is clear (Kalberg & Buckley, 2006).

Attention deficits, behavioural challenges, sensory sensitivities, and adaptive ability can be huge stumbling blocks in the child's ability to learn effectively (Carpenter, 2011; Dörrie et al., 2014; Mattson et al., 2011). Observations by a researcher in a

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South African classroom indicated that some children with FASD were oversensitive to touch and sound and would block out overstimulation from their environment by closing their eyes, covering their ears, or engaging in unproductive actions (Lubbe, Van Walbeek & Vellios, 2017). Other inappropriate behaviours in a classroom include difficulty containing themselves and their actions when they are distressed, speaking before they think and in inappropriate ways such as blurting out information, not being able to await their turn, fidgeting, unnecessary forceful actions, losing personal possessions and school materials and general disorganisation (Carpenter, 2011; Kalberg & Buckley, 2006).

As children with FASD are inconsistent and unpredictable learners with varying educational needs, they are difficult to accommodate in the classroom. Due to their unpredictable learning patterns, it may be difficult to plan their learning. Carpenter (2011), therefore, suggests that planning is done according to each child's individual learning needs, complex as they might be. Such individual learning plans should take the child's unique learning needs, the degree of support needed as well as the family and community's cultures into consideration with the parents and/or caregivers of the child as a vital part of the planning process (Kalberg & Buckley, 2006). Social workers can contribute to the development of individual learning plans by including the development of such a plan in collaboration with the school and teacher in the child's individual developmental plan.

According to Kalberg & Buckley (2006), educational planning starts with a process of evaluation determining what a child can do and what each individual learner's specific needs are. These authors suggest that the following are evaluated:

- what skills the child has and what is emerging or missing,
- the child's attention and ability to focus,
- ability to work independently,
- ability to interact with other students and the teacher,
- ability to process and understand as well as to use language efficiently,
- areas of strength and interest, and
- behaviours that might interfere with learning.

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Kalberg & Buckley (2006) further state that, once a proper assessment was done, practises should be put in place to contribute to the child's feeling of safety in the learning environment. This will enable them to increase their skills by taking risks in a safe environment.

These authors (Kalberg and Buckley, 2006) further emphasise the importance of structure in teaching children with FASD. This includes structuring the learning environment, establishing functional routines with predictability and systematic education through learning the steps involved in activities. The predictability of these structures and routines contributes to a safe learning environment where children with FASD are supported to achieve their academic and educational potential (Carpenter, 2011; Kalberg & Buckley, 2006).

#### *2.4.2.3 Psychiatric conditions*

A variety of psychiatric conditions are commonly found in individuals with PAE. This is attributed to the structural damage caused by PAE on the basal ganglia, which is a part of the fronto-subcortical circuit of the brain. Damage to this area of the brain is associated with mood disorders such as depression, bipolar disorder, mania, obsessive-compulsive disorder, and schizophrenia (Fryer, McGee, Matt, Riley & Mattson, 2007; Mega & Cummings, 1994; Soars & Mann, 1997; Tekin & Cummings, 2002).

Mental health conditions are considered the most common secondary disability in individuals with FASD. Some researchers are of the opinion that the association between FASD and psychiatric conditions is so strong that individuals with FASD must be carefully examined for possible comorbid mental conditions that may require long term treatment. Individuals with FASD have been found to need more psychiatric care and more medication for sleeping problems, anxiety, depression, and psychosis than individuals unexposed to alcohol prenatally. For these reasons, a diagnosis of FASD is considered a strong indicator of the existence of comorbid mental disorders (Weyrauch, Schwartz, Hart, Klug & Burd, 2017).

Psychopathological problems are already present in childhood and persist through adulthood (Fryer et al., 2007). Regulation problems in infancy such as irritability and infant withdrawal symptoms are early indicators of a difficult temperament and

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negative affectivity, which can potentially develop into lasting mood disorders such as depression, attachment disorders, adjustment problems in combination with depressed mood disturbances, oppositional-defiant disorder, and bipolar disorder (Fryer et al., 2007; Lemola et al., 2009; Molteno et al., 2014; O'Connor & Paley, 2009).

To add to the disadvantages children with PAE are born with, they are also more often exposed to adverse life events such as difficult socio-economic circumstances, neglect, physical and emotional abuse, and placements in alternative care, which add to their susceptibility for developing mental health problems (Kambeitz, Klug, Greenmyer, Popova & Burd, 2019; Molteno et al., 2014; O'Connor & Paley, 2009; Weyrauch et al., 2017). It can thus be said that individuals with FASD have an augmented vulnerability for psychiatric conditions. Amongst these conditions, comorbidity of depression and anxiety disorders are considered by some as the rule rather than the exception (Hellemans, Sliwowska, Verma & Weinberg, 2010). Depression and anxiety are, in turn, associated with suicidal risk. The risk of suicide or suicidal attempts in the adolescent and adult population with FASD is, therefore, also elevated (O'Connor & Paley, 2009).

Individuals with FASD often present with substance abuse disorders. Fryer et al. (2009) state that the odds of individuals with FASD for developing substance abuse disorders are two-fold that of the general population. The risk for substance abuse in a heavily exposed group of 14-year-old children was identified as 2.74 times more than that of a similar group of 14-year-olds with less PAE (O'Connor & Paley, 2009). It can thus be concluded that PAE not only affects the physical and psychological health of individuals, but also places them on a trajectory for long-term adverse life situations with potential unfavourable outcomes.

The social effects of PAE on the individual as discussed in the following section, can potentially further aggravate the long-term outcomes of individuals with FASD.

### 2.4.3 Social effects

The social effects of FASD are especially noticeable as effects on behaviour and the individual's ability to adapt socially, making it the effects social workers are most often confronted with. Although it is hardly possible to separate the effects of all the different influences on an individual's life, the neurological impairments of individuals with

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FASD make them especially susceptible to suffer the consequences of poor judgement and limited social skills, which might bring them into conflict with the law or in need of social work services (Fast & Conry, 2009).

#### *2.4.3.1 Behavioural effects*

PAE results in a complex combination of physical, mental, and behavioural harms, which each contribute to learning and educational problems as well as problems with social adjustment and interactions (May et al., 2013; Nguyen et al., 2011). Even though behavioural deficits were only clearly described as part of the neurobehavioural profile in the 2016 updated clinical guidelines for the diagnosis of FASD by Hoyme et al. (2016), the original IOM criteria already referred to behavioural deficits in children prenatally exposed to alcohol in 1966.

Research has shown that PAE causes structural changes in areas of the brain such as the frontal cortex, cerebellum, and the basal ganglia. These structural deficits are linked to problems with behaviour and mood-regulation and contribute to what is seen as secondary disabilities in die person with FASD (Roebuck, Mattson & Riley, 1999 Soars & Mann, 1997). Behaviour is a consequence of information processed through neural circuits in the brain. Complications in these circuits influence higher order facets of functioning such as impulse control, behaviour management and practising discretion (Knudsen, 2004; Wozniak et al., 2019). This can have the effect that a 12-year-old functions on the level of a six- to eight-year-old. Since such a child does not fit in with their peers, their desire to be accepted can cause them to be led astray easily and bring them in contact with social services and/or the criminal justice system (Fast & Conry, 2009).

As with the physical and neurocognitive effects of PAE, the effects of alcohol use on behaviour cannot be summarised in a single behavioural profile. Due to the huge variation in maladaptive behaviours even within the different diagnostic groups, trying to simplify the behavioural profile of alcohol-exposed individuals to a single profile would complicate the diagnostic process to such an extent that it will be almost impossible to assign a diagnosis of FASD (Mattson, Crocker & Nguyen, 2011; May, Hasken, Baete, Russo, Elliot, Kalberg, Buckley, Brooks, Ortega, Hedrick, Tabachnick, Abdul-Rahman, Adam, Jewett, Robinson, Manning & Hoyme, 2020).

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Several studies have indicated that some of the disorders associated with FASD are "invisible" and manifest as extremely challenging behaviour (Carpenter, 2011). Behaviours that are often associated with FASD include deficits in inhibitory control, hyperactivity, attention problems, social problems, aggression, mood disorders, oppositional defiant disorder, conduct disorder and comorbid psychiatric conditions (Kalberg & Buckley, 2006; Mattson, Crocker & Nguyen, 2011; May et al., 2020; Paley & O'Connor, 2011). In addition, many behavioural traits of children with PAE such as hyperactivity, attention problems, and impulsivity overlap with that of attention-deficit/ hyperactivity disorder (ADHD) (Crocker, Vaurio, Riley & Mattson, 2009). These behavioural problems are seldom linked to PAE as maternal drinking information might not be available and a formal diagnosis of FASD are seldom made. However, this is a factor that should not be overlooked by social workers when delivering services to young children, adolescents, and event adults with challenging behaviour.

Some behavioural deficits are already seen in new-borns and manifest as infant irritability, problems with self-regulation, jitteriness, a higher intensity of activity, derangement of sleep patterns and difficulty feeding (Lemola et al., 2009; O'Connor & Paley, 2009). In early childhood these problems continue manifesting as sustained irritability, higher levels of activity, problems with attention and deficits in emotional reactions (Kelly, Day & Streissguth, 2000). In children of school going age many of these problems are amplified bringing problems with social conduct and abilities, sustained attention, or attention deficits such as distractibility, hyperactivity, adaptive abilities, the inability to communicate appropriately, impulsivity, problems with anxiety and mood disorders such as depression or aggression and increased vulnerability, to the forefront (Kalberg & Buckley, 2006; May et al., 2020; O'Connor & Payley, 2009; Sek *et.al*., 2017).

The long-term persistence of these behaviours become evident during adolescence when problems with social skills, mood disorders and psychiatric conditions, adaptive and communication skills may become harder to manage and may lead to mental health problems, problems with the justice system and drug and alcohol abuse. Behavioural problems extend even beyond childhood and adolescence into adulthood, manifesting as problems with communication, life skills and socialisation. According to Mattson et al. (2011) these social problems are, indicative of problems

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with adaptive functioning, do not improve over time but suggest an end to, rather than a delay, in the development of those skills. Alcohol-exposed individuals, therefore, find it increasingly difficult to meet social demands as they age, often leading to adverse life events and even a heightened risk of suicide attempts (Mattson et al., 2011; O’Connor & Paley, 2009).

A Canadian study of adolescents with FASD in the criminal justice system found that the charges adolescents with FASD often are found guilty of are theft, assault, vandalism, or failure to comply (Fast & Conry, 2009). These behaviours, in addition to problems with school attendance, dropping out of school early, aggressive behaviour, challenging parental authority and even drug and alcohol abuse at an early age, are realities social workers are confronted with on a daily basis, often without considering the possible effect of PAE.

Thus, behaviour that started out as infant irritability may over time develop into mental problems, mood disorders, psychiatric problems, a lack of ability to function independently and an incapacity to display socially acceptable behaviours (Lemola et al., 2009; O’Connor & Paley, 2009; Paley & O’Connor, 2011; Soars & Mann, 1997). The unfavourable environmental conditions, in which many children with PAE are brought up, has a further effect on behaviour and even a cognitive development, limiting these already compromised individuals even further (May et al., 2013). With limited mental health and other support services, these individuals often rely heavily on social workers to assist them in their daily functioning.

Problems with social adaption, which increase the difficulties the individual with FASD has fitting into a society with social rules and expectations they find hard to follow, will be deliberated on below.

#### *2.4.3.2 Social adaption*

As with the physical and psychological effects of PAE on the development and functioning of the brain, problems with social adaption is a result of the damaging effect of alcohol on the developing brain. The cognitive deficits caused by PAE, are also reflected in difficulties adapting to social situations, understanding, and applying social skills as well as the ability to live independently (Wozniak et al., 2020). These problems with social adaption become more apparent over the lifespan of individuals

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with FASD as society has increasing expectations of them to function independently and exercise daily living skills (Andrew, 2011; Crocker et al., 2009). Social adaption is considered by some researchers to be the area of adaptive functioning most affected by PAE and that the social ability of individuals with FASD decline as they age (Crocker et al., 2009). Mattson et al. (2011) describe the inability of individuals with PAE to meet the increasing and developmentally appropriate demands of socialisation, independence, accepting responsibility and performing everyday tasks necessary for independent living, an arrested rather than a delayed process in this developmental domain. The increasing difficulty individuals with PAE experience with social skills and independent living as they age, can be the result of the more complex cognitive functioning required from adults compared to that of children at a younger age (Crocker et al., 2009).

Problems with behaviour and social adaption often cause problems in the placement situations of children in foster care. The strain of raising a child with behavioural, emotional, and learning problems are often more than foster parents are able and willing to handle. This can lead to placement breakdown and a further disruption in the care of children who are already compromised in many ways, thus adding more loss in their sense of belonging, the social connections they do have and their feelings of self-worth (Pelech et al., 2013).

Another aspect of social-cognitive ability connected to social adaption, is theory of mind. Theory of mind is defined as the cognitive ability to distinguish between and comprehend the mental state of others to understand what behaviour to expect from other individuals (Lindinger, Malcolm-Smith, Dodge, Molteno, Thomas, Meintjes, Jacobson & Jacobson, 2016). Theory of mind is considered an important element of efficient social communication and “a set of interrelated skills that emerge sequentially as the child matures" (Lindinger et al., 2016:368). A study by these authors indicated that individuals with FASD had difficulty reacting to emotional cues as well as difficulty to determine the mental state of others. This deficit impacts on their ability to read social cues, facial expressions, as well as giving attention to and processing social information to guide their social responses (Lindinger et al., 2016).

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## 2.5 CONCLUSION

The combination of physical or biological, psychological, and social effects of PAE on the individual clearly affects every aspect of the individual's life, physical and mental health, and the basic ability to live and function as an independent human being. The fact that these effects cannot be reversed, that no intervention can undo the harms of PAE on an individual, emphasises the important role of multi-faceted, integrative, and comprehensive prevention efforts and the role social workers has to play in these efforts.

PAE has a profound effect on an individual's behaviour and functioning within their families, schools, work environment, social circles, and the community. Some of these effects are, however, subtle, and the connection between FASD, learning problems, health problems, failure to thrive in children, behaviour problems especially in high-risk populations such as foster care, children's homes, schools of industries and even correctional facilities, are often overlooked.

The specialised needs of individuals with FASD place a heavy burden on health care, the education system, and social services. To address the factors causing FASD and the effects thereof on the individual, social workers need to be knowledgeable about FASD to be able to contribute to both prevention and support services to high-risk women, as well as social support services to affected individuals.

In the next chapter, the biopsychosocial model, and its use in FASD prevention and support services will be discussed.

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# CHAPTER 3
# THE BIOPSYCHOSOCIAL MODEL IN FASD PREVENTION AND SUPPORT SERVICES

## 3.1 INTRODUCTION

This chapter pertains to the second objective of this study, which aims to analyse the maternal risk factors of FASD to understand how prevention and support services to high risk drinking pregnant women should be structured better. It further aims to explore how the biopsychosocial model can enrich the structuring and management of policy and legislation to achieve the goal of a more comprehensive, inter-sectoral and holistic approach to FASD prevention and support services.

In the previous chapter, FASD was described as a condition, which influences the physical (biological), mental (psychological) and social aspects of an affected individual's life. This chapter will explore a holistic approach and assessment of the risk factors for having a child with an FASD and how prevention should be shaped to comprehensively address the multiple factors contributing to risky drinking in pregnancy and, ultimately, FASD in greater detail. The methodology of the biopsychosocial model not only provides a framework for scientific thinking, but also offers researchers the opportunity to both understand and explain the causes of a condition and the effects associated with such a condition (Engel, 1980; Pilgrim, 2015).

For social workers, the biopsychosocial model offers the opportunity to reach deeper, to understand not only social factors and their implications in the field of FASD, but also to gain a deeper understanding of the biological and psychological factors influencing drinking behaviour. The biopsychosocial approach recognises the influence of culture and environment on the individual and their decisions without using these influences to escape personal responsibility in respect of decision-making. The biopsychosocial model, its development, and its potential for the fields of FASD prevention and support services will be described and discussed below.

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## 3.2 THE BIOPSYCHOSOCIAL MODEL

In this section, the history of the biopsychosocial model, the link between the biopsychosocial model and systems theory and the contribution of the ecological perspective to the systems theory and the biopsychosocial model will be discussed.

### 3.2.1 The history of the biopsychosocial model

The biopsychosocial model was developed in 1977 by George Engel who, at the time, was a professor in medicine and psychiatry at the University of Rochester. Engel developed this model to challenge the biomedical model of disease, which focussed solely on the contribution of biological factors in the development of disease, to include psychological and social variables as contributors to disease and concurrently focus on all these factors (Borrell-Carriò, Suchman & Epstein, 2004; Lindau, Laumann, Levinson & Waite, 2003). Engel argued that the biomedical model missed important determinants of health by not acknowledging psychological and social factors to health and disease (Babalda et al., 2017). According to Engel, the problem with the biomedical model lay in the fact that it viewed psychological factors as outside the field and responsibility of medicine and, therefore, did not take the whole human being into account (Engel, 1977; Engel, 1980). Engel firmly believed in the effects of psychological factors on health, as well as in the interrelatedness of body, mind, and environment (Taylor, 2002).

In the biomedical model, disease is seen as any “deviation from the norm of measurable biological (somatic) variables” (Engel, 1977:130). In this model with the standpoint that physics and chemistry explain all biological matters, there is no place for social or psychological contributors to disease. This dualistic mind-body view claimed that mental and biological aspects are completely separate and that the “social, psychological, and behavioural dimensions of illness” will ultimately be explained by “underlying physical mechanisms” (Engel, 1977:130).

In contrast with the biomedical view of disease and patient care, Engel argued that to understand disease fully and to provide the best medical care, the contributing factors regarding the patient, their social environment and the societal systems dealing with the results of disease such as the health provider and health care systems, must also be observed (Engel, 1977). Another element of the biopsychosocial model entails that

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objectivity cannot be assumed since a system cannot be understood from within without disturbing that system in some ways (Borrell-Carriò et al., 2004). Engel stated that the boundaries between health and disease will always be unclear and faded by psychological, social, and cultural factors. As a solution, Engel proposed a biopsychosocial model to include both the patient and the disease. In this way the patient could be an active participant in managing their disease (Wickramasekera, Davies & Davies, 1996). Engel argued that a biopsychosocial model would take social, psychological, and biological factors contributing to a patient's disease into account, creating "a collaboration between psychology and medicine" to prevent and manage disease with behavioural origins (Wickramasekera et al., 1996). Additionally, the biopsychosocial model offered the opportunity to consider how a patient accepts their disease and if they take responsibility for their own health care (Engel, 1977).

According to Engel the biopsychosocial model makes it possible to understand why some people experience somatic symptoms or "illness" as a result of certain conditions or circumstances, while others regard similar conditions and circumstances as "problems of living" (Engel, 1977:133). He acknowledged that a patient's view of the world and their reality might be influenced by what they deem the cause of their problem is (Borrell-Carriò et al., 2004). Engel states that it is imperative for a physician to be knowledgeable not only about physical matters, but also about the social and psychological aspects to make decisions on patients' behalf involving all three components. He argues that a patient sees a physician either because they need help to determine what is wrong or, if they already know what is wrong, because they need help to address and solve their problems. He, however, warns that premature advice might hinder a person's ability to be their own agent of change (Borrell-Carriò et al., 2004).

The development of the biopsychosocial model in medicine was built on an earlier similar development to develop holistic views of life processes in biology. The relationship between the biopsychosocial model and systems theory will be discussed in the following section.

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### 3.2.2 Systems theory and its influence on the biopsychosocial model

In general systems theory, Von Bertalanffy argued that events connected with each other should be viewed more holistically as systems functioning "on a specific level of the whole" (Engel, 1977:134). According to this author, systems theory made it possible to identify uniformity amongst diverse levels of organisation, whether it be on a cellular, molecular, organ, organism, personal, familial, societal or biospheric level (Engel, 1977). By taking this approach, the systems theory provided a conceptual base for the biopsychosocial model's understanding of disease, which Engel described as "a blueprint for research, a framework for teaching and a design for action" (Engel, 1977:135).

One of the important contributions of systems theory to the development of the biopsychosocial model, was the concept that "nothing exists in isolation" (Engel, 1980:537). According to systems theory, all systems are influenced by the environment it forms a part of. Although each system is individually seen as a whole, it also is the lowest part of the higher-ranking systems and the highest part of the lower ranking systems in the hierarchy. Each level in this hierarchy of systems is indicative of an organised and complex system in relationship with other systems in the hierarchy. The relationship between the systems also implies that no system can be called a "dynamic system", without identifying and acknowledging the larger system it forms part of (Engel, 1980:537). In the biopsychosocial model this view would mean that the relationship between the biological, psychological, and social realities of an individual cannot be separated and, although each of these aspects are a unique system on their own, they are constantly in interaction influencing each other's functionality and their combined ability to function as an organised whole. Davidson and Strauss (1995:49) capture the meaning of the combination of the biological, psychological, and social factors and the interaction between the different levels of the organisation successfully by describing it as "concrete instances of disorder and dysfunction".

The systems theory does not suggest a linear influence between systems, but rather cause and effect relationships occurring in cycles (De Vries, 2012). It should be kept in mind that systems are not only characterised by their stability, but also by their ability to change. The systems theory influenced social work in many ways. It

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enhanced the ability to understand how people touch and influence each other's lives. However, the systems theory could not link the individual and their environment satisfactorily. Building on the work of several researchers, such as the ecologist Dobshansky, before them, Germain and Gitterman used ecology, with its focus on the relationship between organisms and their environments, to understand the relationship between people and their environments better. This led to the development of the ecological perspective which, according to Germain (1979), provided insight into the communication between people and their physical and social environments. The influence and role of the ecological perspective on the biopsychosocial model, will be discussed below.

### 3.2.3 The contribution of the ecological perspective

To create a theoretical foundation for the ecological perspective, Germain (1991:16) claimed that a "... biological, physiological, psychological, emotional, environmental, and cultural knowledge and theory" was required. Germain and Gitterman (1996) saw ecology as a metaphor with the potential to be used with success in social work because it focussed on the interdependence between organisms and their environment.

The use of the ecological metaphor provided social work with the opportunity both to help people and stimulate environments to contribute to personal growth, better health, and improved social functioning (Germain & Gitterman, 1996). These authors further state that "people can only be understood in the context of the relationship or the interdependence between and amongst them and the environment" (De Vries, 2012:23; Germain & Gitterman, 1996). The combination of people and their interdependent relationships with each other and their physical environment, forms a whole. All the different parts of this whole are equally important in the cycle of life to ensure the survival of the system as a whole (Donald, Lazarus & Lolwana, 2002). As in the systems theory, the ecological perspective does not view the relationships between people and their environments as linear transactions. Relationships are described as a circular loop where cause may occur in one place in the loop and effect another place in the loop.

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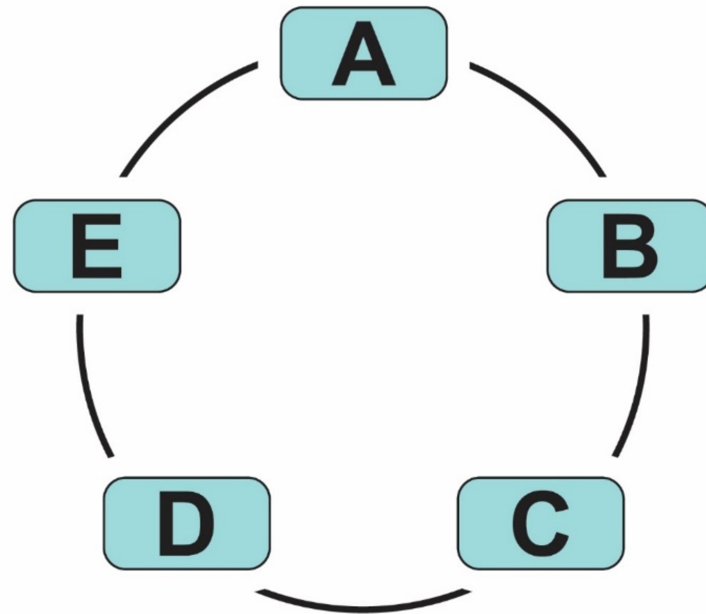


***Figure 3.1: Transactional relationships are a circular loop***
Source: Germain & Gitterman (1996)

Figure 3.1 visually explains that each part of the whole is influenced through interaction with the other parts and affects one another in the continuous flow of interactions. Furthermore, it visually explains the concept of relationships between people and their environment as a visual loop instead of linear processes.

Figure 3.2 (below) indicates that different levels in the whole are, therefore, not only interacting with each other, but also with all the other levels in the ecological system as a whole. By clarifying the interaction and interconnectedness of the different levels of a system, the ecological perspective clearly indicates that behaviour does not take place in a vacuum. It could thus be argued that high-risk drinking in pregnancy does not take place just because an individual makes the wrong choices. These choices and the resulting behaviour take place within, and are affected by, relationships with partners, families, what is deemed accepted behaviour within their community, the individual's culture, and societal norms. The ecological perspective not only recognises the individual's physical environment, but it also links the person and his/her environment on intrapersonal, interpersonal, organisational and community levels. In this perspective, individuals, social processes, and all factors that have an influence on behaviour are, therefore, the combined target for interventions (Ott,

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Quinn & Thompson, 2004). In FASD prevention and support services this would mean that the woman as well as her environment will be targeted for interventions.

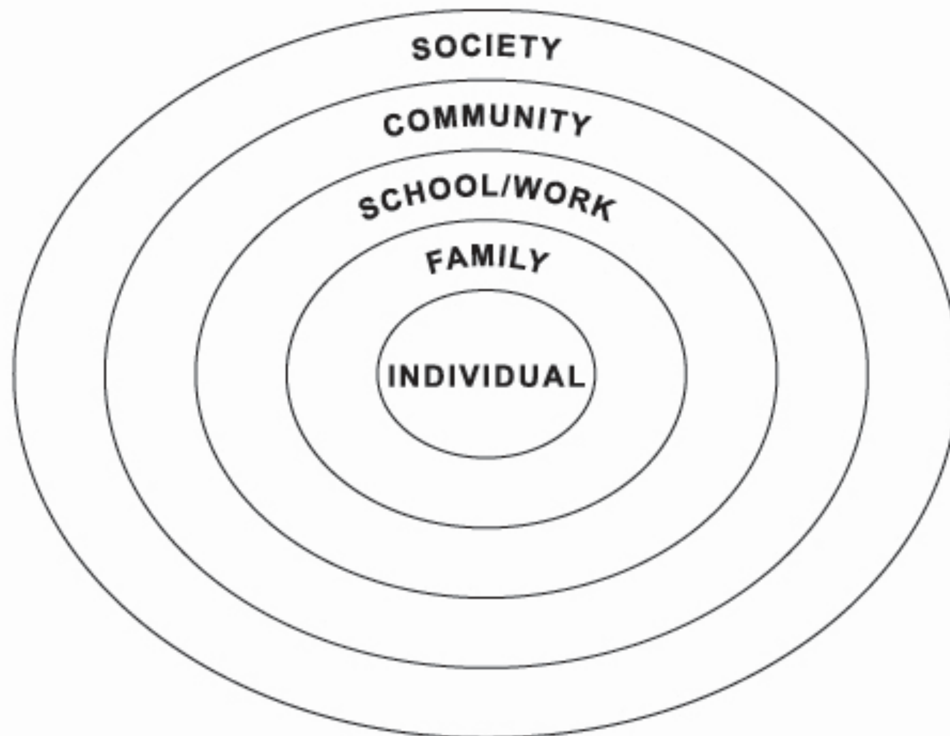


***Figure 3.2: Levels of organisation in the social environment***

Source: Donald et al., 2002

The figure (Figure 3.2) above demonstrates that an individual is part of a family as well as of bigger groups, such as in a workplace or school which, in turn, forms part of a community. Each community forms part of a bigger overall society. In the ecological perspective it is reasoned that an individual is influenced by every level of the social environment they are part of, but also that every individual influences the family, larger social groupings, community, and society they form a part of. This reciprocal effect between the individual and his/her environment has the potential to accelerate change if it is introduced on different levels of the environment. In the prevention of FASD this is an important factor social workers should keep in mind.

Germain (1979) described humans as actively and purposefully striving towards their goals, whilst taking lessons learned from the past and keeping expectations of potential future achievements in mind. Even if people are denied opportunities and

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choices by the society they form a part of, their potential for growth does not disappear, but can be released by changing the environment and the possibilities it holds. To change the lives of people, it is therefore necessary to intervene both in the transactions between people and in the transactions between the people and the environment. In the ecological perspective the goal of social work is to change the transactions to enhance the individual's ability to adapt, as well as to change the environment for the benefit of all who form part of it.

The contributions of both the systems theory and the ecological perspective have enabled the biopsychosocial model to combine the ideas of an individual as part of a whole system consisting of a nervous system, organs, tissues, cells and so forth, simultaneously being part of an environment consisting of a family, work environment, community, and a wider society. Combining these concepts creates the opportunity to view the individual as a unique being with unique physical and psychological characteristics within an environment with specific characteristics and influences on the individual. This underscores the person-in-environment concept, which allows social workers to have insight into their clients' biological, psychological, and social well-being. A biopsychosocial assessment is generally seen as an important part of planning services, setting goals, changing behaviour, or making informed decisions about intervention strategies (Berzoff & Drisco, 2015). These authors continue saying that "humans are profoundly complex, and a stance that is biopsychosocial, which emphases complexity, ambiguity, and self-reflection, which holds onto the tenets of relationship through psychodynamic and neurobiological understanding, are in the long run, not luxuries, but necessities" (Berzoff & Drisco, 2015:270).

This view seems to be very relevant in the complex matter of FASD, where not only the effects of alcohol use on the affected individual are of a biopsychosocial nature, but maternal risk factors for having an affected child also stretches over the boundaries of biological, psychological, and social or environmental factors. The use of the biopsychosocial model in this study, which aims to tell the stories of the lived experiences of mothers with children prenatally exposed to alcohol, is thus relevant and will enable the researcher to tell the story of the woman's life, portray her life trajectory and collect data that will enable social workers to make assessments and formulate plans for prevention and intervention services for FASD (Borrell-Carriò et

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al., 2004). The maternal risk factors for having a child with FASD will hence be discussed from a biopsychosocial perspective in the next section.

## 3.3 MATERNAL RISK FACTORS FOR HAVING A CHILD WITH FASD

Although drinking regularly and heavily during pregnancy poses the biggest risk for producing children with FASD, the variation in the effect on exposed individuals cannot only be explained by variations in quantity and frequency of alcohol use (May et al., 2008). The factors contributing to the risk of having a child with FASD are closely connected to the causes of alcohol abuse and dependence. These factors are multisectoral and involve a reciprocal effect between “genetic, environmental, interpersonal and individual factors” (Garland et al., 2011:745). The risk factors can thus be well described within the framework of the biopsychosocial model as biological, psychological, or social factors, whilst simultaneously demonstrating the continuous interaction between these factors.

### 3.3.1 Biological risk factors

The primary risk factor for having a child with FASD is drinking during pregnancy. Although it is often believed that only heavy drinking or predominantly drinking hard liquor causes damage to the fetus, research has shown that the quantity, timing, and frequency of drinking are not only important contributors to the effects of PAE on the individual, but also point to a dose-response effect between alcohol use and its effects on the individual (May et al., 2008).

Drinking patterns leading to high blood alcohol concentrations (BAC), such as binge drinking, has proved to be especially harmful for the developing fetus (May et al., 2008). Due to women’s smaller body size and less total water in their bodies than men, they can consume less alcohol before they are intoxicated. Smaller amounts of alcohol, therefore, lead to higher BAC’s (May et al., 2008). Furthermore, women metabolise alcohol differently, a factor which may influence their ability to eliminate alcohol in the blood and permit alcohol to pass the placenta and cause damage to the fetus (May et al., 2016). Binge drinking or heavy episodic drinking over weekends being the norm in SA, gives some explanation for the extremely high prevalence of FASD in SA. However, these factors do not fully explain the difference in the levels

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and severity of symptoms found in children with PAE. The conclusion is made that there must be co-factors contributing to, mediating, or altering the effects of PAE on the fetus (May et al., 2008).

According to Burns et al*.* (2019:179) genetics influence an individual's biological make-up as well as their social and intellectual behavioural traits. These inherited traits "interact with environmental systems", influencing a person's development and behaviour. A variety of biological changes during pregnancy impacting on the woman's physical and emotional shape can, in turn, affect drinking behaviour.

Studies in SA (May et al., 2016; May et al., 2008) have indicated that mothers of children with FAS and PFAS are significantly smaller in height, weight, BMI, and head circumference when compared to mothers of normal control children. Smaller body size can be attributed to several possible causes, amongst which genetics, possible PAE themselves and lifelong as well as current malnutrition (May et al., 2008). Maternal nutrition is often compromised by alcohol abuse and may lead to deficiencies in iron, zinc, copper, folic acid and vitamins A, C, and several of the range of B-vitamins (May et al., 2016). Mothers of children with FASD have been shown to eat less during pregnancy and, even if they took the supplements supplied by the antenatal clinics regularly, the effect of those supplements were nullified by excessive alcohol-intake. The needs of the fetus add a further burden to the mother's nutritional status as the fetus is dependent on her intake of nutrients. Undernourished mothers may, therefore, not be able to sustain their fetuses sufficiently (May et al., 2016).

In addition, alcohol disrupts the supply of nutrients to the fetus in several ways, further limiting the supply of nutrients to the fetus (May et al., 2016). Alcohol abuse, and specifically binge drinking, is strongly associated with a low intake of calcium and a low maternal BMI. While an increased intake of micronutrients is generally beneficial to the development of the fetus, excessive use of alcohol limits the benefits of increased nutritional intake and does not add dietary value for drinking women (May et al., 2016).

Several studies (May et al., 2021; May et al., 2015; May et al., 2008; Viljoen et al., 2005) have indicated that mothers of children with FASD are older, had more pregnancies (higher gravidity), more live births (higher parity) and that their later born

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children are more affected. Furthermore, May et al. (2008) indicated that mothers of children with FAS were the only group in their study who had a history of still births. Odendaal et al. (2020) also described a connection between smoking and drinking in pregnancy and the occurrence of sudden infant death syndrome (SIDS).

Unintended pregnancies, due to a lack of or incorrect use of contraceptives, often result in late pregnancy recognition and prolonged alcohol exposure increasing the risk of alcohol-related damage to the fetus (Burd, 2016; May et al., 2020). Risky or binge drinking patterns before pregnancy are considered risk factors for FASD. Research has shown that drinking patterns before pregnancy are the best predictor of drinking especially in the first trimester of pregnancy (Anderson et al., 2014; Lafferty, Becker, Dresner, Meltzer-Brody, Gopalan, Glance, St. Victor, Mittal, Marshalek, Lander & Worley, 2016). The seriousness of prolonged alcohol exposure is emphasised by the finding of May et al. (2021) who state that the odds of children born to mothers drinking alcohol in the first trimester of pregnancy to receive a FASD diagnosis, is six times that of the children of abstainers. This odds ratio increases to 17 – 19 times if a woman continues drinking in the second and third trimesters of pregnancy. This finding highlights the importance of the timing of drinking as a risk factor in producing a child with FASD.

Various biological factors can also serve as protective factors against having a child with FASD. A higher BMI, a healthy, nutritious diet, being pregnant at a younger age, lower gravidity (less pregnancies), not binge drinking and drinking cessation early in pregnancy offer some protection against the effects of PAE (May et al., 2008; May et al., 2022).

The biological risk factors of FASD do not exist in isolation. A combination of risk factors occurs, and it is in some instances difficult to classify a risk factor as either biological, psychological, or social. This highlights the importance of the interconnectedness of the risk factors in the life circumstances of women at risk of alcohol-exposed pregnancies.

### 3.3.2 Psychological risk factors

Burns et al. (2019:178) state that “human behaviour involves interaction between the mind and body as well as the body and the environment.” It is, therefore, important to

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acknowledge that some mental issues are of a biological nature and that there is constant interaction between biological and environmental factors (Burns et al., 2019). Thus, when the psychological risk factors for having a child with FASD is discussed, both the "health determinants of social well-being" and the "social determinants of health" should be considered.

AUDs are often linked to psychiatric problems including depression, anxiety, personality disorders and post-traumatic stress disorders (Coriale, Battagliese, Pisciotta, Attilia, Porrari, De Rosa, Vitali, Carito, Messina, Greco, Fiore & Ciccanti, 2019; McLafferty, Becker, Dresner, Meltzer-Brody, Gopalan, Glance, St. Victor, Mittal, Marshalek, Lander & Worley, 2016). AUDs are, however, frequently misdiagnosed in pregnant women. Women with AUDs are also less likely to make use of prenatal care due to feelings of guilt, shame, a fear of being judged and fear of interventions which might result in alternative placement of their children (McLafferty et al., 2016).

According to Garland et al. (2011) there are risk chains involved in the development of alcohol dependence. One of these risk chains is what is referred to as a "stress-initiated risk chain" where heavy drinking to relieve stress is "hijacked" by the onset of an addictive process (Garland et al., 2011:745). Stress is an important factor underlying the escalation of alcohol use. A linear correlation between increased stress caused by demanding life situations augmenting alcohol use, exists. The relaxing effect alcohol has on an anxious person, reinforces alcohol use under stressful circumstances, leading to a shift towards heavier alcohol use and, eventually, to alcohol addiction.

Mothers of children with FASD have been shown to experience more stressful life events, especially inter-partner violence and other traumatic life experiences (May et al., 2008). An earlier study (Dawson, Grant & Ruan, 2005) showed that each additional traumatic or stressful experience led to a 13% increase in the alcohol consumption of women. SA women reported exceptionally stressful life events during their index pregnancies, resulting in heavy drinking during pregnancy (May et al., 2008). Although stressful lives often lead to an increase in alcohol consumption, the motivation for consuming alcohol has never been found to be deliberate attempts to cause harm to the baby. The claim is often made that some women in SA deliberately

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drink more to cause enough harm to their unborn child to qualify for receiving a Care Dependency Grant. This claim has been found without any substance (Olivier, 2017). On the contrary, the biggest motivation for changing drinking behaviour in pregnancy is the health of the baby (Crawford-Williams, Steen, Esterman, Fielder & Mikocka-Walus, 2015).

A South African study regarding women's attitudes towards alcohol use in pregnancy showed that harmful attitudes such as denying that a pregnant woman should not drink during pregnancy, was related to a history of physical or sexual abuse, symptoms of depression, drinking during a previous pregnancy, meeting criteria for harmful drinking and having negative feelings about the pregnancy (Fletcher, May, Seedat, Sikkema & Watt, 2018). Furthermore, this study showed that women who did not plan their pregnancies were more likely to have negative attitudes towards alcohol use in pregnancy than women who planned their pregnancy. The importance of pregnancy planning in the prevention of FASD is underscored by this finding. It also has relevance to social workers who might reason that pregnancy planning is the sole responsibility of the Department of Health. This aspect will be discussed in more detail in the next chapter.

Women in the aforementioned study also reported that they felt more relaxed, happier, and could forget about financial problems, absent partners, abuse, and unwanted pregnancies when they drank. Their claim that they were "too stressed or depressed to deal with a life without alcohol," clearly indicates the importance of health determinators of social well-being (Fletcher et al*.,* 2018:103).

Misbeliefs about the possible effects of alcohol use on the fetus, was reported by Eaton et al. (2012) as an important contributing factor to how much and how often pregnant women drank alcohol. These authors showed that both pregnant women and their partners' beliefs about how much and how often pregnant women could drink without causing harm to the fetus, was predictive of their alcohol use during pregnancy. Their study further indicated that women who disagreed that alcohol use was a problem in their communities, drank more often than those who agreed with the statement. Another study (Muggli, O'Leary, Donath, Orsini, Forster, Anderson, Lewis, Nagle, Craig, Elliot & Halliday, 2016) found that women's perception of how they are affected by alcohol use, was a protective factor against drinking during

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pregnancy. Those who believed they were affected rapidly or very rapidly were less likely to drink during pregnancy.

Another SA study (Spedding, Sorsdahl, Parry, Mathews, Stein & Petersen Williams, 2020) indicated a clear link between psychological distress and social factors. The contribution of social factors to the risk of having a child with FASD will be deliberated below.

### 3.3.3 Social risk factors

Various studies and reports around the world (Ezekwe, Nkwanko & Osayi, 2019; May, Brooke, Gossage, Croxford, Adnams, Jones, Robinson & Viljoen, 2000; Parry, Gossage, Marais, Barnard, De Vries, Blankenship, Seedat & May, 2012; Popova et al., 2018) have shown that a community's knowledge, attitudes and behaviour regarding alcohol use, the acceptability of alcohol use and drinking patterns in a community, are amongst several societal and environmental factors contributing to the high rate of FASD. Binge drinking, one of the biggest contributors to producing a child with FASD, is an institutionalised form of drinking and widely accepted as the norm and a way of recreation in the WCP in SA. However, binge drinking is not limited to the WCP. A report by the World Health Organisation (WHO) in 2014, found that the African region had the highest prevalence of binge drinking worldwide. This report, which considered a binge as four or more standard drinks per drinking occasion, further indicated that an estimated 31% of pregnant women in the African region, compared to 10.7% in the European region, binge drank during pregnancy (WHO, 2014). In addition, SA is part of the WHO's category with the highest level of binge drinking over a period of 12 months (World Health Organisation, 2011).

In the WCP where a large part of the economy is driven by the production of wine and deciduous fruits, binge drinking has been described as a subculture where heavy drinking often occurs on Friday and Saturday nights (De Vries et al., 2015). A community survey in the Langeberg Municipal area amongst a group of randomly selected participants indicated that 48% of women in this area drank three or more drinks on a typical drinking day. Of this 48%, 9% drank five or more drinks and 7% drank ten or more drinks on a typical drinking day. The mean number of drinks per drinking occasion amongst drinkers only, was 6.4 in females (Parry & Gossage,

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2011). However, the mean number of drinks per week in a group of high-risk women participating in case management, was 20 in the three months prior to pregnancy and 19.3 in the first trimester when they were generally unaware of their pregnancies (May et al., 2013).

Although drinking patterns in the WCP are often linked to the “Dop” system, this system was outlawed in 1961. A study in the Langeberg municipal area regarding farmworkers’ conditions and exposure to this system, found that the “Dop” system was abolished and that only some farm workers older than 50 years ever received “Dop” in their lifetime (Gossage, Snell, Parry, Marais, Barnard, De Vries, Blankenship, Seedat, Hasken & May, 2014). However, the legacy of this system remains in problematic drinking behaviour and to some extent in the prevalence of FASD. Rural residence and being a farm labourer are two factors posing a higher risk for having a child with FASD (May et al., 2008). Falletish (2008) states that, for farmworkers, giving up drinking is giving up instant gratification for the dream of a better life, but that the dream is not strong enough to be able to take the leap.

The influence of the community or environment on an individual’s drinking behaviour is further underscored by findings that the extended families, partners, and friends of women with children with FASD are often heavy drinkers (May et al., 2008). Drinking is to a large extent a social affair where groups of friends or family members drink together. Fifty-seven per cent of participants in a case management study indicated that most or all their friends drank while for another 28% some or half of their friends drank (De Vries et al., 2015). Giving up drinking is, therefore, not only giving up alcohol, but also giving up a lifestyle, a circle of friends and in some cases family or relationships. Le Roux (2020) states that, especially on farms, a lot of planning is done for weekend drinking events. Drinking is of such importance that workers will not buy all the food their household needs to be able to purchase more alcohol. This keeps a cycle of violence, harm to their families as well as physical and mental health going. It can even affect the workplace and expose them to dangerous situations such as operating machinery while under the influence of alcohol.

Low SES have been linked to increased rates of FASD worldwide. In SA, studies have shown that women with children with FASD are from even lower SES than the mothers of controls who are from low SES themselves (May et al., 2008; May et al.,

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2021). Low SES is associated with lower educational attainment, lower household income, less access to resources and exhilarated levels of stress. SA studies have consistently shown that mothers of children with FASD have the lowest education, lowest weekly income, are not married but cohabitate with partners who often drink heavily, that FASD often clusters in family groups and are exposed to high levels of stress and inter-partner violence (May et al., 2008; May et al., 2021).

Higher educational attainment, on the contrary, is a protective factor against having a child with FASD (May et al., 2022). A healthy family life, positive interpersonal relationships, taking care of the physical, emotional, and social well-being of all members of a household and community, a community culturally and normatively supportive of light drinking or abstinence, and religiosity also serve as protective factors against alcohol abuse and drinking in pregnancy (May et al., 2008; May et al, 2022; Van Schalkwyk, 2021).

FASD is not limited to disadvantaged groups and communities only (Muggli et al., 2016). Their study in Australia showed that the more educated women were, the more they drank. An earlier study in Italy (May et al., 2011) also showed that mothers of children with FASD did not binge drink but were daily drinkers with no disparity between their SES and education level than that of mothers of normal control children. The South African reality with mothers from extremely low SES, poor nutrition, a combination of drinking and smoking and a constellation of environmental factors influencing behaviour, anxiety levels and a lack of support systems, is vastly different from those of developed countries. Social factors combined with maternal drinking and household income proved to be the strongest predictor of having a child with FASD in SA (May et al., 2021).

Since the risk factors for having a child with FASD stretches over the borders of biological, psychological, and social factors, all these factors should be considered in both the planning and implementation of prevention and support services for FASD. The prevention of FASD from a biopsychosocial stance will be deliberated in the section below.

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## 3.4 A BIOPSYCHOSOCIAL VIEW OF THE PREVENTION OF FASD

> "Humans are profoundly complex, and a stance that is biopsychosocial, which emphases complexity, ambiguity and self-reflection, which holds onto the tenets of relationship through psychodynamic and neurobiological understanding, are in the long run not luxuries, but necessities" (Berzoff & Drisko, 2015).

This view also rings true for the prevention of FASD. Not only does the consequences of PAE cause complex problems in and for the individual with FASD, but the factors contributing to FASD are similarly complex and multifaceted with biological, psychological, and social components. Short-lived or once-off prevention efforts aiming to inform and educate in order to change attitudes and increase knowledge about the harmful effects of drinking in pregnancy alone are by far not enough to ensure changes in drinking behaviour (May, 1995; Poole, Schmidt, Green & Hemsing, 2016; Symons, Pedruzzi, Bruce & Milne, 2018). A comprehensive, multi-level approach with "overlapping levels of reinforcement consisting of education as well as persuasion" on all three levels of prevention, addressing biological, psychological as well as social risk factors is, therefore, strongly advised (De Vries, 2012:40; May, 1995; May et al., 2007; Stratton, 1996).

FASD is not limited to poor or underprivileged communities, but is found in all populations, ethnic groups, and socio-economic clusters regardless of education and social standing (Popova, Lange, Probst, Gmel & Rehm, 2018). For this reason, it is important that FASD prevention must be shaped to incorporate the culture, language, norms, and values, as well as visual images associated with the community where prevention programmes are implemented (Baydala, Worrell & Fletcher, 2011).

Barkley (2009) states that social workers tend to put so much emphasis on the unjust social circumstances and cultural forces influencing people that they often portray them as victims of their social and cultural environments. This is the exact opposite of the biomedical model, which places the emphasis on physical and internal experiences, implicates that people are unable to change or to take responsibility for the choices they make. This researcher suggests that, although individuals are part of a culture and involved in an active relationship with their society, they form the core

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of a range of concentric circles, in which they are closely influenced by family and friends, their neighbourhood, the greater community, and society (See Figure 3.3). An individual's life experiences are, therefore, influenced by factors such as social class, ethnicity, age, gender, and their society's views thereof, but they are still intellectual beings responsible for their own choices and future. The implication of this reasoning for the prevention of FASD is that, although the individual eventually makes their own choices, the focus of prevention cannot be on the individual alone but must include the groups and systems influencing the individual's choices. The biopsychosocial model allows for the inclusion of all these individual elements, as well as the different layers of society in the prevention of FASD, thereby creating the opportunity for a multi-faceted and holistic approach to FASD prevention.

## 3.5 SUPPORT SERVICES

Women with children with FASD have been shown to have more limited access to resources than women with children who are not on the FASD spectrum. In addition, these women are in general lacking support from their partners, family and friends who are often heavy drinkers themselves (May et al., 2008). Being part of such a heavy drinking environment where inter-partner violence, traumatic life experiences, low-socio-economic circumstances and a lack of resources are coupled with low levels of education and limited access to resources, necessitates support from other sources than what is normally regarded as a pregnant woman's support systems.

One possible method of support that has proved to be effective, is case management. Case management is a form of indicated prevention on the tertiary level with pregnant women who use alcohol. The aim of case management is to support women through pregnancy to stay healthy and alcohol-free. To achieve this goal, a range of social services are provided to help women discover and apply their inner strengths and develop their ability to access available resources. This includes physical and mental health, social services, and community resources (May et al., 2013). Case management, which will be described in detail in chapter four, as well as other forms of support, can benefit from the biopsychosocial perspective, which also calls on social workers to take an integrated view of biological, social, and psychological needs to empower women to take responsibility for their past choices as well as their future decisions and actions (Barkley, 2009).

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## 3.6 FASD POLICY

FASD is a complex problem rooted in complex socio-economic circumstances, lifestyles, health, and cultural factors also known as the social determinants of health (Adebiyi, Mukumbang, Cloete & Beytell, 2018; Olivier, 2017). Addressing FASD as a preventable condition, therefore, calls for a comprehensive, multi-level, collaborative approach driven by government policies and resources to guide and manage the nature and extent of prevention and interventions (Adebiyi, Mukumbang & Beytell, 2019a).

A study in 2012 (De Vries & Green, 2013) showed that prevention efforts in SA are hamshackled by a lack of coordination between role players. Recommendations made by this study was that the specific aims and roles of NGOs and government departments should be defined considering their specific knowledge and skills; that the aims, roles, and policies of all government departments and NGOs involved should be coordinated; that integrated prevention should be done on all three levels of prevention and that collaborations between government departments and NGOs should be formalised.

Olivier (2017:88) highlights the need for a "national coordinating structure or network" similar to the structures in Canada and Australia. Furthermore, Olivier states that SA is missing opportunities for both prevention and intervention due to a lack of coordination, support, and leadership in the FASD field. This view is upheld by Adebiyi, Mukumbang and Beytell (2019b) who state that the high prevalence of FASD in SA can partly be attributed to the absence of comprehensive, multi-sectoral and holistic policies. Government departments and NGOs are currently addressing needs and services regarding FASD according to their own policies, leading to ineffective, uncoordinated services being delivered "in silos" (Adebiyi et al., 2018). This is directly in conflict with the goals of the Integrated Service Delivery Model (ISDM), which states that service delivery should be "intersectoral and integrated between the various government departments and sectors" as it works towards collaboration and coordination (Department of Social Development, 2006:7). Furthermore, this document claims that "owing to the interrelatedness of social phenomena and the impact that one department's functions have on the next, it is crucial to understand the roles and responsibilities of all the other sector departments and how their

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functions relate to the Department of Social Development" (Department of Social Development, 2006:18). Adebiyi et al. (2018) underscore this statement when they declare that a holistic policy for FASD, which accosts the social determinants of health, should involve all role players involved in the prevention and management of FASD.

Although various policy documents in different government departments comprise clauses applicable to FASD prevention and management, SA lacks the whole government approach described and practiced in Australia, as well as the efficacy of the Canadian policy's approach of individual and collaborative actions of all sectors and government departments on all levels of government (Adebiyi et al., 2018). These authors further state that the shockingly high prevalence of FASD in SA proves that how prevention efforts and the social determinants of health impacting on the risk of women to have a child with FASD are approached, should be reassessed. A sustainable commitment by the government to develop much-needed policy will be regarded as an acknowledgement of the severity of the problem and a response to set appropriate actions in motion (Adebiyi et al., 2019a).

A review of policy documents in government departments revealed that some of these departmental documents proposed FASD prevention strategies involving a reduction in the availability and accessibility of alcohol (Adebiyi et al., 2019b). These strategies proposed a ban on alcohol advertisements, raising the age for legal alcohol use, regulating alcohol sales by limiting trading hours and enforcing existing liquor laws. Enforcing liquor laws are, however, handicapped by the existence of up to 25 000 illegal liquor outlets in the WCP alone (Adebiyi et al., 2019b). These illegal outlets are responsible for round the clock availability of alcohol, selling cheap alcohol and often disregarding the legal drinking age. As a first step towards making progress in managing the availability of alcohol, especially where women of childbearing age are concerned, government must prioritise the enforcement of liquor laws.

Adebiyi et al. (2019a) identified several matters which should form part of FASD policy in SA. This includes comprehensive prevention efforts with routine alcohol screening of pregnant women and women of childbearing age in clinics, targeted FASD education and prevention programmes, increased availability of treatment options for alcohol dependent women and support to high-risk pregnant women. Early

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identification and increased availability of early intervention services for affected individuals, inclusive educational opportunities, skills development, training for teachers, training of all professionals involved in the multi-disciplinary team and acknowledging FASD as a disability to increase the accessibility of social services for these individuals and their families are further recommended. The importance of cultural diversity and sensitivity, contemplation of the needs of the affected individual over their lifespan, human rights, cost-effectiveness, and women- and family centred policies are emphasised by these authors.

It is further proposed by Adebiyi et al. (2019a) that a specific policy for FASD will improve communication between the different government departments as well as with NGOs, leading to an improvement in collaboration and coordination of services. Relevant and effective policies will provide strategic guidelines for prevention, promote services and support to individuals, promote integrated care and enable stakeholders to make informed decisions about their roles and services offered (Adebiyi, Mukumbang, Okop & Beytell, 2018). It can thus be concluded that a national policy for FASD will enable all stakeholders in this field to respond to the problem of FASD in a multisectoral and coordinated manner, providing a fair starting point to prevent and manage FASD in SA (Adebiyi et al., 2019a).

## 3.7 CONCLUSION

The biopsychosocial model acknowledges the role of biological, psychological, and social factors in the physical and mental health of individuals as well as in the decisions individuals make about their health and well-being. In the field of FASD the biopsychosocial model offers the opportunity to see and act upon the fact that both the causes and effects of PAE on an individual involves biological, psychological, and social factors. To address the causes and effects of FASD in a comprehensive and effective way, requires a multi-sectoral and comprehensive approach guided by a national policy clarifying the roles and responsibilities of stakeholders both in government and the private sectors.

The extent of FASD in SA and its consequential influence on various sectors of government and society in general, calls for action to address FASD in a holistic and multi-sectoral way. The current fragmented prevention, intervention, and support

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efforts are not sufficient to address the full scope of the effects of FASD and can benefit from an inclusive approach such as offered by the biopsychosocial model.

In the next chapter, FASD prevention and support services will be discussed.

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# CHAPTER 4
# FASD PREVENTION AND SUPPORT SERVICES

## 4.1 INTRODUCTION

This chapter refers to the third objective of this study as described in chapter one and it aims to describe FASD prevention and support services found around the world. The three levels of prevention employed in FASD prevention services will be described and discussed. This will be followed by a brief description of FASD prevention services and some well-researched prevention efforts around the world will be cited. This is followed by a discussion of FASD prevention services in South Africa with a focus on the prevention services in the WCP. Case management (CM) as a method of tertiary prevention is discussed to provide a basis for understanding the process of CM and the principles and techniques of motivational interviewing as employed in CM.

According to the Integrated Service Delivery Model (Department of Social Development, 2006:20), the aim of prevention programmes and services are to "enhance the process whereby people are provided with ways and means of taking greater control of factors that impact on their well-being." Furthermore, in this model, prevention is described as protective actions taken to reduce the possibility of adverse circumstances by identifying and addressing individual, environmental and societal factors impacting on the development of adverse situations or circumstances.

Alcohol abuse and other alcohol-related problems are described as behavioural health problems, which, according to Jensen (2020), can be prevented effectively. Jensen postulates that the basis and core principles of social work naturally matches prevention practice and should be used more often and more effectively to assist individuals and communities to make healthy behavioural choices. This is especially true in the prevention of FASD where women of childbearing age are crucial to successful prevention efforts (Rosenthal, Christianson & Cordero, 2005). Furthermore, these authors are of the opinion that FASD prevention efforts should include education, counselling endorsing changes in alcohol use behaviour, planning

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of pregnancies, better nutrition and delaying pregnancy in women with the highest risk.

May et al. (2008) state that many of the risk factors for FASD as described in chapter three, can be addressed by improving the social environment and using proven prevention techniques such as CM, alcohol treatment and birth control. FASD can be prevented by implementing behavioural interventions to reduce drinking or to cease alcohol use during pregnancy. The IOM recommends that prevention efforts should be comprehensive and implemented on all three levels of prevention, namely universal/primary prevention, selective/secondary prevention, and indicated/tertiary intervention (May et al., 2013). Prevention services for FASD on these three levels of intervention will be discussed in more detail below.

## 4.2 THE THREE LEVELS OF PREVENTION

Various programmes for the prevention of FASD on all three levels of prevention have been tried and tested around the world. For prevention efforts to be successful, it is desirable to intervene on all levels of social organisation, from the individual to the societal level. Of further importance in prevention efforts, is to be conscious of biomedical, behavioural as well as social realities of individuals and communities (Rosenthal et al., 2005). This view confirms the fit of FASD prevention with the biopsychosocial model.

Several researchers have confirmed the importance of prevention on all three levels of intervention beginning with public education and knowledge building, which trickles down to secondary prevention to specific groups and eventually tertiary prevention to high-risk individuals (De Vries, 2012; Hankin, 2002; May, 1995; May et al., 2007; Stratton, 1996; Symons et al., 2018).

### 4.2.1 Universal / Primary intervention

Primary intervention can be described as broad interventions focussed on raising public awareness and increasing knowledge at the community level (Baydala et al., 2011, May, 1995; Poole et al., 2016). According to Poole et al. (2016), primary prevention, which has the purpose of encouraging changes in the larger community by empowering and motivating the community and its people to change behaviour

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patterns such as harmful or high-risk drinking behaviour, serves as the foundation for the other levels of prevention. Successful primary prevention efforts should, according to May (1995), not only educate, but also influence the knowledge, attitudes, beliefs, and social structures guiding accepted behaviour in a community. May further states that family and peer groups are the most important social groups in the lives of individuals and, in order to change their behaviour, primary prevention efforts must influence individuals and their social groups in various ways and in various settings. This view is confirmed by Hankin (2002:61) who states that the “level of knowledge of the risks associated with drinking during pregnancy improve with an increasing number of different message sources.” This is an important aspect of primary prevention social workers should keep in mind, especially since prevention messages often tend to focus on a specific group in a community and not a community with all its different groups as a whole.

Primary prevention efforts usually include information and media campaigns, public service announcements, pamphlets, posters, presentations, school-based or community wide education campaigns and using websites or social media campaigns (Baydala et al., 2011; Hankin, 2002; Masis & May, 1991; May, 1995). Although warning labels on alcoholic beverages has become a widely accepted example of primary prevention, some researchers are of the opinion that it has a limited influence on the reduction of drinking (Hankin, 2002). Some studies indicate that giving specific information about the harmful effects of alcohol use alone during pregnancy is not effective in limiting alcohol use in subsequent pregnancies (Odendaal, Brink, Carstens, De Jager, Potter, Du Plessis & Groenewald, 2020). This finding emphasises the importance of multiple-level comprehensive prevention efforts where a “trickle-down” effect between the different levels of prevention is possible (May, 1995).

Although such multiple-level prevention activities may be costly, a comparison between the cost of prevention efforts reducing the risks of alcohol-exposed pregnancies and the cost of the life-time care of an individual with FASD, proves that the cost of preventing a FASD birth is only a fragment of the cost of raising a child with FASD (Popova et al., 2020; Symons et al., 2018). If a risk-adjusted approach is followed by matching the level of risk of a woman to the level of prevention applied,

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the yields on investment in FASD prevention in a community prove to be much higher (Symons et al., 2018).

### 4.2.2 Selective / Secondary intervention

Secondary approaches of preventing FASD focus on women of reproductive age at greater risk of producing a child with FASD because they either drink alcohol or belong to a subgroup at increased risk for having a child with FASD (Symons et al., 2018). Since a high percentage of pregnancies are unplanned, it is important to identify alcohol use both prior to and during pregnancy (Burd, 2016). Unplanned pregnancies frequently result in late pregnancy recognition, which can lead to prolonged alcohol exposure during pregnancy (May et al., 2020). One estimate suggests that 35% of women use alcohol at some point in their pregnancies. It is, therefore, not only imperative to screen all pregnant women for alcohol use, but also to screen women seeking preconception care since alcohol use prior to pregnancy is a proven, reliable predictor of drinking during pregnancy (Chang et al., 1999; Lafferty et al., 2016). The WHO, in its recent first draft of the global action plan for 2022 – 2030 to reduce the harmful use of alcohol (World Health Organisation, 2021), felt so strongly about the dangers of drinking prior to and during pregnancy that they made the controversial suggestion that not only pregnant women, but also women of childbearing age, should be prevented from drinking alcohol to prevent FASD and to relieve the societal pressure encouraging harmful drinking practises in high-risk communities.

Secondary interventions with pregnant women often occur when they receive their first antenatal care. These interventions can be done by conducting brief screenings usings screening tools such as the AUDIT or T-ACE. Lafferty et al. (2016) are of the opinion that all pregnant women should be screened for alcohol use by using a screening tool to determine both their risk and the interventions needed to assist them to abstain from drinking during pregnancy. Some studies have shown that screening alone can influence women to change their drinking in pregnancy (Chang, Wilkins-Haug, Berman & Goetz, 1999). A description of the AUDIT, T-ACE and other screening tools is given in the discussion of prevention efforts around the world (under heading 4.3).

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The importance of secondary interventions is underscored by the results of a South African study demonstrating that mothers of children with FAS recognise their pregnancies later than mothers of children with ARND or normal controls (May et al., 2020). Furthermore, this study showed that 85.1% of mothers of children with FAS drank in the first trimester of pregnancy, that these mothers had more drinks per drinking day and if they cut down in the second and third trimester, they cut down less than mothers with children towards the lower end of the FASD spectrum.

Some studies on the susceptibility of women to brief interventions on substance use such as alcohol use, have shown that women in their reproductive years are exceptionally responsive to these interventions as they realise that their own health as well as that of their children are at stake (Martino, Ondersma, Forray, Olmstead, Gilstad-Hayden, Howell, Kershaw & Yonkers, 2018). Brief interventions have also proved to be effective in reducing the risk of alcohol-exposed pregnancies in pre-conceptional women (Floyd, Sobell, Velasques, Ingersoll, Nettleman, Sobell, Mullen, Ceperich, Von Sternberg, Bolton, Skarpness & Nagaraja, 2007; Hanson, Nelson, Jensen, Willman, Jacobs-Knight & Ingersoll, 2017).

As early as 1995, May and Moran referred to FAS as “a perfect spark or motivating topic” for prevention efforts. Combining this “spark” with the susceptibility of especially pregnant women to information that could benefit the health of their babies, creates “teachable moments” that can lead to changes in drinking behaviour. This view is of importance for social workers who often work with individuals or groups of people either at risk of alcohol or drug abuse or those struggling with the consequences of substance abuse on family and community life. FASD and the prevention thereof can be a “spark topic” to educate, inform and stimulate thinking amongst individuals and groups of all ages, irrespective of gender, socio-economic background, morals or beliefs as no individual, group or community is completely untouched or indifferent to the harms inflicted on alcohol-exposed individuals.

#### 4.2.3 Indicated / Tertiary prevention

Tertiary prevention methods target women at the highest risk for alcohol use during pregnancy. This includes women with alcohol use disorders, women who drank during previous pregnancies, those with a child with FASD and pregnant women

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consuming large amounts of alcohol (De Vries, Joubert, Cloete, Roux, Baca, Hasken, Barnard, Buckley, Kalberg, Snell, Marais, Seedat, Parry & May, 2015; Symons et al., 2018). Research has shown that women with risky drinking behaviour tend to continue their risky drinking during pregnancy (Anderson, Hure, Forder, Powers, Kay-Lambkin & Loxton, 2014). This finding confirms the results of an earlier study exploring the efficacy of case management as a tool for tertiary prevention. Participants in a case management study reported a mean number of 20 drinks per week prior to pregnancy compared to a mean of 19.3 drinks per week during the first trimester of their pregnancies (May et al., 2013).

According to Popova et al. (2018), the World Health Organisation region with the highest prevalence of binge drinking, is the African region. In this region, amongst women who use any alcohol, the proportion of women who binge drink during pregnancy was estimated at 31% (Popova et al., 2018). In SA where binge drinking often is the norm amongst drinking women, CM as a method of tertiary prevention has been utilised by a few studies to coach and support pregnant women to either abstain or drink less during their pregnancies (De Vries et al., 2015; May et al., 2013). CM, according to May et al. (2013:62), "consists of a set of social service functions that helps women access their inner strengths and external resources in order to reduce alcohol use during pregnancy." Studies making use of motivational interviewing, social work principles and methods, as well as the community reinforcement approach (CRA) in CM, have proved CM to be "a major vehicle for tertiary prevention of drinking during pregnancy" amongst high-risk drinking women in SA (De Vries et al., 2015).

Since CM is labour-intensive and costly, some studies are also investigating brief interventions with high-risk women as a means of tertiary prevention (Hanson et al., 2017). Some brief interventions made use of motivational interviewing with the dual goal of reducing binge-drinking as well as preventing unintended pregnancies by promoting the use of contraceptives (Hanson et al., 2017). Another study in SA, with which this researcher is involved, is currently investigating the efficacy of brief interventions through the use of Motivational Enhancement Therapy.

Worldwide, prevention efforts on all three levels of prevention are adapted, tested, and implemented by countries realising that FASD is a global problem affecting their

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general populations. A few of these prevention efforts will be discussed in the following section.

## 4.3 FASD PREVENTION EFFORTS AROUND THE WORLD

To plan and deliver the prevention services needed and then determine whether these services are effective, it is useful to know what the prevalence of FASD in a given community is, in order to be able to compare pre- and post-intervention prevalence figures (Tough & Jack, 2011). Some of the best-known prevention programmes used across the world are the "Changing High-risk Alcohol use and Improving Contraception Effectiveness Study" (CHOICES-programme), "Screening, Brief Intervention and Treatment" (SBIRT) approaches and the use of Motivational Interviewing (MI). These programmes are often adapted for use in specific sub-populations. The CHOICES-programme and SBIRT-approach are both supported by the Centre for Disease Control and Prevention (CDC) and recommended for preventing and reducing the prevalence of FASD (World Health Organisation, 2014).

In one of the first comprehensive prevention efforts amongst Native Americans in the USA, the objective was to enable communities with the necessary information and resources to deal with FASD prevention themselves. In this programme the focus was on primary prevention efforts that enabled local communities to provide prevention efforts on all three levels of prevention. To achieve this goal, materials to inform different groups such as school-going children of different ages, men, women and people with varied educational backgrounds and tribal affiliations, were developed. The results of this study showed a significant increase in and retention of information about FASD throughout these communities and additionally indicated a community-wide transfer of knowledge (May & Hymbauch, 1989). More recently the CHOICES programme was implemented in one of the largest Native American reservations.

The use of the CHOICES programme will be discussed below.

### 4.3.1 The CHOICES programme

The focus of this programme in Native American reservations was on reducing the risk for alcohol-exposed pregnancies by limiting binge-drinking and avoiding

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unplanned pregnancies (Hanson et al., 2017). The core of the intervention of the CHOICES programme is centred in the use of motivational interviewing, a technique focussing on the woman's own perception of the need to change her behaviour and determining her own goals as well as actions to bring about the needed change. The results of this programme showed a significant decline in the risk for alcohol-exposed pregnancies in pre-conceptional women. This was achieved by an increase in the use of contraceptives as well as a reduction in binge-drinking (Hanson et al., 2017).

An earlier multi-site collaborative study implementing the CHOICES programme indicated that the use of brief motivational interviewing techniques led to a significant reduction in the risk for alcohol exposed pregnancies amongst high-risk pre-conceptional women (Floyd et al., 2007). High-risk drinking women not planning a pregnancy can, according to this study, be made aware of their risk and guided to make the changes needed to reduce their risk of an alcohol-exposed pregnancy.

The CHOICES programme's methodology was also adapted, and its methods of data collection simplified, for use in SA (Rendall-Mkosi, Morojele, London, Moodley, Singh & Girdler-Brown, 2012). This study, as other CHOICES programmes, made use of motivational interviewing based on the four key principles of motivational interviewing. These principles are showing empathy by means of reflective listening, rolling with resistance, developing discrepancy between current behaviour and the goals they want to achieve, as well as encouraging self-efficacy (Rendall-Mkosi et al., 2012). The study also proved that motivational interviewing can be used with success by lay-counsellors in the prevention of FASD.

The CHOICES programme was also implemented in the Manitoba province in Canada where a high incidence of FASD was found. In Manitoba, the CHOICES project focuses on sexually active, substance-abusing women who are not pregnant. The Canadian FASD research network (CanFASD) follows a four-level approach to the prevention of FASD, supported by the overall alcohol policy in the country.

Level 1 comprise broad awareness building initiatives, promoting public health activities in support of girls' and women's health as well as community involvement to support and promote change in drinking behaviour.

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Level 2 initiatives provide girls and women of childbearing age with opportunities to safely discuss issues such as pregnancy, contraception, and alcohol use with health care providers.

Level 3 services provide “specialized, holistic support” to women with alcohol problems and/or exposure to violence or trauma prior to and during pregnancy and continues this support throughout the women’s childbearing years (CanFASD: Prevention of fetal alcohol spectrum disorder, 2013:4).

Level 4 provides services to new mothers to uphold the choices they made with regard to their health and alcohol use after the birth of their babies (CanFASD, 2013). This level of service, which includes the postnatal period when mothers breastfeed, adds the important aspect of the influence of alcohol use whilst breastfeeding, to prevention.

Breastfeeding is still widely promoted as the safest and best method for feeding infants and it is recommended that infants are exclusively breastfed during the first six months of life. Worldwide up to 40% of infants are exclusively breastfed during their first six months. However, many women who cut down on their alcohol use during pregnancy, start using alcohol at pre-pregnancy levels soon after the birth of their babies. A study with South African women indicated that normal control children exposed to alcohol via breastfeeding, were significantly lower in weight and had lower verbal IQ scores by the age of seven than those who did not receive alcohol via breastmilk (May, Hasken, Blankenship, Marais, Joubert, Cloete, De Vries, Barnard, Botha, Roux, Doms, Gossage, Kalberg, Buckley, Robinson, Adnams, Manning, Parry, Hoyme, Tabaschnick & Seedat, 2016). In children with FASD the effects of alcohol exposure were amplified by the addition of alcohol via breastmilk, and it was evident in the fact that these children had even more minor anomalies than children with FASD whose mothers did not drink whilst breastfeeding. May et al. (2016) concluded that alcohol use during breastfeeding was associated with a six-fold increase in the probability of a FASD diagnosis. In addition, alcohol exposure via breastmilk was found to be responsible for significant delays in growth and development in children. These findings underscore the importance of continuing prevention services after birth for at least the breastfeeding period.

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The Canadian four-level approach is part of a structured, government supported FASD prevention strategy, which includes all levels of society, service delivery and government policies that support their prevention efforts. With its structured approach, Canada is, next to the USA, the country with the most research on FASD prevention as well as on interventions with affected individuals (Adebiyi et al., 2019).

Next, another well-known and widely practised prevention programme, the Screening, Brief Intervention, and Referral to Treatment (SBIRT) programme, will be discussed.

#### 4.3.2 SBIRT programmes and screening for alcohol use

SBIRT programmes are described as a "comprehensive, integrated public health model to deliver early intervention services for at-risk alcohol use" (Shogren, Harsell & Heitkamp, 2017:747). The goal of the SBIRT model is to raise awareness by screening and setting goals for behavioural change. Screening can be done in any setting, but is especially successful in health care settings where women trust their health care provider. Screenings can be done using any of a variety of screening instruments such as the AUDIT, AUDIT-C, T-ACE (tolerance, annoyance, cut-down, eye-opener), CAGE or CRAFFT (car, relax, alone, forget, friends and trouble). Shogren et al. (2017) advise that screening should be done whenever the opportunity arises, throughout the lifespan of women and should start in adolescence, well before a pregnancy is planned as well as during antenatal care to prevent any possibility of an alcohol-exposed pregnancy.

The AUDIT is widely used to determine levels of alcohol consumption, recognise risky drinking behaviour and problems attributed to alcohol use. This 10-item screening tool developed by the WHO can either be completed by an interviewer or self-administrated. An AUDIT score of eight or more indicates risky drinking (National Institute on Alcohol Abuse and Alcoholism: Alcohol Use Disorders Identification Test, 2000). The AUDIT-C is a modernised version of the AUDIT. This brief screening tool has three questions with five answer choices each. In women a score of three or more is considered indicative of hazardous drinking or alcohol use disorders (Instrument: AUDIT-C questionnaire, n.d.). In both the AUDIT and AUDIT-C higher scores indicate more severe drinking problems. The T-ACE as a screening tool consists of four

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questions that measures a person's tolerance for alcohol (T), annoyance with people criticising their dinking (A), if a person ever felt that they should cut down on their drinking (C) and if they need a drink first thing in the morning (an eye opener) to recover from previous drinking (E) to assess their drinking risk (Chang, Fisher, Hornstein, Jones & Orev, 2010). The CAGE, another four-item screening tool and acronym for cut, annoyed, guilty and eye asks if a person feels they should cut down on their alcohol intake, are annoyed with people who tell them to cut down, have feelings of guilt because of their drinking and if they ever need an eye-opener (WebMD: What's the CAGE assessment, 2021). The CRAFFT is often used to determine adolescent alcohol and drug abuse and includes questions on driving or being in a car after drinking or using drugs, drinking for relaxation, drinking alone, forgetting things that happened whilst under the influence, family or friends telling them to cut down and getting into trouble due to using alcohol or drugs (Massachusetts Department of Public Health Bureau of Substance Abuse Services, 2009). All of these questionnaires can be accessed on the internet and can be useful for social workers in interviewing adults and adolescents where substance abuse is present as well as in prevention efforts.

Screening is needed to determine which women are risky drinkers, who need to be followed up with brief interventions. Brief interventions are in essence short discussions using motivational interviewing to help women determine which behaviours they should change in order to prevent an alcohol-exposed pregnancy. Brief interventions can be once-off interventions or several 10-to-15-minute interventions over time to help women set their own goals to improve health and pregnancy outcomes. This programme can be adapted to be culturally appropriate, trustworthy, and sustainable. Several countries such as the USA and Australia have successfully adapted the SBIRT programme for use in their indigenous communities (Shogren et al., 2017; Symons et al., 2018). These adaptions are of great importance and emphasised the need for context-related and culturally appropriate interventions (Adebiyi et al., 2019).

In Detroit in the USA, the SBIRT programme was adapted to an electronic intervention (e-SBI) making use of computer-based screenings and brief interventions (Ondersma, Beatty, Svikis, Strickler, Tsilos, Chang, Divine, Taylor & Sokol, 2015).

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This study proved to be very successful, and participants found it acceptable due to the anonymity and less time constraints. The success of these interventions was reflected in an increase in the birthweight of the babies of participants. These results are promising for developed countries where technology is readily available, but does not offer a solution for rural areas in developing countries where even cell phone availability poses problems. However, electronic monitoring of alcohol use along with other prevention measures has been successfully implemented in other developed countries. This will be discussed in the following section.

### 4.3.3 Other prevention efforts

A recent pilot-study in Minnesota in the USA studied the possibility of biochemically monitoring pregnant women's alcohol use with mobile technology as a method of FASD prevention. In this programme abstinence was rewarded with shopping vouchers. The vouchers were given as a means of reinforcement of positive behaviour change when women did not drink and were withheld when goals regarding drinking behaviour were not met. This is part of a technique known as "contingency management", which is often used in alcohol and drug treatment programmes (Washio, Frederick, Archibald, Bertram & Crowe, 2017). In this study, drinking pregnant mothers were referred to social workers to support them to abstain during pregnancy. Pregnant women who consented to participate, received mobile breathalysers combined with a camera for facial recognition to ensure that the breath sample provided is that of the study participant. The breathalysers were connected to a cellular network and was sent with the photo taken of the study participant on collection of the breath sample, via the cellular network to the researchers. Samples were sent at least twice a day, one in the morning and one in the evening. Incentives were given once a week if all samples provided were alcohol negative (Washio et al., 2017). Although the sample size in this pilot study was very small, it had promising results showing that the use of mobile technology is compatible with case management and advanced a healthy, alcohol-free lifestyle in pregnancy.

A study in Norway examined the use of screenings by midwives delivering antenatal services (Wangberg, 2015). This study found that most midwives do alcohol use screenings but that the use of screening tools are not common. Brief interventions

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are occasionally done by midwives, but the general use of brief interventions is limited by the midwives' perception of their ability to do brief interventions (Wangberg, 2015).

FASD prevention in Australia is guided by the National Fetal Alcohol Spectrum Disorder Strategic Action Plan of 2018. The three aims of this plan are to deliver services to reduce the prevalence of FASD, to limit the associated impact thereof and to improve the quality of life of affected individuals and their families (Australian Government, Department of Health and Aged Care: National fetal alcohol spectrum disorder (FASD) strategic plan 2018-2028, 2018). The two main objectives regarding FASD prevention in this country is to "reduce access and consumption of alcohol in the Australian community" and to "increase community knowledge and awareness about the harms and consequences of drinking during pregnancy or when planning a pregnancy" (Australian Government, 2018:19). This plan also recognises the importance of the role of health care workers in FASD prevention, as well as that of pre-pregnancy screening. Universal screening of all pregnant women is also recommended.

The Australian government itself is involved in employing prevention efforts through social and mass media campaigns. These campaigns are supported by the work of non-government organisations who are also involved in social media campaigns. In addition to these campaigns, the Education Department includes information for secondary school students in their alcohol education programmes (FASD HUB Australia: Prevention strategies, 2021). Furthermore, the National Health Medical Research Council (NHMRC) in Australia advises that no amount of alcohol is safe during pregnancy and encourages women to abstain when they are pregnant or plan a pregnancy. The Australian Telethon programme further offers a wide variety of services to individuals with FASD but is also involved in prevention activities, of which most are on the level of primary intervention (FASA HUB Australia, 2020). It is, therefore, clear that the prevention of FASD in Australia is, as in Canada, a well-structured, collaborative action with clear goals supported and prioritised by their government.

The European FASD Alliance (EUFASD), which consists of most European and a number of East European countries as well as Russia, was founded in February 2011 with the goal of forming a network, in which professionals and non-government

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organisations (NGOs) across Europe can work together and share ideas and knowledge. Although each of the countries in this alliance still has their own prevention campaigns, the alliance also creates the opportunity to share knowledge, support its members and collaborate in order to increase the quality of services they can deliver (European FASD Alliance: Linking European professionals concerned with alcohol and pregnancy, n.d.). France, for example, had an awareness campaign which featured warning pictures on alcohol containers whereas Italy initiated a social media campaign called “Mamma Beve Bimbo Beve" (Mother drinks baby drinks). The Italian campaign, which pictured babies in different alcohol containers, was widely promoted and received a lot of attention. Most of these campaigns are on the level of primary interventions and have its focus on raising awareness and spreading knowledge (European FASD Alliance, n.d.). However, despite the prevention activities in countries such as France, Italy, and some in the United Kingdom (UK), prevention efforts in Europe are comparatively low to those in the USA and Canada despite a relatively high FASD prevalence in Europe (Adebiyi et al., 2019).

According to Adebiyi et al. (2019), the uneven distribution of FASD prevention programmes and activities around the world calls for a globalisation approach enabling global collaborations not only in research, but also between clinicians, service providers and communities. These researchers are of the opinion that sharing knowledge and experiences will enhance capacity-building worldwide and enrich policies and strategies globally.

In the next section, FASD prevention efforts In SA will be discussed.

## 4.4 FASD PREVENTION IN SOUTH AFRICA

Contrary to the structured, collaborative prevention work done in countries such as Canada and Australia, a study in 2012 showed that FASD prevention services in SA are still fragmented and that formal collaboration agreements between organisations are hard to find (De Vries, 2012). Adebiyi et al. (2021:2) confirmed this finding and declared that FASD prevention and intervention services in SA are “fragmented across relevant departments at national and provincial levels.” These authors attributed this lack of services and coordination to the absence of multi-sectoral policy as well as a lack of inclusivity in the enactment of policy.

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In the following two sections, FASD prevention by research groups, prevention by NGOs and collaboration in FASD prevention will be discussed.

### 4.4.1 FASD prevention research

Two research groups, the Fetal Alcohol Syndrome Epidemiological Research group (FASER) and the Foundation for Alcohol Related Research (FARR), are active in the field of FASD research. The FASER group who are active in FASD research in SA since 1997, are responsible for much of the epidemiological research, which provided statistics for the prevalence of FASD in SA.

Although the primary focus of the FASER research group is conducting research on different aspects of FASD, it is also involved in prevention efforts on all three levels of prevention. Primary interventions include presentations in primary health care clinics, schools, churches, on farms and in collaboration with other NGOs and community structures. Children, adolescents, women, and men are involved in primary prevention efforts. Banners with an FASD prevention message in busy parts of town, newspaper articles, posters, pamphlets and a prevention doll showing how alcohol reaches the fetus are employed in primary prevention efforts. International FASD day (9 September) is generally used to collaborate with the community and other organisations to create awareness by employing various primary prevention efforts.

As a measure of secondary intervention, all women in the areas where this team works are followed up for an alcohol risk screening interview after their first antenatal visit. Many women were involved in more than one study over time, reinforcing their knowledge and influencing drinking behaviour especially in pregnancy. The influence of these interventions can be seen in the fact that women in these areas mostly stop drinking as soon as they suspect they are pregnant or when their pregnancies are confirmed, thereby limiting the fetus' alcohol exposure. In addition, high risk women were recruited for a variety of prevention research studies measuring the efficacy of specific tertiary prevention efforts such as case management (as discussed in detail under heading 4.5), brief interventions making use of motivational interviewing and motivational enhancement therapy (De Vries et al., 2015).

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FARR has developed several intervention and prevention programmes in concurrence with their research and work in specific communities on invitation of those communities (Olivier, 2017). These programmes include prevention activities on all three levels of prevention. A part of the FARR methodology includes engaging the community and following an interactive approach to develop specific programmes and an intervention model according to the needs and realities of each community where they get involved. Primary prevention programmes by this group aims to include as many as possible members of a community. These programmes include workshops and presentations to community groups, for instance on International FASD day (9 September). Publications in the media as well as a radio-drama is also used to further primary prevention (Olivier, 2017).

One study conducted by FARR (Chersich, Urban, Olivier, Davies, Chetty & Viljoen, 2011) evaluated the impact of primary prevention activities on FASD awareness and knowledge about the detrimental effects of alcohol use during pregnancy on two Northern-Cape communities. These primary prevention activities included the display of posters in health facilities, shops, taverns, and government buildings. The study also used events such as Women's Day, International FASD day and national health campaigns such as Breast Cancer Awareness month to further FASD awareness and broaden the community's knowledge about the topic. Community health workers were employed to deliver informational talks in clinics, churches, and other community gatherings. These activities were complemented by training workshops for health workers and social workers. The results of this study showed increased awareness and knowledge about the harms inflicted by alcohol use during pregnancy coupled with modified drinking behaviour. The effects of the interventions were further noticeable in a reduction in the prevalence of FASD from the pre-intervention to the post-intervention phase, demonstrating that primary prevention alone can have an effect on drinking behaviour and lower the prevalence of FASD (Chersich et al., 2011).

### 4.4.2 FASD prevention by NGOs

Other NGOs such as Pebbles, FASfacts and smaller NGOs connected to welfare organisations and churches, play an important role in delivering FASD prevention services. Many of these services are, however, limited to primary prevention.

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FASfacts, for example, make use of experiential learning methods with grade 6 and 7 learners and adults. Handing out t-shirts, wristbands and caps are used in addition to posters and rap songs to enhance the learning experience. This organisation further uses advertising campaigns in the media by publishing articles in printed media and participating in radio talks. Since this group sees FASD as a "moral issue" also, they organise prevention programmes in cooperation with churches and other spiritual workers to share the FASD message as broadly as possible (FASfacts: Fetal Alcohol Syndrome [FAS] Programme, n.d.). FASFacts further partners with the Department of Agriculture to prevent FASD by educating farming communities (Western Cape Government: Fetal alcohol syndrome awareness programme, 2020).

Other organisations, such as the Hantam Community Education Trust (HCET) in the Colesberg district have a broader scope of services including educational and health services, but include FASD prevention services as a part of their health services. The HCET, for instance, introduce all new families in the district to FASD prevention by offering workshops and reinforcing FASD awareness during home visits by field workers (Hantam Community Education Trust: FASD awareness programme, 2022). The work done on FASD prevention by the HCET has some resemblance to the work of the Pebbles Project functioning in the farming areas of Somerset-West, Stellenbosch, Wellington, Citrusdal and the Hemel-en-Aarde Valley near Hermanus.

As the HCET, the Pebbles Project focusses on education but also offers health services, nutrition programmes, community development programmes and social work services (Pebbles Project: Community programmes, 2021). While some of the FASD prevention done by the Pebbles project is on the level of primary prevention, other aspects of their FASD prevention are on a tertiary prevention level. Workshops offered by a nurse practitioner who shows anatomically correct models of the developing fetus as part of informational talks about the harms done by alcohol during pregnancy, forms part of their primary prevention programme. Pregnant women are invited to participate in a tertiary prevention programme where they participate in a programme consisting of two in-person contact sessions, which includes discussions about FASD. These women sign a pledge not to drink during pregnancy, give permission to be breathalysed and are supported by social workers doing home visits. On completion of this programme, participants receive a "baby box". A "baby box"

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consists of consumables the mother and baby will need after the birth and is valued at approximately R1 700. Except for the motivation this clear goal of completing the programme and receiving the “baby box” offers for participants, the experience of this programme turns its participants into “ambassadors who go into their communities and spread the word that alcohol and pregnancy is a no go” relationship (De Jager, 2021). This programme shows similarities with the study by Washio et al. (2017) where mobile breathalysers were used, shopping vouchers were given as motivators for alcohol-negative breath samples while contingency management, which included social worker support enabling pregnant women to maintain a healthy lifestyle and alcohol-free pregnancy, was applied. A roll-out of this study by Washio et al. was recently funded for implementation in SA. The study will be replicated on a larger scale in a collaboration between Washio and the Medical Research Council in areas around Cape Town (Erasmus, 2021).

Another organisation involved in primary FASD prevention efforts, is Home of Hope. This organisation has a special focus on taking care of children with FASD. Home of Hope, however, also promotes FASD awareness amongst professionals by offering professional education and training workshops for teachers, nurses, social workers, students, lawyers, and community workers (Home of Hope, no date). Early Years Services, an organisation with a focus on early childhood development, offers awareness training for teachers, care givers, community workers and family members to recognise and manage the needs of children with FASD in a similar way. This organisation further promotes FASD awareness under expectant mothers and youth (Early Years Services: Early years services programmes, 2017).

Although social workers employed by welfare organisations such as Badisa and the ACVV are from time to time involved in primary prevention projects in schools or with specific groups, neither these NGOs nor the Department of Social Services have formal FASD prevention programmes.

With limited prevention being done on the level of primary prevention, even less is done on the level of secondary prevention. One secondary prevention project is the “Pregnant women mentoring programme” of FASfacts (FASfacts, n.d.). In this project, “project monitors” are trained to approach pregnant women and inform them about the effects of alcohol on the development of the fetus. The monitors then engage with

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these women for the remainder of their pregnancy and while they are breastfeeding to support them to abstain from alcohol (FASFacts, n.d.).

The "Healthy Mother Healthy Baby" programme is implemented by FARR as a secondary prevention programme aimed at pregnant women to promote the health of both the mother and her unborn baby. Amongst other health-related goals, this programme has an aim to encourage abstinence in pregnancy. Involvement with the women start with screening of pregnant women under 20 weeks gestation at the antenatal clinic using the AUDIT as a screening tool, followed by brief motivational interviewing with individuals as well as in groups.

From the above it is clear that, although there are several organisations addressing FASD through a variety of prevention services, each of these organisations are largely functioning on their own and driving their own interventions. The importance of collaboration between groups to further FASD prevention will be discussed next.

#### 4.4.3 Collaboration in FASD prevention

Between 2001 and 2006 attempts were made in the Western Cape to bring together government departments, role players from the Universities of Stellenbosch and Cape Town, as well as several NGOs to work together in raising FASD awareness, implementing prevention programmes and to share skills and information (Fetal Alcohol Spectrum Disorder: The FASD Task Team, n.d.). This followed on the declaration of FAS as a provincial health priority by the Member of the Executive Council (MEC) of Health between 2001 and 2002. The group, then known as the FAS Reference Group, was chaired by the Deputy Director of the Provincial Maternal Child and Women's Health Directorate in the WCP. One of the aims of this group was to coordinate FASD services between the Departments of Health, Education, Social Services and NGOs involved in this field. Some of the successes of this group included the development of a training manual, executing training, the identification of gaps in the management of FASD and creating a "service and research database" (Olivier, 2017:88). Over time, however, this group lost the participation of the Departments of Education and Social Services and a shift in the focus of the group, now known as the FASD Task Team, occurred. The current FASD Task Team is mainly involved in FASD prevention. It also organises an annual International FASD

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Day conference to inform and train role players about research, new prevention efforts and programmes. This conference brings together role players across government departments, NGOs, and research groups. Despite the importance of the functions still executed by the FASD Task Team, the original vision of a body that could coordinate, manage, and enhance collaboration, never materialised.

What is also telling from the prevention services that are taking place is the small part social workers play in the prevention of FASD. Social workers are often part of the multi-disciplinary team delivering services but, given the impact of FASD on an individual and the support they will need from social workers and other professionals, the role of the social worker as a driver of FASD prevention, should be reconsidered and enlarged.

Additionally, SA needs clear policies and national strategies to enable collaboration between NGOs, government departments and research groups in order to implement a comprehensive and coordinated FASD prevention service to be able to fill the gaps left by the insufficient attempts by individual groups and organisations to further FASD prevention (De Vries, 2012; Olivier, 2017). The only example of collaboration between government departments, research groups and welfare organisations involving FASD prevention the researcher could find, was the process followed for the development of the “1 000-Days” initiative. This initiative by the Western Cape Department of Health focusses on the 1 000 days between conception and a child’s second birthday. The 1 000-Days initiative aims to impact three key-areas namely the child’s ability to grow, learn and thrive. Information about the harmful effects of alcohol in pregnancy forms part of this initiative (Western Cape Government: First 1 000 days. Grow, love, play, 2022).

Below, case management and how it can be utilised as a method of FASD prevention and a support service to pregnant women, will be discussed.

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## 4.5 CASE MANAGEMENT AS A METHOD OF FASD PREVENTION AND SUPPORT IN SOUTH AFRICA

Case management, as a tertiary level approach to prevention can be used to educate, coach and support women through a healthy, alcohol-free pregnancy (May et al., 2013). Comprised of a set of social service functions, case management aims to assist women to access both their own inner strengths and the resources in their environment to enable them to stay sober during pregnancy. Although case management as a method of social work is well known and practised by social workers, the distinction between this method in social work and the application of case management as a method of FASD prevention, lies in the focus of the latter on the use of Motivational Interviewing (MI).

Miller and Rollnick (2009:137) describe MI as "a collaborative, person-centered form of guiding to elicit or strengthen motivation for change." In FASD prevention, the purpose of MI is to guide pregnant women to elicit and reinforce their motivation to change their drinking behaviour. MI is practised by showing respect, by quiet attentiveness and by supporting the individual's right to make their own decisions and choose their actions (May et al., 2013). The four principles of MI used in case management are: (1) showing empathy by means of reflective listening, (2) cultivating discrepancy in the women by making them aware of the negative consequences of their drinking behaviour on their own ambitions and principles, (3) rolling with resistance to evade conflict that can subvert change and (4) supporting self-efficacy by articulating hope for change and emphasising that the onus to make the decision to change and to carry out this decision, is the woman's own (May et al., 2013). In addition to MI, the CRA, an approach proved successful in treating alcohol and substance abuse disorders, is used. CRA aims to make an abstemious lifestyle more fulfilling than substance abuse. To achieve this goal, the woman's family, friends, and partner are involved to support changes in drinking behaviour and to reinforce choices beneficial to the health of the woman and her baby (May et al., 2013). Of importance for social workers is to understand in MI is that, using this method, the social worker does not offer solutions or intervene to direct the woman towards a specific solution. In MI, the woman is guided to identify her own problems and to find the steps that can help her change her behaviour and/or circumstances. This is done by asking open-

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ended questions, affirmation of her ability to change, reflection on decisions made and steps taken and emphasising and supporting the individual's self-efficacy (Snell, 2019).

Using MI as the method to motivate change and based on the above principles, May et al. (2013) conducted a study whereby case management was used to support high-risk drinking pregnant women to abstain during pregnancy to prevent damage to their fetuses. Criteria for participation in this study was that women had to have an AUDIT score of 8 or more, were no more than 21 weeks pregnant at intake in the study, were pregnant with at least their third pregnancy and were 25 years of age or older. These criteria were indicative of high risk drinking as well as high risk with regard to age and gravidity.

All women visiting the antenatal clinics in the Langeberg municipal area, were screened for alcohol use by field workers within days after their first antenatal visit and the confirmation of pregnancy, an event many women view as the beginning of their pregnancy (De Vries et al., 2015). The Self-Administered Questionnaire (SAQ) and AUDIT were used to determine the extent of their of alcohol use (De Vries et al., 2015). High-risk women fitting the study criteria were invited to participate in a follow-up screening where more detailed information about their alcohol and drug use and the individual's view of its influence on their lives and functioning was collected. After this, women were invited to participate in 12 months of case management. Informed consent for their participation was obtained. The case management process started with an interview collecting detailed biographical and demographical information, details of education and employment, family composition, pregnancy history, health details, information about domestic violence, nutrition, drinking history prior to and in all trimesters of the pregnancy, smoking and other drug use. Study participants with an upper arm circumference of 23 cm or less also received a nutritional supplement, Nutrimil.

Each study participant was assigned to a specific case manager with whom they worked for the duration of case management except in the case of staff turnover. Case managers were mostly social workers trained in MI, CRA and prevention before the study commenced. Professional mentoring and coaching were continued throughout the study to ensure that the techniques and principles of MI and CRA were

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consistently practised to inspire lifestyle changes supporting abstinence (May et al., 2013). The primary goals of case management were safeguarding the fetus against harm inflicted by prenatal alcohol use and supporting the women in case management by ongoing motivation to abstain from or cut down on their alcohol use and, thereby, improving their daily lives and reducing the possibility of a child with FASD (May et al., 2013).

The case management process further consisted of one to two follow-up visits per month to each participant and telephone calls between visits if needed. Visits were either home visits or interviews in the study offices depending on the woman's circumstances and choice and lasted more or less 30 minutes. Interviews were often conducted during lunch hours since many women could not afford to lose a day's wages. Women were also provided with a cell phone number they could use to send "please-call-me" messages to whenever they needed support (De Vries et al., 2015). In the case management process, case workers made use of a variety of tools such as timelines of significant life events, eco charts to help study participants plot and explain all the significant people, groups, and community systems in their lives, genograms, emoticons to help identify and express feelings, the adult Happiness Scale, illustrated pamphlets explaining the growth and development of the fetus from conception to birth and the effect of alcohol during each period in development, as well as a true to life model of a 12-week-old fetus indicating its size and development (De Vries et al., 2015; May et al., 2013).

Follow-up data on drinking behaviour was collected three-monthly at three, six and nine months into the case management process, making use of timeline follow-back methods and the AUDIT as screening tool. More comprehensive information about drinking, smoking, drug use, family violence and psychological pain was collected at six months and 12 months into case management. This was done in addition to the completion of the Happiness Scale to measure their general welfare and happiness in areas such as relationships with family and partners, emotional happiness, alcohol and drug use, money management, cultural life, work and educational progress, health, communication, and social life. Each of these areas were evaluated on a 10-point Likert scale (De Vries et al., 2015; May et al., 2013).

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The case management process, indicating the inclusion and exclusion criteria, the tools used in each part of the process and the time frame connected to the process, is visually explained in Figure 4.1.

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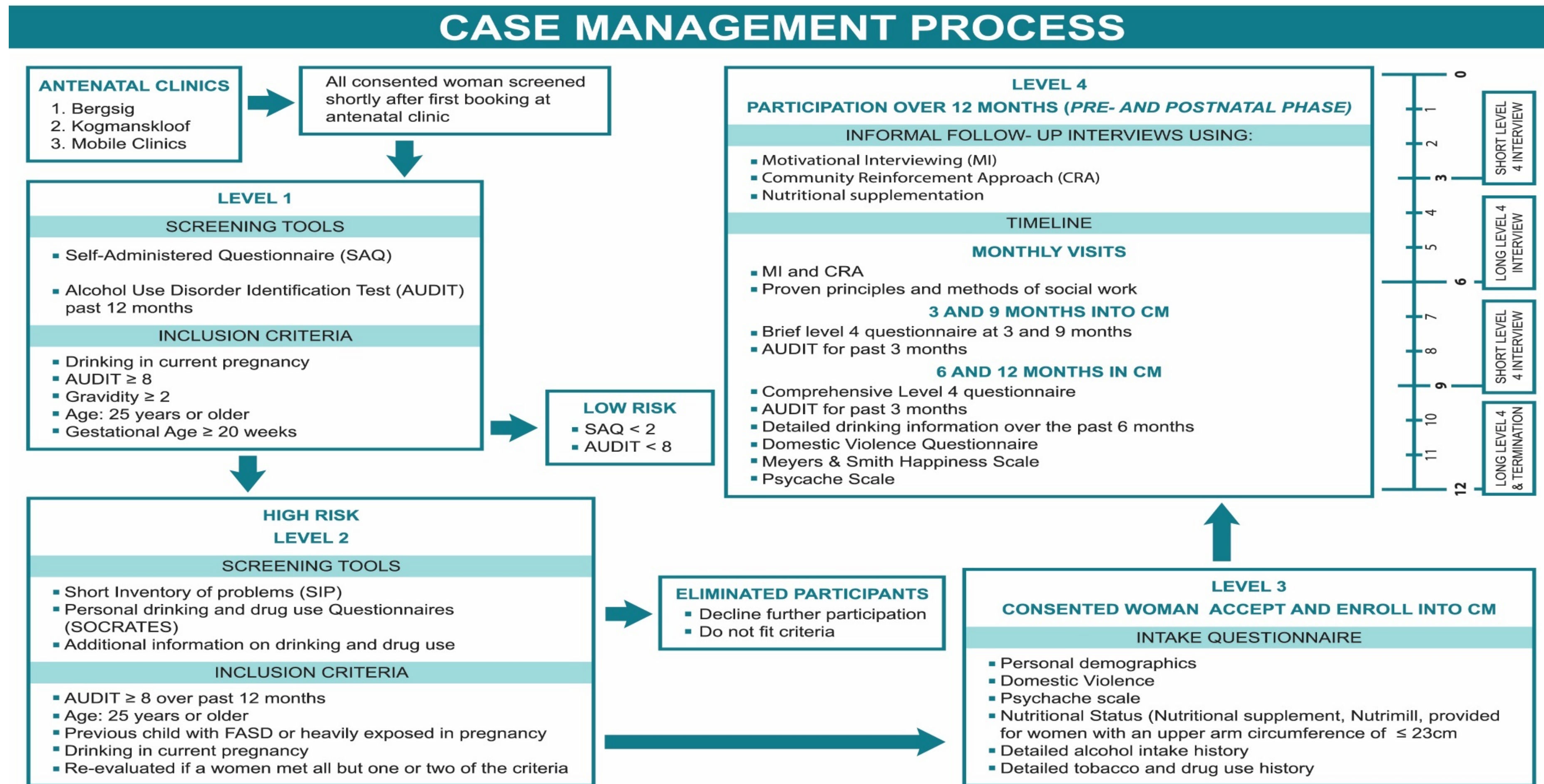


***Figure 4.1: The case management process***

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The figure above summerises the case management process, which started with an alcohol use risk screening shortly after the pregnant women's first antenatal visit, a second screening, during which more detailed information was collected and an intake questionnaire collecting detailed personal demographic, alcohol intake, drug and tobacco use history employing a variety of scales to determine mental status. Following the intake interview, MI, the CRA and proven principles and methods of social work were used during the active case management process over a period of 12 months.

Some findings from a similar study conducted between January 2009 and July 2011 in another Western Cape town similar to the rural area of the Langeberg Municipality, indicated that although only 29.9% of study participants in that study did not drink in the 30 days prior to intake in case management, 55.2% of the study participants did not use alcohol during the 7 days prior to the intake interview. This was ascribed to the fact that the screening interview was conducted a week or more before the intake interview and was an indication that even a screening interview can have a positive effect on drinking behaviour in pregnancy (De Vries et al., 2015).

Another finding of this study was that study participants drank significantly less in the second and third trimesters of their pregnancies than in the three months prior to pregnancy. A reduction in alcohol consumption was in most cases only seen after the pregnancy was confirmed by the clinic, usually only in the second trimester. This is partially because many women only perceive themselves to be pregnant once their pregnancy is confirmed by the clinic (De Vries et al., 2015). A further decrease in alcohol consumption was correlated with enrollment in case management. This reduction was maintained over the rest of their pregnancy and in the first months after the birth of the baby (De Vries et al., 2015). This decrease in alcohol intake was also reflected in a reduced AUDIT score between intake in the study and 6-month follow-up and it remained lower for the entire period in case management. These results show that case management can be efficacious as a method of tertiary prevention of FASD in SA (De Vries et al., 2015).

In addition to the positive drinking outcomes observed during case management, happiness scores collected at intake and all follow-up timepoints indicated that happiness is correlated with drinking quantity. The biggest increase in happiness during case management was seen in women with the lowest happiness scores at

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intake. However, women who had higher happiness scores at intake also had increased scores during the period in case management. A further interesting finding of this study was that the less the study participants drank, the happier they were and that an increase in drinking led to a decrease in happiness (De Vries et al., 2015).

One of the benefits of case management was that the biggest decrease in alcohol intake was found in the women who drank most. A significant decrease in alcohol intake does not only have a positive effect on the outcome of a woman's current pregnancy, but can also have a ripple-effect influencing others in her social environment and even her drinking behaviour in future pregnancies. However, this study also found that, although case management was very efficacious in reducing alcohol-intake during pregnancy, many women returned to pre-pregnancy drinking levels after the birth of their babies (De Vries et al., 2015). The importance of family planning methods to prevent future unplanned pregnancies is thus underscored as an addisional method of prevention.

One of the key reasons for the success of case management as a method of tertiary prevention is the importance of the relationship and interaction with the case manager. Many pregnant women are deserted by their partners during pregnancy and have little or no support from family or friends. Case management offers women the opportunity to talk about their lives and hardships with somebody who listens without being judgemental or offers advise but instead makes them feel worthy and supports their ability to find their own solutions (De Vries et al., 2015).

## 4.6 CONCLUSION

Although FASD is a world-wide phenomenon affecting a large number of individuals, there are few countries with coordinated efforts to prevent FASD. This is despite FASD theoretically being a 100% preventable condition. Most existing prevention efforts are on the level of primary prevention and focusses on broad awareness and educational campaigns. These campaigns are of great importance in educating the general public and communities about FASD but more is needed to have an impact on the drinking habits of women at high risk for having a child with FASD. A risk-adjusted approach to prevention, which offers different levels of intervention that fits the needs of communities and individuals with different degrees of risk, is recommended.

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Case management as a means of tertiary prevention in the highest risk women, has proved to be very succesful. Not only did it enable women to abstain or drink less during pregnancy, but women in case management were in general happier and able to build good therapeutic relationships with their case managers. The therapeutic value of feeling accepted and not judged, listened to and not blamed, supported and enabled to make their own choices and being in control of their own destiny, should not be underestimated.

There are several ways in which social workers can be a driving force in the prevention of FASD. Primary prevention efforts are important and much needed but not the only form of prevention and intervention needed. Social workers, along with health care providers in family planning and antenatal clinics, are well positioned to be involved in secondary prevention services too. Social workers' involvement with high-risk groups such as youth in foster care, adolescents with high-risk behaviour, women with children in alternative care and adults with known high-risk drinking, should see this involvement as golden opportunities for secondary prevention.

Social workers are also well positioned to be involved in tertiary prevention efforts such as case management and brief interventions. Pregnancy has often been described as a "teachable moment" when women are receptive to information and the support they might need to change their lifestyle behaviour for the benefit of their own and their unborn babies' health. Using MI to guide and support women to make their own decisions about the changes they want to bring about in their lives and bahaviour, takes the responsibility for change away from the social worker and involves the woman and her support structure to work together to bring about change. This is directly in line with the developmental approach described in the ISDM, which has an aim to "collective empowerment, facilitating processes that help the poor, vulnerable and marginalised to regain control over their lives" (Department of Social Development, 2006:7).

However, the task of prevention is not that of social workers alone. For successful interventions on all three levels of prevention, a well-planned, coordinated, and structured FASD prevention plan is needed. Since FASD is not the problem of some communities in SA only but stretches over the boundaries of socio-economic, class,

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religious and regional divides, a national action plan that includes policy and a negotiated plan of action involving all role-players, is long overdue.

In the next chapter, chapter five, the research methodology employed in this study, is described.

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# CHAPTER 5
# RESEARCH METHODOLOGY

## 5.1 INTRODUCTION

Brekke (2012) states that the social work profession is best understood in terms of two broad areas linked to one another, namely, pursuing to understand and, secondly, seeking to promote change. This statement pinpoints the aim of this research which intended to gain an in-depth understanding of the lives, realities and needs of women with a high risk of having a child with FASD, adding to the existing body of knowledge in social work as well as contributing to a better understanding of how to structure prevention and support services to high-risk women. To understand the lives, realities and needs of women with a high risk for having a child with FASD, it was imperative to seek an understanding of the biological, psychological, and social factors underlying the realities and lives of these women. Schurink et al. (2021) suggest that qualitative research provides the opportunity to explore, describe and understand realities from the inside out. This, coupled with "personal interest and intellectual curiosity" about the topic, motivated the choice for qualitative research (Fouché, 2021:61).

In this chapter the research methodology employed, will be discussed.

## 5.2 RESEARCH DIMENSIONS

A researcher's strategy or research approach starts off with a specific design, which shapes the research and is followed throughout the research process. The strategy followed is ascertained by the researcher's own paradigm as determined by the aim and research question of the study, ontology, epistemology, methodology and axiology (Schurink et al., 2021).

Of importance in the development of a research design and the execution of the research methodology, is the researcher's own view of the research question and how it should be answered (i.e., the ontology). The basic ontological beliefs are that reality should either be viewed objectively or interpreted and conveyed to create an

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understanding of social reality. Underlying ontological beliefs are different theories of epistemology, defined as knowledge and perception (Sefotho, 2021).

Researchers describe a variety of research strategies. Schurink et al. (2021) combined these strategies into: phenomenology, ethnography, grounded theory, and case studies. For the purpose of this study, the case study as research strategy was employed. The benefit of using the case study as strategy is that it can be used to contextualise, describe, compare, and interpret a phenomenon. Case studies describe how the parts of a phenomenon are connected to each other as well as to overarching systems. Furthermore, it aims to find patterns in people’s lives and experiences, thereby providing “a slice of reality” (Schurink et al., 2021:303). With the purpose of understanding the lived realities of the participants, this case study can best be described as a descriptive case study providing detailed information about complex situations. In this sense it also connects to aspects of phenomenology, specifically descriptive phenomenology. The purpose of descriptive phenomenology is to describe how a person experiences their life and the factors that shape those experiences from the philosophical point of view that it is consciously experienced (Creswell & Poth, 2018). Maree (2020) adds that the researcher’s focus in phenomenology is to factor out yourself and your own view of the phenomenon to truly experience and view the world from another’s perspective.

In this study the researcher utilised a case study strategy by exploring the phenomenon of women with a high risk of having a child with FASD. The researcher also empirically investigated these women's lives, realities and needs in order to gain more insight into this phenomenon. Furthermore, this investigation enabled the researcher to provide recommendations regarding improved prevention and support services to high-risk women.

Fouché (2021) summarises the research process as consisting of four phases subdivided in 13 steps. The research process followed in this study, will be described below according to these phases and steps described by Fouché (2021).

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## 5.3 RESEARCH PROCESS

The first phase in the research process as described by Fouché (2021), is framing the proposed study. This phase consists of seven steps. The second phase, planning the project, has three steps. Phase three comprises of one step only, while phase four entails the final two steps. Phase one with the seven steps implemented in this study, will be discussed in the following section.

### 5.3.1 Phase 1: Framing the proposed study

In this phase, also known as the predesign phase, planning of the study from identifying the research topic, through writing up the research findings, is done. The first step in this planning process is to identify a topic for research. The steps followed in this phase, will be discussed hereafter.

#### *5.3.1.1 Step 1: Identify a researchable topic*

Fouché (2021) postulates that a good starting point to identify a researchable topic, is to determine what motivates the research. This researcher's involvement in the field of FASD research since 2008 for a collaborative NIAAA funded study by the Universities of Stellenbosch, North Carolina, and New Mexico, has led to a special interest in FASD as a research topic. This, coupled with practical experience of previous research in this area, served as motivation to continue with a research topic in the field of FASD. Fouché (2021) points out that previous research, a personal interest in a research topic and experiences in practise can all contribute to the choice of a research topic.

During a meeting with the supervisor in January 2020, various possibilities for a study with a focus on the lives of women with a high risk for having a child with FASD were discussed. Fouché (2021) states that talking possible research topics through with supervisors is recommended given their experience and ability to add value to the initial idea. With the guidance of the supervisor the original idea was adapted to fit the criteria for appropriate researchable topics. The decision to do case studies about the lives and lived experiences of women with a high risk of having a child with FASD was suitable in the sense that it was possible to research the topic, it had clear significance in the WCP where the highest recorded prevalence of FASD was established as discussed in chapter two, it adds a novel element to previous research and can be

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linked to existing knowledge (Fouché, 2021). The relevance of this study is further underscored by De Jong, George and Jacobs (2021:1 466) indicating a need for research "using phenomenological or case study methods which attempt to provide detailed, nuanced accounts of women's experiences and which attempt to understand how women make sense of their choices and how drinking is serving them within their contexts." It can thus be concluded that this topic also fits the criteria of significance to prevailing knowledge, a practical need for the research, significance in terms of timeliness with regard to current matters and the ability to finish the study in time, and if it is of relevance to the researcher's personal interests and career (Fouché, 2021).

#### *5.3.1.2 Step 2: Formulate the research question*

Kumar (2019) indicates that the importance of formulating the research question is demonstrated in its ability to help create a conceptual framework allowing the researcher a more specific focus and greater clarity about the research question. Creswell and Poth (2018) advise researchers to narrow a study down to one broad central question with a variety of sub questions. These sub questions should typically start with the words "who", "what" and "why". It is further suggested that a case study should first describe participants' experiences and then find themes representative of the participants' responses (Creswell & Poth, 2018).

This method was followed in the formulation of the research question with its sub questions. As discussed in chapter 1, the aim of the study was to gain an in-depth understanding of the lives, realities and needs of women with a high risk of having a child with FASD, adding to the existing body of knowledge in social work as well as contributing to a better understanding of how to structure prevention and support services to high-risk women. The following objectives were formulated to meet the aim of the study:

- To give a detailed description of the effects of prenatal alcohol exposure on the developing fetus, as well as on the long-term functioning and health of the affected individual.
- Based on the biopsychosocial model, to analyse:
  a) The maternal risk factors for FASD,
  b) The prevention of FASD,

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c) Rendering support services to high-risk drinking pregnant women, as well as

d) The structuring and management of policy and legislation that can lead to a more comprehensive, inter-sectoral and holistic approach to FASD prevention and support services.

- To describe FASD prevention and support services.
- To empirically investigate the realities and needs of women with high-risk drinking behaviour in pregnancy.
- To make conclusions and recommendations regarding the effective prevention of FASD and support services to pregnant women by health care providers, social service professionals, communities, organisations, and policy makers.

Creswell and Poth's (2018) method of first describing study participants' experiences and finding themes from their responses later, was also used in data analyses, which will be discussed later on in this chapter.

#### *5.3.1.3 Step 3: Assess the suitability of the research approach*

In this step, the researcher has to choose between a quantitative, qualitative, or mixed methods approach (Fouché, 2021). According to Babbie (2014) each approach has its strengths and weaknesses, and it should be known that the choice of the research approach will influence every following decision. For the purpose of this study, a qualitative approach was chosen. As explained in chapter one, this approach befits the study due to its ability to provide thick, vivid descriptions of complex situations and to get an insider's perspective on these situations. Creswell (2013:48) states that qualitative research is used to "empower individuals to share their stories [and] hear their voices." This description matches the aim of this study, which is to gain an in-depth understanding of the lives, realities and needs of women with a high risk of having a child with FASD, perfectly. This is in concurrence with Babbie's (2014) view that qualitative research often describes the history of people's lives.

#### *5.3.1.4 Step 4: Write the research proposal*

A research proposal is developed to outline and describe the plan, according to which the research will be carried out (Fouché & Geyer, 2021; Kumar, 2019). According to Fouché and Geyer (2021) the research proposal maps out the research journey.

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Furthermore, these authors suggest that a research proposal should answer questions about what you plan to study, contextualise the study, provide a short discussion of relevant literature on the topic, and briefly discuss the theoretical underpinning of the study. It should reflect the problem statement, the rationale for the study and the envisioned results. It is further recommended that the research proposal should outline the intended methodology, pay attention to ethical considerations as well as data collection and analyses. Thus, the research proposal is a working document looking forward in planning the research, but also looking backward to evaluate and rethink the research as it is documented (Fouché & Geyer, 2021).

After attending a workshop for prospective post-graduate students in January 2020, a research proposal containing all the elements as described by Fouché and Geyer (2021) was completed by the end of 2020. As per the policy of Stellenbosch University, a research proposal has to be approved by a research committee. The research proposal serves as a means to convince reviewers of the need for the study and to obtain the necessary permission to continue with the study. Due to the disruption of Covid-19 on the academic environment, the research proposal only served before the research committee in 2021. However, the researcher was allowed to register as a PhD student in 2021 without an approved research proposal. The research proposal was refined with minor edits as suggested by Fouché and Geyer (2021) and approved in 2021. The research proposal serves as chapter one of this dissertation.

#### *5.3.1.5 Step 5: Literature study*

Research aims at more than only gaining knowledge. “Growing a knowledgeable person” is of equal importance (Schurink, Roestenburg & Fouché, 2021:93). These authors define literature as a collection of reliable sources securing the research topic in the current body of knowledge. Creswell and Poth (2018) state that a literature study enriches the understanding of the researcher about existing knowledge, but it also provides a link to a larger discourse by comparing the results of different studies. In this way the researcher exhibits their knowledge and builds credibility in their field (Neuman, 2014). This author further states that a proper literature review contextualises a study and provides links between prior studies and the proposed study. According to Schurink et al. (2021) this way of using literature strengthens existing knowledge and stimulates novel ideas.

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For this study, a literature study of the phenomenon of FASD, the context of FASD in SA, and especially the WCP, was compared to the realities of FASD prevalence, risk factors, the consequences for the individual and the need for services worldwide. This was done in chapter two of this document. This laid the foundation for the literature study, which was expanded over the course of this study to reflect on information and by validating and corresponding findings to current knowledge as was done in chapter six. The literature study confirmed the use of the biopsychological perspective in correlation with the researcher's ontology and epistemology as discussed earlier on in this chapter. It also confirmed the need for this study by uncovering a gap in knowledge about the lived experiences and realities of women with a high risk of having a child with FASD (De Jong et al., 2021). The biopsychological model and its applicability for FASD prevention and intervention efforts was researched in literature and discussed in chapter three. The literature study further investigated FASD prevention strategies and support services around the world and in SA. These strategies and services were described and deliberated in chapter four.

#### *5.3.1.6 Step 6: Ethical Considerations*

Strydom and Roestenburg (2021) state that social sciences research is complicated by widespread ethical concerns associated with unpredictable and erratic actions and reactions. Social workers are bound to a set of ethical principles and rules set forth by the South African Council for Social Service Professions (SACSSP). The principles and values guiding the social worker include promoting social justice, respecting human rights, worth and dignity, integrity, upholding professional standards and caring about the well-being of others (South African Council for Social Service Professions: Policy guidelines for course of conduct, code of ethics and the rules for social workers, n.d.). As a social worker, the researcher is thus bound by this set of rules. In addition, she completed the Good Clinical Practice course presented by the Centre for Medical Ethics and Law at Stellenbosch University in 2021.

An application to conduct this research was presented to the Research Ethics Committee in May 2021. Approval to continue with the research as a medium risk study, was granted in July 2021 (Annexure G). The study was approved as a medium risk study. This was due to access to personal information and expecting of study participants to revisit a time in their lives that might have been emotionally painful and

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upsetting. However, participation was voluntary, participants had the right to withdraw, and debriefing by an independent counsellor was offered by the researcher. These actions are representative of ethical principles such as doing no harm, beneficence, voluntary participation, giving informed consent, confidentiality, and more (Strydom & Roestenburg, 2021).

This study was also regarded medium risk since research interviews were done during a time when all face-to-face interviews were regarded medium risk due to Covid-19 restrictions. Since the researcher wanted to do conduct in-depth interviews in an environment where study participants felt safe, accepted, and enabled to share their true feelings and experiences, the decision was made to conduct face-to-face interviews whilst following strict Covid-19 protocols. More details about the interviews and processes followed will be discussed in steps nine and eleven.

#### *5.3.1.7 Step 7: Consider dissemination and impact*

Fouché and Chubb (2021) recommend that researchers should not leave the dissemination until the end of the study but should already consider dissemination in the early stages of the planning. The factors to be considered must include the purpose of the dissemination providing for contextual intricacies, the key message and timeliness of the messages. The researcher should also consider who the target audience is and ensure credibility by ensuring that the findings are accessible.

Since the main purpose of this research is obtaining an academic qualification, the target audience is mainly other researchers and academics. However, the knowledge base of social work as a profession, social work professionals and social work services can benefit from the results of this study too. Adapting the most important findings for use in an article in a social work journal, will add to the credibility of the dissemination.

### 5.3.2 Phase 2: Plan the project

This phase, also described as the design phase of the research project, consists of three steps: deciding on a research design, how data will be collected and analysed and sampling. These three steps will be discussed below.

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#### *5.3.2.1 Step 8: Research design*

As discussed in chapter one, this study employed the case study as design. In this study a small group of women with a high risk for having a child with FASD were the focus of the study. Schwandt and Gates (2018) refer to a case study where more than one case is studied, as a collective case study. The collective case study seeks commonalities between the cases by comparing them to each other. In this study a combination of descriptive and explorative case studies was used. While a descriptive case study aims to "describe, analyse and interpret" a phenomenon, the explorative case study typically asks questions starting with "what" and "why." (Shurink et al, 2021; Schwandt & Gates, 2018:348). This combination was effective for this study, which aimed to describe, analyse, and interpret the phenomenon of FASD and simultaneously investigate the complexities of the real-life context of high-risk women.

Schurink et al. (2021) state that the multi-layered and complicated nature of case studies allows for different factors to connect to each other and larger structures, to bring present, past, and future in relation and to holistically connect all these factors in the context of scientific expertise. This statement confirms the choice of a collective case study investigating and connecting the biological, psychological, and social needs, realities and lived experiences of high-risk pregnant women as discussed in chapter one, as a suitable design for this study.

#### *5.3.2.2 Step 9: Data collection and analyses*

One of the main characteristics of a case study is that more than one source can be utilised to collect data and develop better insight into the case or collection of cases (Schurink et al., 2021). It is reasoned that the diverse perspectives from a variety of sources enhance an understanding of the underlying dynamics of a case. For this reason, two sources were employed to collect data. All the participants in this study were previously involved in a case management (CM) study for high risk drinking pregnant women. Therefore, file content with information collected over the period of one year while they were in CM, was available. File content included detailed information about drinking history prior to and during their pregnancies, physical and mental health in pregnancy, the challenges they had to overcome during that time and how they utilised the CM process to support the changes they wanted in their lives.

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File content of all the participants in the CM study were studied carefully over a period of four weeks to develop a better understanding of each of the study participants' background, their circumstances prior to and during pregnancy, and what happened during the CM process. The researcher summarised each participant's file content to group together important information about the participant's circumstances, demographical information, pregnancy history and observations by their case managers. This summary of the case files provided a solid base of information about the study participants as persons, what their lives in general entailed with regard to socio-economic circumstances, relationships, health, number of children and a full drinking history prior to and during their pregnancies in CM. These summaries were studied again before each interview and was used as background knowledge about the study participant to formulate questions and direct the semi-structured interview to obtain all the necessary information.

The second source of information was semi-structured interviews. In this study, face-to-face interviews were conducted. This was possible because the researcher lives in the same area as the study participants and travelling time and costs were not a limiting factor (Geyer, 2021). When the study was planned, telephonic interviews as an alternative to face-to-face interviews were considered due to restrictions on direct interviewing during the Covid-19 lockdown period as described in chapter one. However, the interviews could be done during a time when the restrictions were lifted.

The background information collected from the files was used during the interviews to personalise questions in the semi-structured interviews by referring back to specific situations and information. This proved to be very successful because the general questions in the interview guide could be shaped to obtain rich, in-depth information about each participant (Geyer, 2021). It was especially helpful in formulating follow-up questions to further explore their initial answers and in determining the order of the questions on the interview schedule as described by Roulston and Choi (2018). Another benefit of face-to-face interviews in this situation was the ability to pick up on both verbal and non-verbal clues during the interviews (Geyer, 2021). It should, however, also be noted that wearing masks and practising social distancing during the interviews limited the researcher's ability to read facial expressions and, at times to hear what the participants said.

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#### 5.3.2.3 Step 10: Sampling

Sampling in qualitative research is associated with the use of methods such as interviewing and observing participants (Strydom, 2021). Due to qualitative research focussing on a deeper, more holistic understanding of a phenomenon, transferability is of greater importance to the qualitative researcher than generalisability (Creswell & Poth, 2018). The qualitative researcher thus collects data until saturation is achieved rather than predetermining a specific quantity for the sample size (Strydom, 2021).

Creswell and Poth (2018) state that a qualitative researcher must purposefully select participants who can make the best contributions to the study. Strydom (2021) agrees with this notion when stating that study participants should be selected from environments where the problem studied is likely to be found. Therefore, this study made use of purposive sampling, selecting study participants from a specific group of individuals who participated in a CM study in the Langeberg Municipal area. As discussed in chapter four, women participating in this study had to be high-risk drinking pregnant women defined by an AUDIT score of eight or more, matching specific criteria regarding age, number of pregnancies and gestation. In total, twenty-two women participated in the CM study.

The researcher started the process of sampling by creating an Excel sheet with particulars of the 22 CM study participants containing information about their AUDIT scores at recruitment and over the duration of the CM process, biographical information, how much and how often they drank before and during pregnancy, whether they smoked or used drugs prior to and in pregnancy as well as the pregnancy outcomes. At recruitment for the CM study, all the study participants signed consent to participate not only in the CM study, but also indicated whether they were willing to be contacted for future studies. Five study participants did not sign the latter and were thus excluded as potential study participants.

The remaining study participants were then divided into two groups, one group who completed the full 12 months programme and another group who did not complete the full 12 months, mostly because they had to start working after the birth of their babies. Of the 17 remaining study participants, nine completed the full programme and eight did not. The researcher originally hoped to interview only study participants who

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completed the full programme, but after discussion with the supervisor, it was decided rather to choose the participants best suited to provide rich, detailed information from both groups due to the small sample size (Creswell & Poth, 2018).

The researcher then arranged a meeting with the research assistant for the FASER study. A part of her responsibility in the FASER study is to stay in contact with the participants and ensure their and their children's ongoing participation in a longitudinal study. Her role as a regular contact person between the FASER study and the study participants provided the opportunity to have a first contact with potential study participants via a well-known and trusted person who, in this situation, acted as a gatekeeper.

The remaining list of 17 possible participants were discussed with the research assistant to determine who is still available for follow-up and would be able to participate in in-depth interviews, providing rich and descriptive details. Of the 17 possible participants, three were removed from the list because they had moved away, two were removed due to drug-related problems, two due to being poor communicators who would not be able to provide the rich and descriptive detail needed, and one due to a hearing problem. The remaining nine were arranged on a list from most accessible and fitted for participation to least fitted. This correlates with literature (Creswell & Poth, 2018; Strydom, 2021) stating that participants in qualitative research should be selected according to their suitability to provide the thick descriptions needed.

The research assistant then visited each of the remaining nine CM participants to determine whether they would be interested in participating in this study. Brief background information regarding the aim of the research and what would be expected from them, was provided. After they had agreed to participate in this study, the researcher contacted each of the participants giving more detail and making appointments for the interviews. One potential participant never reacted to the researcher's attempts to make contact and one did not show up for four consecutive appointments. Another potential study participant was not contacted for an interview after the researcher and her supervisor agreed that a sufficient amount of data were collected, indicating that data saturation was reached (Strydom, 2021). The final sample consisted of six study participants.

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### 5.3.3 Phase 3: Implement the project

During the implementation phase, the planning for the research process is set in motion by collecting and recording the data. This phase consists of one step only, which will be discussed below.

#### *5.3.3.1 Step 11: Conducting the research*

Conducting the research process consists of two parts. Firstly, it is advised that a pilot study should be conducted in a less formal manner to pre-empt the possibility of problems during the data collection process. The formal process of data-collection, in this study via face-to-face interviews, followed after that. Next, the pilot study will be discussed.

*5.3.3.1.a Pilot study*

Strydom (2021) is of the opinion that, before the formal research process starts, a few respondents can be interviewed to determine whether the needed data can be obtained, to test the interview schedule and to smooth out any problems that may occur. This author further identifies four traits in pilot studies. Firstly, the role of literature to support findings and build logical arguments throughout the research process can assist the researcher to use the knowledge and information obtained from the literature study. This researcher read extensively before the pilot study and established a thorough knowledge base, which positively contributed to the exploration of the study participants' experiences. Secondly, discussions with experts can help establish the boundaries of the field of study. The researcher did this by discussing the study with her supervisor who guided the parameters of the case study, the qualitative nature of the study and the steps the researcher needed to follow. The researcher also discussed the use of qualitative data with the principal investigator of the FASD research study who supported and encouraged the use of qualitative data and acknowledged that there was a need for qualitative data in FASD research (May, 2021).

The third trait is that of assessing the feasibility of the study by determining the frankness and cooperation of the study participants, as well as getting an indication of the size of the study population needed to achieve data saturation. This was done by

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interviewing a study participant known as a more reserved person and low on the list of possible study participants to test the interview schedule and the researcher's approach in the interview. This interview confirmed the effectiveness of the interview schedule and revealed some practical issues, which will be discussed under the fourth trait.

The final trait is that of testing the interview schedule to evaluate the phrasing and order of the questions (Strydom, 2021). Since the potential participants in this study consisted of a very small group of women, only one interview was conducted for the pilot study. It was established that the interview schedule enabled the researcher to move between questions and sections in the schedule without disrupting the flow of the interview. Although this study participant was not a good conversationalist, it was possible to guide her to disclose important information by asking as many as possible open-ended questions and phrasing the questions as simple and straight-forward as possible.

The pilot study also enabled the researcher to evaluate practical aspects such as the influence of wearing masks on the quality of the recording of the interview and the effect of social distancing while wearing masks on the clarity of the conversation and the recording for both the researcher and the study participant. The researcher also realised the value of using travel time with the study participant to build rapport and then easing into the research questions without having to spend valuable interview time to start building the relationship. The researcher continued by conducting the research interviews after this, as described in the next section.

##### *5.3.3.1.b Interviews*

According to Geyer (2021) verbal communication is of the utmost importance in the collection of rich, in-depth data describing a phenomenon. This author recommends the use of individual interviews when sensitive topics are explored. Semi-structured, in-depth, face-to-face interviews were chosen for the purpose of this research. (Annexures C and D). This was done to be able to guide interviews and have flexibility in the process of investigating the topic (Geyer, 2021). Since the use of more than one source of data collection is recommended, study participants' files from their participation in CM were studied before the interviews (Babbie, 2014). This provided

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background information informing the researcher about demographics, drinking histories prior to and during their pregnancies, specific struggles they had during their time in CM and the influence of the CM process on their lives.

For the purpose of this study, arrangements were made to conduct the interviews on the same premises where study participants previously attended their CM interviews, albeit in a different building. This was done in order to make a clear distinction between the two studies whilst benefitting from the familiarity of the setting and the connection with their positive experiences in CM. Since the interviews were conducted during the third wave of Covid-19 infections, both the interviewer and study participant wore masks covering their noses and mouths during the interview. A social distance of 2 metres was maintained during the interviews that were conducted in a space with good ventilation.

Interviews were done between November 2021 and January 2022. Before conducting the interviews, the aim of the research, the researcher's expectations and the confidentiality of the interviews were discussed. The informed consent (Annexure A and B) was explained to the study participants, and they were allowed to ask questions before the forms were signed. It was originally envisaged that two interviews would be conducted with each participant, correlating with Creswell and Poth's (2018) opinion that the number of qualitative interviews with participants are limited. It was, however, not possible to do a second interview with two of the study participants due to work and other circumstances. Four participants were interviewed twice. No new information was gathered from one of the study participants during the second interview. The researcher only clarified aspects that were covered in the first interview. In two cases where second interviews were conducted, the study participants needed time to vent their feelings and traumatic experiences during their first interview. Much time was, therefore, used to allow them to talk about their circumstances and trauma during the first interviews. The interviews were directed to cover most of the questions in the semi-structured interview schedule (Annexures C and D), but more information had to be collected during the second interviews. With the fourth participant who took part in a second interview, most of the information was collected during the first interview but some aspects of the semi-structured interview schedule had to be covered during the second interview while other aspects had to be clarified. Even though the researcher

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was of the opinion that data saturation was reached after the fifth interview, a sixth interview was conducted to ensure that no new information emerged. The researcher limited the length of the interviews to about an hour each to prevent long, tiring interviews. Participants received a R50 Pick n Pay voucher after each interview to thank them for their time and participation. This gesture had very positive responses as some needed food and one study participant wanted to do something for herself and planned to buy skin lotion.

### 5.3.4 Phase 4: Data analyses

This phase is used for the analyses and dissemination of data (Fouché, 2021). During this phase, data are processed, analysed and the results verified, after which the research findings are disseminated. There are two steps in this phase. The processing and analyses of data will be discussed next.

#### *5.3.4.1 Step 12: Process and analyse data*

Schurink et al. (2021:397) describe qualitative data analyses as "the process of bringing order, structure and meaning to the mass of collected data." The task of the researcher in this step is to sift through the raw data, find meaningful patterns and themes and eventually communicate the core of what the data tells.

This researcher followed the steps of data analysis as described by Schurink et al. (2011) starting with planning for the recording of the data. A digital recorder was initially used to record the interviews. The informed consent form made provision for recordings and participants were ensured of its confidentiality and use strictly for the purposes of this study. After the pilot study interview, the researcher realised that the sound quality was impaired by wearing masks and social distancing, causing great difficulty to transcribe the interview. After the first interview, a cell phone was used to record the interviews and the digital voice recorder was used as a backup device should the cell phone run out of space. Recordings were downloaded onto a computer directly after the interviews and stored in clearly marked files for each participant by date of the recordings.

The researcher transcribed the recordings as soon as possible after the interviews. Transcription is a powerful tool that influences how participants are understood, what

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they said, and the conclusions reached (Oliver, Serovich & Mason, 2005). These authors advise that researchers critically reflect on whether to choose naturalised or denaturalised transcription. This researcher decided on denaturalised transcriptions allowing for the full meaning and context of the interview to be conveyed (Nascimento & Steinbruch, 2019; Oliver et al., 2005). This was important in this study where interviews were all conducted in Afrikaans with participants speaking the language in a less formal, more descriptive manner using expressions unique to their culture and environment and not always understandable in formal Afrikaans. This approach is supported by Schurink et al. (2021) who state that study participants should speak for themselves, and that data should portray their intimate personal experiences. Back-up copies of both the transcriptions and recorded interviews were made and stored in a locked safe as described in the application to the REC.

After transcribing the interviews, the researcher read the transcriptions several times to familiarise herself with the available data and find commonalities in the participants' stories (Schurink et al., 2021). Field notes were consulted to add observations to the available data. Following on this process, the researcher started first order analysis (coding) by highlighting similar responses in colour. This was done with all the interviews, along with moving between interviews to compare responses and possible codes. After that the researcher moved on to second order analysis and the formulation of themes by grouping similar codes together on a separate document to identify themes and categories (Schurink et al., 2021). Creswell and Poth (2018) describe themes as broad groups of data consisting of several codes grouped together to create a general concept. To identify themes, the researcher used a biopsychosocial stance as discussed in chapter three and took a social work perspective in identifying the themes. The researcher consequently made a list of overlapping matters and organised it into themes, sub-themes and, eventually, categories. In accordance with Creswell and Poth's (2018) suggestion of using five to seven themes, seven themes were identified. They were:

- Childhood
- Intergenerational patterns
- Level of education and work circumstances
- The role of partners

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- Pregnancies and children
- Psychological factors, and
- The availability of services and a need for more services.

In keeping with the title of the study and the aim of the research as discussed in chapter one, the researcher used the thick descriptions obtained from the in-depth interviews to tell the story of the real-life experiences and the realities of every study participant. These stories aimed at giving the “insider’s perspective” of the study participants’ lives and the choices they make as described by Garland et al. (2011) whilst providing “detailed, nuanced accounts of women’s experiences” attempting to create an understanding of “how women make sense of their choices and how drinking is serving them within their contexts...” (De Jong et al., 2021:1466). This understanding can benefit the social worker in planning and delivering services to women at risk for having a child with FASD.

The data obtained by this process is reflected in chapter six. The researcher linked and interpreted the data obtained from the literature study. Schurink et al. (2021) describe literature study as an ongoing process continuing throughout the research process. This was true in this researcher’s experience, where the initial literature study provided a firm base for the research, but had to be supplemented with more literature for the process of literature control.

The final step in the process of data analyses, is data verification. Schurink et al. (2021) state that the quality and trustworthiness of qualitative research is measured according to its credibility, dependability, confirmability, and transferability. According to Schurink et al. (2021) credibility aims to prove that the study participants were identified and depicted correctly. In this study, credibility was achieved by identifying study participants from a group of high-risk women who participated in a previous study with very specific recruitment criteria. In-depth interviews ensured the collection of rich, thick, and descriptive data, portraying the perspective of the study participants.

Dependability in qualitative research refers to how well the research process is documented and evaluated (Schurink et al., 2021). Creswell and Poth (2018) state that ensuring that transcripts are a true reflection of the interview, adds to dependability. The researcher ensured dependability by documenting every step of the data collection

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process through creating Excel files for the selection of study participants, taking field notes, checking the accuracy of transcriptions and by ensuring that the research process as reflected in chapters five and six of this document, is truthful.

Conformability depicts the concepts of dependability and objectivity (Schurink et al., 2021). The researcher tended to conformability through the literature control, comparing the study participants' experiences with findings in literature. In addition, two participants were asked to read the transcriptions of their interviews and confirm that it is a true reflection of the interviews (See Annexure G). Finally, an independent decoder was used to ensure that the researcher correctly identified the themes, sub-themes, and categories (See Annexure H).

In qualitative research transferability refers to the ability to apply the findings of one case to another (Schurink et al., 2021). These researchers further claim that this is best done by using triangulation. Triangulation ensures that the data gathered from more than one source improves the study's applicability in another situation. This was done by using both file content from the previous CM study and the information gathered in the interviews. Schurink et al. (2021) further emphasise that the contextual understanding of a study enhances the extent to which the reader can associate with the lived realities of the study participants, therefore allowing transferability. The researcher thus had to continuously reflect about how her own background, culture and lived realities influence her interpretation of the findings of this study (Creswell & Poth, 2018). Being a social worker involved in FASD research for the past 14 years, the researcher became aware of the difficulties of high-risk pregnant women over time and developed a sense of the struggles of the women and how big the need for services is. The researcher, however, had to be cognisant of the fact that the study should be a true reflection of the study participants' realities and needs and not the way she interpreted it. The literature study was an important tool in reflecting and keeping an open mind. In addition, a reflective report was written after completion of the study (See Annexure J).

#### *5.3.4.2 Step 13: Write up the research findings*

The final step in the research process was writing up the research findings. Babbie (2014) states that if the findings of research are not properly communicated, the

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research is of no value. The purpose of the research report is threefold: to communicate explicit data and findings, to strengthen the existing body of knowledge and to inspire further research. Schurink et al. (2021) describe the qualitative report as more complex because is it less structured, more interwoven with the entire research process and frequently lengthier and more descriptive. This was true for the research report in this document, which aimed to provide a full picture, thick descriptions, and a contextual understanding of the lived realities of the study participants. This was done in order to guide and evoke new ideas for future social work services and to highlight the significant role social workers should play in the prevention and management of FASD as a phenomenon.

## 5.4 LIMITATIONS OF THE STUDY

Babbie (2014) states that researchers have a responsibility to point out the limitations and mistakes made in the process of their research to their readers. The limitations of this research are the following:

- This study describes the lived realities and experiences of high-risk pregnant women by presenting it as case studies. This research, however, was done five to six years after the pregnancies, during which the study participants were in case management. The lapse in time could have influenced participants' memory about factors influencing their decisions and circumstances at the time, highlighting the more pressing factors, and forgetting smaller details about that time. The lapse in time, however, had positive effects too. Study participants were more honest about their drinking during pregnancy, since they did not feel threatened or guilty about their drinking behaviour years ago. Some study participants recognised the effect of alcohol on their children and, therefore, felt the need to admit the effect of their drinking behaviour on their children.
- In addition, this was a very small sample of high-risk women in the Langeberg Municipal area, a factor which might affect the generalisability of the study. Although the study used a small sample of women in one specific area, neither the women who participated nor the area where the study was done are completely unique and are comparable to other communities in especially the WCP.

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- It should further be acknowledged that the bulk of the literature regarding FASD as a phenomenon is scientific in nature and that access to literature linking social work with FASD is limited. It was, however, possible to use the scientific literature to identify gaps in the literature regarding the role of social workers in the multi-disciplinary team.
- Another limitation is the fact that some of the literature used in this study, is dated. Recent literature was used as far as possible.
- Wearing of face masks and social distancing were imperative during the time when the face-to-face interviews were conducted. Face masks limited the researcher's ability to read facial expressions and, at times, to hear some words. However, the study participants' body language and use of colloquial expressions made amends for this limitation.

## 5.5 CONCLUSION

In this chapter, the research process according to the four phases and thirteen steps described by Fouché (2021) is reported. The process starts with the identification of a researchable topic and leads to writing the research proposal depicted in chapter one. The research methodology, ethical considerations. planning for data collection, the process of data collection and analyses followed the planning as described in this chapter. The study was not significantly affected by the Covid-19 pandemic, since the researcher was able to do face-to-face interviews as planned by following Covid-19 regulations and protocols. The pandemic had smaller effects such as limiting the observations that could be made due to mask wearing, but in general the planned process could be followed. In the next chapter, chapter six, the empirical results of this study are presented.

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# CHAPTER 6

# EMPERICAL INVESTIGATION OF STORIES OF STUDY PARTICIPANTS

## 6.1 INTRODUCTION

A discussion of the research methodology was presented in chapter five. In this chapter, the empirical findings of the data collection phase, which consisted of a combination of data obtained from study participants' case management (CM) files and semi-structured, in-depth interviews with six study participants will be presented. This represents the fourth objective of the research.

Since this study employs a qualitative research approach and aims to provide thick, vivid description of the realities of women at high risk of having a child with a contemporary phenomenon such as FASD, the findings will be presented as narratives divided into seven themes (Miles and Huberman, 1994; Yin, 2009). The themes will be further divided into two or more subthemes each and then split further into categories.

Firstly, the biographical details of the study participants and the seven themes identified, will be presented. Then, a short description of every study participant's life story will be given. In these stories, the seven themes will be identified and linked to the literature control. After that, a discussion will be presented of the themes, subthemes, and categories, verifying the data with relevant literature.

## 6.2 IDENTIFYING PARTICULARS OF STUDY PARTICIPANT

Pseudonyms were used to protect the identity of the study participants and all other individuals they named during the interviews. The first time any individual is named, an asterisk will be used to serve as a reminder that pseudonyms are used.

In Table 6.1 below, the pseudonyms for each study participant will be presented with her age at the time of the interview, her age at the time she was in CM, the number of pregnancies she had, the number of live children born from these pregnancies, her marital status, level of education and the kind of work she normally does.

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**Table 6.1: Biographical information of study participants**

| Partici-pant | Age | Age when in CM | Number of preg-nancies | Number of live children | Marital status | Level of education | Work |
|---|---|---|---|---|---|---|---|
| **1. Ansa** | 32 | 25 | 4 | 4 | Separated, co-habitate | Grade 7 | Unemployed, Farm work |
| **2. Bella** | 35 | 28 | 5 | 2 | Co-habitate | Grade 10 | Unemployed, seasonal (canning factory) |
| **3. Celia** | 36 | 29 | 3 | 3 | Co-habitate | Grade 5 | Farm worker |
| **4. Drika** | 35 | 27 | 2 | 2 | Single | Grade 11 | Farm worker |
| **5. Emily** | 38 | 31 | 2 | 2 | Co-habitate | Grade 10 | Farm worker |
| **6. Flora** | 35 | 28 | 5 | 4 | Married, separated | Grade 10 | Farm worker |

From the above table it is clear that the study participants were between the ages of 25 and 31 years while in CM, therefore considered as "older" mothers and had two or more pregnancies, of which the pregnancy in CM was at least their second pregnancy. This is in keeping with literature (May et al., 2008; May et al., 2015; May et al., 2021; Viljoen et al., 2005) and previous findings in regard to the physical risk factors for having a child with an FASD. Additionally, most of the women were not married, did not complete their schooling, and work low-income jobs (May et al., 2008; May et al., 2021). All these biographical details fit the description of high-risk factors associated with having a child with an FASD. The interviews were conducted in Afrikaans, the home language of all the study participants. The seven themes identified from the interviews with these study participants, are presented in Table 6.2 below.

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**Table 6.2: Themes identified from semi-structured interviews**

| | |
|---|---|
| Theme 1 | Childhood |
| Theme 2 | Intergenerational patterns |
| Theme 3 | Level of education and work circumstances |
| Theme 4 | The role of partners |
| Theme 5 | Pregnancies and children |
| Theme 6 | Psychological factors |
| Theme 7 | Availability of services and a need for more services |

As explained in the introduction to this chapter, the findings of the study will be presented as narratives divided into the above seven themes. In the next section, a brief "story" of the life and lived experiences of each of the study participants linked to the themes in table 6.2, will be presented.

## 6.3 STORIES OF STUDY PARTICIPANTS

### 6.3.1 Study participant 1 (Ansa*)

Ansa is a 32-year-old woman who was born on a farm in the rural area of the Langeberg District Municipality. Both her parents were farm workers who lived and worked on the farm (Theme 3, Level of education and work circumstances). Before she was born, both Ansa's parents abused alcohol (Theme 2, Intergenerational patterns). Her mother told her that they used to spend all their money on alcohol over the weekends and often did not have any food for themselves or the children on a Monday and had to struggle without food all week. This correlates with the findings of May et al. (2008) that the extended family and friends of mothers of children with an FASD are often heavy drinkers, as well as that of Le Roux (2020) stating that farm workers will not buy all the food needed for the household to be able to purchase more alcohol. However, when Ansa's mother was pregnant with her, she decided to stop drinking and never drank again. Although her father continued drinking, relationships in the household were positive and her father never was abusive. His occasional raving when he was intoxicated, did not seem to upset her much and was accepted as normal behaviour (Theme 2). Despite Ansa's acceptance and normalising of her father's

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verbal outbursts, verbal abuse, and harassment form part of the definition of domestic violence (Slabbert, 2016; Vetten, 2005).

When Ansa was 11 years old, her parents moved to town where her father found a job working for a labour broker. Labour brokers are often contracted by farmers to provide the workforce for farm work. This practise enables farmers to cut down on the cost of their workforce. Additionally, labour matters become the responsibility of the labour broker disposing the farmer of any responsibility towards the workers (Le Roux, 2020). Since Ansa's family were not eligible for housing on the farm anymore, they moved into an informal structure as backyard dwellers. Ansa remembers her childhood as difficult, poverty-stricken, never having everything they needed, going to school barefoot in winter because they did not have shoes and struggling in school because they did not have school supplies (Theme 1, Childhood). After completing grade seven, she dropped out of school because there was no money for her to go to high school (Theme 3). This is in keeping with the findings of Hall and Mokomane (2018) that children in high-risk communities have a high risk for dropping out of school. Fransman and Yu (2019) add that a lack of schooling is one of the three biggest contributors to poverty. However, despite the hardship and poverty Ansa experienced as a child, she takes pride in the fact that she did not grow up in a house with a drinking mother. One of her strongest childhood memories is that her mother insisted that one cannot drink one's problems away (Theme 2).

After Ansa left school, she started working on farms. In keeping with the findings of Boyden and James (2014), her interrupted schooling affected her ability to provide for her own livelihood. At the age of 16 she had her first drink with friends and started drinking and smoking. By the age of nineteen she was pregnant with her first child (Theme 1). Van Schalkwyk and Naidoo (2021a:12) describe dropping out of school early and falling pregnant soon after that as a "perpetuating cycle" with serious consequences for the woman and her children. Due to the influence of the community on the farm where she was working at the time, Ansa married the father of her unborn child (Theme 4, The role of partners). Her view of this situation was that she and her boyfriend were brought together by the farm community who expected of them to marry (they "had to"). Although she was not keen to speak about this marriage, file content (FC) from the time she was in CM reveals that there was inter-partner violence, which

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she attributed to her husband's jealousy when he used alcohol (Theme 3). On one occasion he even stabbed her with a knife. This confirms the opinion of Van Schalkwyk (2021) that alcohol use is often associated with domestic violence. Ansa's marriage was no exception in this regard. The marriage did not last long, and she moved back in with her parents. Although she and her husband have been living apart ever since, they never divorced.

When Ansa's child was five years old, she met her current partner on a farm where they both had temporary jobs as farm labourers. She left her child in her mother's care and moved with her partner into a two-roomed informal structure in a township backyard housing eight other informal structures. After a partnership of about three years, Ansa was pregnant again. In this pregnancy she was recruited to participate in a research study using CM as a method to support and guide women to abstain from alcohol during pregnancy by making use of Motivational Interviewing (MI) and the Community Reinforcement Approach (CRA) as discussed in chapter four. At the time of recruitment, she was 25 years old and about 13 weeks pregnant. According to FC, she admitted during her screening interview that she still drank and had seven standard drinks on one occasion during the past 30 days (Theme 5, Pregnancies and children). Literature (Anderson et al., 2014; Lafferty et al., 2016) describes drinking prior to pregnancy as the best predictor of drinking in especially the first trimester of pregnancy. This is confirmed by Ansa's drinking pattern.

During the early months of her pregnancy, Ansa's happiness about her pregnancy was interspersed with fear that her partner would reject her as she had seen happening so often to other women. Her biggest fear at the time was being left to struggle alone with another baby. This experience confirms the role the added stress unplanned pregnancies have in the mental well-being of pregnant women and the risk it adds to increased alcohol use in those pregnancies (De Jong et al., 2021; May et al., 2008). Her partner was, however, delighted about the pregnancy and supported her as best he could, also at times when she did not feel well (Theme 4). She explains her feelings as follows:

> *Jy vertrou ook nie die mansmense … party mansmense is so, hulle maak jou net swanger en dan los hulle jou net so dat jy sukkel met die kind en met die ou toelae wat die staat gee dat jy die kind daarmee grootmaak. Maar hy't nie dit gedoen nie.*

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> *Hy het my ondersteun tot nou toe ...* [You do not trust the men. Some men just get you pregnant and then they leave you high and dry to struggle with the child and raise the child with the grant the government gives. But he did not do that. He supported me and still supports me …]

Before her pregnancy, Ansa was a heavy drinker having an average of 22.7 drinks two to three times a week. In addition to this, she also drank 45.3 drinks in one drinking session once a month. This was significantly more than the mean number of 6.4 drinks per drinking occasion amongst drinkers in the Langeberg area as described by Parry and Gossage (2011). However, her drinking pattern was similar to that of a group of high-risk women participating in a case management study (May et al., 2013). In this study, the mean number of drinks of the participants were 20 in the three months before pregnancy and 19.3 in the first trimester when they were generally not aware of their pregnancies. After the screening interview for Ansa's recruitment into the CM study, she stopped drinking and remained sober for the rest of her pregnancy (FC) (Theme 5).

Being unemployed and with her partner working a temporary job with a minimal income, she often worried about money, food, basic necessities, and how they would provide for the baby (Theme 3). Literature (May et al., 2008; May et al., 2021) found all these factors associated with low socio-economic circumstances (SES) to correlate with an increased risk for having a child with FASD. In an attempt to save more money to buy the things she needed for the baby her partner gave up drinking. The couple later had two more children and is still in a stable relationship. She describes him as a person who does not talk much and does not discuss matters with her. Being from different cultural backgrounds, she does not speak his language and he communicates in Afrikaans with her and the children (Theme 4).

Ansa has a close bond with her mother who has a positive influence on her life (Theme 2). She shows great respect for her mother's sobriety, takes her mother's reprimands seriously and models her life to a large extent on her mother's way of living. Ansa admits that she was influenced by her friends when she was a young girl, but claimed that this did not happen any more (Theme 1). This correlates with literature (Mchunu, Peltzer, Tutshana & Seutlwani, 2012) stating that one in five adolescents participates

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in harmful alcohol use. Ansa now drinks with one friend only but not to the extent that she is too intoxicated to take care of her children (Theme 5). Ansa said:

> *Nee, ek het 'n vriend wat langsaan my bly. Ons drink saam. As sy nie drink nie, drink ek ook nie en as sy drink, dan drink ek ook …* [I have a friend who lives next door. We drink together. If she does not drink, I do not drink either and if she drinks, I drink too.]

After being sober during her pregnancy, Ansa started drinking again when her baby was six or seven months old. This correlates with the findings of May et al. (2013) that women usually return to slightly lower levels of drinking than prior to pregnancy after the birth of their babies. In correlation with the finding of May et al. (2016) that drinking whilst breastfeeding is a common occurrence in women who drank during pregnancy, Ansa shared how she drank alcohol while she was breastfeeding (Theme 5):

> *Ek wil nou nie lieg vir mevrou nie. Terwyl ons drink, dan borsvoed ons.* [I do not want to lie to you. While we were drinking, we would breastfeed.]

Ansa feels alienated and alone in her community where most of her neighbours are either from Zimbabwe or Xhosa-speaking, a language she has not mastered (Theme 7, Availability of services and a need for more services). She said:

> … *die mense gee nie vir mens om nie* ... [The people do not care about you …]

Fletcher et al. (2018) highlights the role of social connections in drinking behaviour and emphasises women's need for a social environment where they feel at home. Ansa found CM and being able to talk to a supportive, empathic project officer who listened to her without judgement, very helpful. Bella, Celia, and Flora shared similar experiences with their case managers. Ansa stated:

> …. *buite is nie sulke mense nie. As jy vir die mense jou probleem sê gaat die mense… die mense dinges praat daaroor. Hulle help jou nie. So is die mense*. […there are not people like that outside. If you tell other people about your problems, they talk about it. They do not help you. That is how the people are.] (Theme 7)

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Ansa sees her and her partner's lack of permanent jobs as the biggest challenge they have to deal with (Theme 3). About her own financial contribution to the household, she said:

> *My vaste inkomste is mos maar die kindertoelae. En meeste van die tyd het jy wat jy nie, soos byvoorbeeld kos en so aan dit wat jy moet, dit het jy nie. Daagliks.* [The childcare grants are my fixed income. And most of the time you do not have, for example food and things the things you must have, you do not have. Daily.]

Their financial situation and the fact that she cannot always feed her children, cause a lot of stress (Theme 6, Psychological factors). The effect of unemployment on drinking during pregnancy is described in detail in literature (De Jong et al., 2021; Urban et al., 2016). As Ansa explained:

> *Oor die kinders is so mevrou, hulle wil mos altyd brood en so hê. Nou as daar nie is nie, dan huil die kinders en jy kan hulle nie slaan nie. Hulle is darem so hulle verstaan nou nog. Soms is daar en soms is daar nie.* [The children are such, they always want bread and so. Now, if there is no bread, the children cry, and you cannot punish them. Fortunately, they understand. Sometimes there is and other times there is no food.] (Theme 3)

Despite her daily struggles to survive, her big dream for her children is for them to complete their schooling and have a better life than what she and her partner can provide for them (Theme 3).

### 6.3.2 Study participant 2 (Bella*)

Bella is a 35-year-old mother of two children who was in CM at the age of 28 years during her pregnancy with her first child. Bella was her mother's oldest child and born from a different relationship than her siblings (FC). Her biological father was murdered when she was one year old. Her mother worked in Cape Town and left Bella with her grandmother where she grew up cherished and protected by a god-fearing grandmother (Theme 1, Childhood). Growing up with grandparents as a result of parents migrating to job opportunities, is common and a generally accepted practice in SA (Hall & Mokomane, 2018). Bella described herself as her grandmother's child ('n "ouma-kind"). Despite her close relationship with her grandmother, she missed her

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mother and at a very young age started feeling the absence of a father figure (Theme 1).

Bella attended Sunday school and participated in their church's youth activities. When she was in primary school, her mother returned to the Langeberg area. This, too, concurs with the finding of Hall and Mokomane (2018) that households are dynamic and that parents may move in and out of households as their work circumstances change. Soon after her return, Bella's mother started a new relationship, married, and moved to the township where she started a new family. Shortly after Bella started high school, her grandmother died. Bella had to move in with her mother and alcohol-abusing stepfather who, by this time, had three other children together. Bella's life was turned upside down. Not only did she lose her grandmother, but she moved into a home where her stepfather abused her mother and used every opportunity to abuse and belittle Bella. According to literature (Dawson et al., 2005; May et al., 2008), traumatic life experiences such as these increase the risk for alcohol abuse. At this difficult time in her life where she already struggled to fit in with her peers, she also felt that there was no-one left who cared about her (Theme 2, Intergenerational patterns).

> *Die dag wat my ouma oorlede is toe het ek maar net gevoel ag, niemand gee om nie so hoekom moet ek die pad loop wat sy vir my gewys het, want daar is nie iemand waarnatoe ek kan gaan nie.* [The day my grandmother died I just felt nobody cares so why should I do as she taught me because I have no-one to go to.]

Bella was schooled in Afrikaans and attended a high school some distance from their home. Her stepfather refused to pay for transport, and she had to walk to school. Her daily "chore" after school was to take her stepfather's bicycle to a farm where cheap wine was sold, to buy his wine for the day. Her mother never intervened because she was too afraid of abuse. Literature (Englund, Egeland, Oliva & Collins, 2008; Slabbert, 2016) links alcohol abuse with domestic violence including child abuse. Other studies (Loudermilk, Loudermilk, Obenauer & Quinn, 2018) in turn link abuse and childhood trauma to alcohol abuse later on in life.

Bella, who excelled in athletics and netball, was selected to participate in the SA netball trials in her age group. Her mother was willing to allow her to go but, in fear of her stepfather who asked her mother who she thought would buy his wine if Bella left, her

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mother refused to sign permission and Bella lost the opportunity. She was deeply disappointed and furious with her mother and stepfather. She still feels that she could have used this opportunity to improve her life and blames her mother and stepfather for taking it from her.

Due to her difficult circumstances at home and her stepfather's refusal to support her financially, Bella left school after she had completed grade 10 at the age of 17 years (Theme 3, Level of education and work circumstances). She started working in a fruit canning factory during the apricot season and supplemented this income with seasonal work on farms. At the age of 19, she started drinking heavily (Theme 2). This, again, underscores the role of the environment in drinking patterns (Ezekwe, et al., 2019; May et al., 2000; Parry et al., 2012; Popova et al., 2018). After an incident, during which her stepfather assaulted her with a spade, she moved out of her mother and stepfather's home and back to her grandmother's house where other family members now lived. Around this time, she met her current partner, a Zimbabwean. They started a friendship, which soon developed into a relationship and moved in together in an informal structure in the backyard of the house where she grew up. Not long after that, the relationship deteriorated. Regular fighting turned into domestic violence. At the time, Bella drank heavily, and her partner used alcohol and marijuana in combination (Theme 4, The role of partners). She was also aware that he cheated on her with several other girls (Theme 4). Cohabitating with heavy drinking partners, stress and inter-partner violence are all described in literature as factors contributing to the risk of having a child with an FASD (May et al., 2008; May et al., 2021). After having had two previous miscarriages from a former relationship (FC), Bella had another miscarriage during this time. Although her partner supported her at the time, she knew that he blamed her heavy drinking for losing the baby.

Bella's fourth pregnancy was unplanned (Theme 5, Pregnancies and children). Their relationship was violent at the time and the pregnancy was characterised by physical and verbal abuse (Theme 4). Her own behaviour towards her partner was as violent and she thought nothing of stabbing him with a knife during their fights. At 8 weeks gestation, Bella was recruited for participation in CM (Theme 7, Availability of services and a need for more services). At that time, she claimed to drink only 1.4 drinks once or twice a week with 5.3 drinks on one occasion during the month before recruitment

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(FC). This information is in contrast to Ansa's reporting of her drinking which, at times, exceeded 45 drinks per drinking occasion. However, during the interview with the researcher, Bella admitted to drinking much more and that she only started cutting down on her drinking when she was five months pregnant and realised that this pregnancy was not going to go away (Theme 5). Up until that time, she now admits, she did not care how much she drank, as long as she could forget the difficulties she had to face for the moment (Theme 6, Psychological factors). This correlates with the findings of Fletcher et al. (2018) that women drink to forget about a number of factors. As Bella stated:

> *Ek het net gedrink. Net gedrink en nie vergeet nie. So môre, môre is dit maar net weer dieselfde, môre is ek maar net weer dieselfde.* [I just drank. Just drank and did not forget. So tomorrow, tomorrow things are the same, tomorrow I am the same all over again.]

The only support she felt she had during this pregnancy was her aunt and the project officer to whom she was assigned for CM (Theme 7). According to Bella, she felt an immediate connection with her case manager. This confirms Ansa's experience that she could talk to her case manager without fear of judgement and feel accepted and supported. About her relationship with her case manager Bella said:

> *Die manier waarop sy met my gepraat het, dit het my dadelik laat voel ek kan haar vertrou, ek kan jou vertel van my lewe.* [The way she talked to me immediately made me feel that I could trust her, that I could tell her about my life.]

Bella's feedback of her relationship with her case manager confirms the efficacy of respect, reflective listening and continued support offered through MI (May et al., 2016). Bella describes this pregnancy as extremely stressful (Theme 6). She saw her life, her circumstances, and the abuse she suffered as such a hopeless situation that she often wished for another miscarriage (Theme 6). Her situation reflects the link Loudermilk et al. (2018) established between childhood abuse, dysfunctional households, and alcohol abuse. Due to Bella's previous miscarriages, she attended a high-risk clinic where her pregnancy was monitored weekly, and monthly ultra-sound scans were done (Theme 7). These visits added to her stress, because she felt nothing was explained to her. Because she knew her drinking could damage her baby, she worried about her baby's health and the possibility that her child might be handicapped.

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The effects of an unhealthy lifestyle including drinking and smoking in pregnancy on the health of the baby is a reality and include risks such as low birth weight, intra-uterine deaths and even sudden infant death syndrome (SIDS), also known as cot death (Odendaal, Kruger & Botha, 2020). Other worries included if her partner would rise to the challenge and be a father to their child and if her mother would be able to love her child. However, Bella hardly allowed herself to hope for a live baby. Only after her baby was born, did she allow herself to love her baby and feel happy.

Except that she now had a newborn to care for, few things changed in her life. She found it very hurtful that her mother showed little interest in her baby (Theme 2). Violence was an engrained part of her life (Theme 4), connecting her experiences to that of Celia and Flora and correlating with literature regarding the connection between violence and drinking behaviour (De Jong et al., 2021). To add to the horror of inter-partner violence, there was an incident where her brother hit her baby on the head twice, snarling that the child should rather be dead anyway. Talking about this incident six years later was still so traumatic for Bella that she broke down and cried.

Over the years, her relationship with her partner remained troublesome. Although he has a regular job, his contribution to the household is minimal (Theme 4). Her partner regularly reminds her that he is the breadwinner and that she should be content with whatever he feels to make available for the household (Theme 3). This correlates with the description of financial violence as later discussed in theme four and confirmed in literature (Bornstein, 2006; Slabbert & Green, 2013; Slabbert, 2016). Bella's situation worsened when she had another unplanned pregnancy two years later. During this pregnancy she was so desperate that she actively tried to terminate the pregnancy by practising an old custom of drinking an extract of newspaper soaked in water, which is believed to cause a miscarriage. However, when she accepted this pregnancy, she found it easier to practise what she learned in CM during her previous pregnancy. She achieved this despite the findings of McBride and Johnson (2016) that unsatisfactory relationships negatively impact on a pregnant woman's drinking habits. Her partner's emotional absence adds to Bella's unhappiness seeing her own experiences as a child reflected in the lives of her own children who now grow up with a father who is present, but in her eyes not "a real father" (Theme 2). She feels that there is little, if any, hope that this relationship is salvable.

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However, other meaningful relationships in her life prevents her from falling back into depression, a condition she has suffered from, was treated for before (Theme 6) and is associated with maternal drinking in pregnancy (Fletcher et al., 2018; May et al., 2008). Her relationship with her mother who left her husband and now lives with her family on the same premises as Bella, her involvement in Bella's children's lives and the role she now plays as a caring grandmother, is valued and cherished (Theme 3).

### 6.3.3 Study participant 3 (Celia*)

Celia is a 36-year-old farm worker and mother of three children who was in CM during her pregnancy with her youngest child at the age of 29 years. She grew up as one of seven children of two farm worker parents. Despite both parents being weekend drinkers (Theme 2, Intergenerational patterns), she has fond memories of her childhood and her parents. She describes her father as a good, soft-hearted man who, although he drank and smoked marijuana, never got aggressive, but drank on his own and slept it off afterwards. Her view of her mother's drinking is that it did not interfere with her household or caring for the children because she always saw to it first that the household chores were done and there was food available before she would start drinking (Theme 2). As Ansa, Celia normalised her parents' alcohol and drug habits and did not acknowledge the effect it had on her own life choices. This is in keeping with literature (Englund et al., 2008) stating that the environmental influence of parental drinking may cause children to see drinking as acceptable. However, several factors such as her parents being farm workers, being one of her mother's later born children and her mother's drinking, puts Celia herself at risk for being affected by alcohol prenatally (May et al., 2008).

Celia left school after completing grade five (Theme 3, Level of education and work circumstances). Low educational attainment is a confirmed risk factor for having a child with FASD (May et al., 2008). At the time, school fees were still compulsory, and her parents could not afford to pay school fees for all the children anymore. This, again, relates to Ansa's experience of parents not being able to pay school fees and an interrupted education. This will be a recurring theme in the stories of Emily and Flora too. Celia's mother, who worked for the farmer as a domestic worker at the time, arranged with him to employ Celia on the farm and she started working as a farm labourer shortly after that (Theme 3). The generational pattern of working on farms,

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staying dependent on the farmer and being unable to live independently as described by Le Roux (2020), is thus confirmed.

Around the age of 13 years, Celia started drinking and smoking with a friend (Theme 1, Childhood). They were soon part of a larger group of friends who regularly drank over weekends. The group quickly developed a pattern of buying beers on a Friday night and drinking until they were intoxicated. Even at this young age, they started a pattern of binge drinking commonly occurring in the Western Cape Province (WCP) on Friday and Saturday nights (De Vries et al., 2015). Celia often slept over at a friend's house without her parents knowing of her whereabouts. The group's behaviour became riskier, and they started stealing alcohol from other people (Theme 1). This correlates with the literature (Englund et al., 2008) stating that externalising behaviour in youth may be connected to alcohol abuse in adulthood.

When she was 18 years old, Celia became involved with her current partner and moved in with him. She started working on another farm where they now lived on their own. Soon she was pregnant with their first child (Theme 5, Pregnancies and children). At this time there were already cracks in their relationship. Their fights were physical, both abused alcohol over weekends and Celia accuses her partner of having affairs since very early in their relationship, as well as during her pregnancy with their first child (Theme 4, The role of fathers). Their unstable relationship is in correspondence with literature (Mchunu, et al., 2012) stating that 35% of pregnant teenagers in Sub-Saharan Africa have unplanned pregnancies from unsteady relationships.

Over the years their relationship had many ups and downs. Alcohol abuse and inter-partner violence was part of their lives over weekends (Theme 2), correlating with literature linking maternal alcohol abuse and inter-partner violence (Fletcher et al., 2018). When Celia realised she was pregnant with her third child, their relationship was more stable, and they were both delighted about the new baby (Theme 3). She said:

> *Ja, hy was baie bly gewees, baie opgewonde. Ons altwee was baie opgewonde gewees en toe ek sonar toe gaan toe hulle sê dis 'n seuntjie, toe kon hy nie wag wanneer kom sy seuntjie nie.* [Yes, he was very glad, very excited. We were both very excited and when I had an ultra-sound and they said it was a boy, he could not wait for his son to arrive.]

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Shortly after her pregnancy was confirmed, she was recruited for participation in CM. At recruitment she was about 14 weeks pregnant and admitted to drinking 13.2 standard drinks two to three times per week (FC). This, once again, confirms the findings of literature that drinking prior to pregnancy is the best predictor of drinking in the first trimester (Anderson et al., 2014; Lafferty et al., 2016). The relationship Celia developed with her case manager and the information she received about the detrimental effects of alcohol use during pregnancy, motivated her to stop drinking completely (Theme 7, Availability of services and a need for more services). The significance of the support of their case managers were also mentioned by Ansa, Bella, Emily, and Flora who all felt they were heard, never judged, and continuously encouraged, thus matching their experiences in CM with the principles of MI (May et al., 2013). Celia stayed sober for the remainder of her pregnancy (Theme 3). She described how her partner stopped drinking too and their household and relationship changed for the better:

> *Nee, toe het hy opgehou drink saam met my. Nee, hy het vir my daai tyd baie ondersteuning gegee. Ek kon gevra het, want hy het my baie gehelp met als. En nou met die geboorte, toe ek die geboorte opgegee het, hy het my baie ondersteun met als, als … Daar was 'n groot, groot verskil in die huis en op my kinders. Dis amper soos my kinders hulle wil by my wees.* [He stopped drinking with me. He gave me a lot of support during that time. I could ask him because he helped me with everything. And with the birth, when I registered with the clinic for the birth, he supported me with everything, everything … There was a huge, huge difference in our home and in the children. It was almost as if my children wanted to be with me.]

Celia maintained her sobriety for four years. She even significantly cut down on her smoking and tried to give it up completely. During this time, she attended church and felt supported by her congregation (Theme 7). This experience relates to findings that religiosity is a protective factor against alcohol abuse and FASD (May et al., 2008). However, when Celia's youngest child was four years old, she discovered that her partner had a sexual relationship with a close relative (Theme 3). This was a devastating blow that sent her into a downward spiral, and she started drinking again, correlating with the findings of Dawson et al. (2005) that traumatic events increase women's alcohol consumption. With Celia and her partner now both drinking again,

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their relationship became more violent than ever before. Regular beatings and verbal abuse became their weekend norm. She described one incident:

> *Hyt my kop oopgeslaan met daai paaltjie … Hy het my geslaan dat ek gepie het in my broek.* [He beat me over my head with a small pole causing an open wound … He beat me until I wet myself.]

Celia's experience of her situation is that she is alone with very little support from her immediate community or sources in the community that are supposed to protect her (Theme 7). Celia's experience is supported by literature (Matsika, 2021; Slabbert & Green, 2013) confirming that abused women do not feel protected by community resources such as the police. Celia said:

> *Ek soek hulp! Niemand wil my help nie mevrou … Ek was hof toe. Niemand wil my glo nie. Die polisie het my al kom laai. Hulle staan nie my kant nie. Hy het my geslaan, maar as ek hier ingaan, hulle wil niks weet nie van my saak nie.* [I want help. Nobody wants to help me … I went to court. No-one believes me. The police have picked me up. They do not take my side. He beats me but when I go in to the police, they do not want to take my case.]

Celia's experience is that her life is falling apart in all respects. She has problems at work where she received a warning for absenteeism, her three young children are all presenting with behaviour problems (Theme 3), her partner's affair has caused problems between her and some of their neighbours on the farm and her own drinking is out of control (Theme 7). Despite all these problems, she expressed her desire to get help, to mend her family and to give her children an opportunity to progress in life as follows:

> *Ek … huil baie dae dan dink ek, ek wil weer daai lewe hê wat ek gelewe het al is my kinders hoe groot nou al. Ek kan nie uitstap saans, altans soggens, en kom saans weer terug en daar is 'n probleem nie. Ek wil 'n goeie huis inkom. My kinders moet in 'n goeie huis. Hulle moenie kan, saans as ek aankom, daai een is nie hier nie, daai een is nie hier nie. Hulle moet amper, hulle moet soos hulle tuis voel, hier moet liefde wees.* [Many days I cry, and I think I want to have that life I lived again no matter how big my children are now. I cannot walk out in the morning, come back at night and there are problems. I want to get back to a good home. My children must live in a good home. They must not each go in their own direction

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> and not be at home when I get back at night. They must almost, they must feel at home, there should be love in our home.]

Celia's life story portrays a myriad of risk factors for the situation she currently finds herself in. Starting out as the child of alcohol abusing, farm worker parents, having hardly any education, exhibiting externalising behaviour including alcohol use from a young age, being pregnant as a teenager and finally finding herself in an abusive relationship, contains almost all the risks for alcohol abuse described in literature (Englund et al., 2008; Garland et al., 2011; Le Roux, 2020; May et al., 2008; May et al., 2021; Mchunu et al., 2012).

### 6.3.4 Study participant 4 (Drika*)

Drika is a 35-year-old single mother of two children. She was recruited for CM when she was 27 years old and pregnant with her second child (FC). Drika grew up as the middle child of three children of a divorced mother (Theme 1, Childhood). She still lives with her mother and younger brother in a semi-attached house, to which they added a Wendy house. Her mother is a pensioner and her brother unemployed but has an income as a marijuana dealer. Although her parents were divorced, they continued living in the same house. Drika's father was a migrant worker and not home often, correlating with the findings of Hall and Mokomane (2018) that a substantial number of children's fathers are not present in their lives. Drika's mother never drank but her father abused alcohol (Theme 2, Intergenerational patterns).

Her mother later had another relationship with a man who abused alcohol too. During this time, she left the children with her brother to take care of them over weekends while she spent time with her boyfriend. This is in correlation with the concept of "kinship care" where extended families take care of children (Hall & Mokomane, 2018). Drika did not like this arrangement and was also very unhappy about her mother's boyfriend disciplining them physically (Theme 1). As a 15-year-old, she showed her unhappiness about this relationship by starting to drink with friends (Theme 1). She does not attribute her drinking at that time only to her resistance to her mother's relationship, but also to the fact that she was young and was part of a group of friends who wanted to enjoy themselves. Drinking was seen as one of the things one needs to do to enjoy yourself and she went along with that. This, once again, connects the

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role of friends and drinking as a social affair with women's drinking behaviour (De Vries et al., 2015; May et al., 2008). Drika's initial drinking with her peers relates to that of Celia, Emily and Flora who all started drinking to have fun with their friends.

When Drika was in the eleventh grade, she met the father of her first child (Theme 1). Her mother's reaction to this relationship was that if she wanted to act like a grown-up, she did not belong at school (Theme 3, Level of education and work circumstances). Although Drika's mother's reaction could not be verified in literature, the researcher in her experience as social worker, often encountered this belief amongst parents in this community. Drika explains:

> … *toe sê my ma: "Nee, as jy 'n grootmens wil wees, dan moet jy maar uit die skool want 'n grootmens kan nie op 'n skool nie. Jy behoort nie op 'n skool nie."* [My mother then said: "No, if you want to be an adult you must leave school because an adult cannot be in school. You do not belong in a school."]

Despite Drika's father trying to convince her to complete her schooling by attending evening classes, she decided to get a job (Theme 3). During her pregnancy with her first child, her boyfriend ended their relationship (Theme 4, The role of the father). This correlates with the findings of Mchunu et al. (2012) that teenage pregnancies are mostly unplanned and the relationships unstable. Drika admits that she was really hurt by him not supporting her and decided that she would raise and provide for her child on her own. Drika explained:

> *Tot nou maar toe het ek vir Philip* gesorg. Ek het altyd vir myself gesê ek gaan vir hom niks vra nie, niks. Ek werk maar vir Philip. Want hy het nie.* [Up until now, I have provided for Philip. I always told myself I am not going to ask him for anything, nothing. I work to provide for Philip. Because he did not.]

How deeply she was hurt by his rejection still shows in her determination not to allow him any space in her or her child's life and to show him that she can manage without any financial or other support from him. According to Hall and Mokomane (2018) 54% of absent fathers make no financial contribution towards their children, proving that Drika's situation is not unique. However, her resistance against claiming child maintenance through the court system speaks of a total lack of trust in the system and its ability to follow through with this process (Theme 7, Availability of services and a

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need for more services). Her feeling in this regard resonates with that of Emily as discussed in Emily's story. Drika expressed her feelings as follow:

> *Want baat dit nou ek gee hom aan? Dan bring hy nou weer einde van die maand vir 'n maand of twee dan gee hy nou weer iets, dan sê ek hy moet maar daai geld vat vir homself. Ek gaan nou nie worry met die geld nie. Hy't vir Philip nou 'n "fifty" 'n maand gegee. Toe sê ek: "Nee, hou daai geld. Ek kan vir Philip alleen sorg."* [What benefit will there be if I lay a claim? He will bring something for a month or two, so I told him to keep his money for himself. I do not care about his money. He gave Philip R50 for a few months recently. I told him: "No, keep that money. I can take care of Philip on my own."]

Despite this facade of strength and independence, her fear of another betrayal surfaced when she was pregnant with her second child (Theme 5). Drika said:

> *Die bangste was dat ek het gedink hy gaan soos die vorige een wees, nie my help nie, onbeskof wees … maar dis net meer hy het sy plig nagekom en om vir my te help.* [My biggest fear was that I thought he would be the same as the previous one, not supporting me, being rude … but he took responsibility and helped me.]

The reality of a lack of father involvement on women's drinking behaviour in pregnancy is confirmed by McBride and Johnson (2016). Drika's appreciation of her partner's support is clearly reflected in the following remark:

> *Hy was elke dag by my. Hy het saans as hy uit die werk uit kom dan kom sit hy, hy praat en hy en my ma-hulle praat.* [He was with me every day. When he came from work in the evenings, he came and sat with me. He talked to me, and he talked to my mother and family.]

He also supported her financially and took care of her needs for the baby with whatever little he had; an experience similar to Ansa's (Theme 4). Thinking back, Drika described this pregnancy as a very happy time in her life (Theme 6, Psychological factors). Drika's experience confirms the importance of the role of fathers in pregnancy, which is still often overlooked (De Vries, 2012; Olivier, 2017). Although the couple is still in a relationship, they live separate lives choosing the time they want to spend together.

When Drika became aware of her pregnancy, she thought she was around 12 weeks pregnant, but an ultra-sound a few days later, revealed that she was already 22 weeks

pregnant (FC). At the time, she was under-weight and received nutritional supplementation. May et al. (2016) describe malnutrition as a risk factor influenced by alcohol use and contributing to a range of nutritional deficiencies. Drika was also diagnosed with gestational diabetes and her way of cutting down on her sugar intake, was to drink less coffee and tea. There were no changes to her diet in general and it seems that she did not understand that taking care of her blood sugar also asked for dietary changes (Theme 7). She does not remember receiving information about alcohol use in pregnancy at the clinic either. Her only recollection of such information was a poster she saw in the clinic and the information she received in CM, correlating with the experiences of Emily and Flora (Theme 7). However, according to Odendaal et al. (2020) even detailed knowledge alone is not enough to prevent women from drinking in pregnancy and more interventions than only providing knowledge are recommended by these authors.

Up until recognition of her pregnancy, Drika drank between eight and ten standard drinks two or three times per week. This is in keeping with the findings of May et al. (2013) regarding the drinking pattern of high-risk women in CM. During CM Drika claimed to have cut down to two drinks once a month or less, but her case manager did not believe her (FC). During her interview with the researcher, she had the courage to admit that she continued drinking up to the seventh or eighth month of pregnancy. Drika’s drinking behaviour is in contrast with findings showing that problematic drinking during pregnancy was reduced by CM (De Vries et al., 2016). Although she almost always drank with friends, she never felt that she was forced to drink when she did not want to or to drink more than she wanted to (Theme 7). She now describes her motivation for cutting down in the last month or two of her pregnancy as fear for having a child with FASD. Her carefree attitude about her drinking during this pregnancy, correlates with the influence of negative attitudes towards the effects of alcohol use in pregnancy as described by Fletcher et al. (2018).

Drika experienced CM as extra support given to her during the ups and downs of a pregnancy, but had difficulty verbalising how it helped her change her drinking habits (Theme 7). This is in contrast with the experiences of Bella, Celia, Emily, and Flora who clearly expressed that the supportive and non-judgmental attitude of their case managers enabled them to speak freely about their problems. The experiences of

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support and encouragement benefitting women in CM is supported by literature (De Vries et al., 2016; May et al., 2013). Drika had more clarity about her mother's role (Theme 2), saying:

> *Sy sal nou sê: "Jy moet minder drink en kyk na jou kinders" en dit. Sy sal dit sê.*
> [She will tell me: "You should drink less and take care of your children," and so. She will tell me that.]

Although she does not always live up to it, Drika, similar to Ansa, takes her mother's advice to heart and strives to be like her (Theme 2). Despite her mother's influence, a supportive partner, and the extra support, information and guidance provided through CM, Drika drank almost throughout her pregnancy (Theme 5). This is related to the embeddedness of alcohol use as a means of relaxation and a way of life, especially over weekends, and proves that knowledge about the dangers of alcohol use during pregnancy may not be enough to change deeply engrained patterns of drinking behaviour (Falletisch, 2008; Fletcher et al., 2018). The general acceptance of Drika's drinking behaviour and even the fact that her brother deals in marijuana from their shared home, raises questions about their mother's "protection" of their unwanted behaviour and her role as an enabler of that unwanted behaviour (Theme 2).

### 6.3.5 Study participant 5 (Emily*)

Emily is a 38-year-old mother of two children who was in CM during her pregnancy with her second child. She was 31 years old at the time (FC). Emily was the older of two children born to their mother from different fathers. When Emily was born, her mother was young and worked in Cape Town (Theme 1, Childhood). She left Emily in the care of her grandmother in the Langeberg area, who took over the responsibility to raise her (Theme 2, Intergenerational patterns). This once again confirms the pattern of migrant worker parents leaving their young in the care of family to be able to earn an income (Hall & Mokomane, 2018). Although her mother came visiting once a month, she spent very little time with her child and Emily's experience was that she came home to drink with her friends and to see her boyfriend (Theme 2). The children were, however, well cared for by their grandmother, a devout Christian who saw to it that they attended Sunday school and participated in the church's youth activities. Although their grandfather abused alcohol and raved when he was under the influence of

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alcohol, it was Emily's grandmother's religious beliefs and values that stuck with her (Theme 2).

A timeline of Emily's life experiences from FC while she was in CM, revealed that her father was in prison while she was growing up. She expressed feeling ashamed and embarrassed when she had to visit him (Theme 1). When Emily's mother later moved back to the Langeberg area, the family all lived together at times. This too is in keeping with the findings regarding the fluidity of households where parents migrate trying to earn an income (Hall & Mokomane, 2018). Emily's mother later married a man Emily did not get along with. An interesting observation made was that, except for this one instance where she mentioned that her mother married, she never mentioned her stepfather again and no more information about him is available. This is in contrast with Bella and Drika who clearly voiced their dislike in their stepfathers.

When Emily was 16 years old, her mother was awarded a government-funded reconstruction and development programme (RDP) house and Emily and her brother moved in with her. This changed their way of life. Where their grandmother was strict and kept a firm hand on them, her mother allowed them more freedom and, at the age of 17 years, Emily started drinking with her friends at parties and immediately became a regular weekend drinker (Theme 1). This relates to the opinion of Englund et al. (2008) concerning an association between adolescent drinking and heavy drinking in adulthood. After passing grade 10, Emily decided to leave school and start working to add to the household income (Theme 3, Level of education and work circumstances). However, as soon as she started earning money, she started drinking heavily with her friends over weekends. Emily's actions correlate with the importance of weekend drinking and prioritising alcohol as a preferred expenditure above other necessities as described by Falletisch (2008) and demonstrated by Ansa's parents' spending pattern before her birth. A year later Emily was pregnant with her first child who was born shortly after she turned 19 (Theme 1). Her pregnancy was the result of a one-night stand. The father distanced himself from the pregnancy and did not take any responsibility (Theme 4, The role of the father). This again correlates with the view of Mchunu et al. (2012:426) that the bulk of teenage pregnancies are "unplanned, unwanted and untimed" and from unstable relationships. Emily explained:

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> *Ek het vir hom gesê, maar hy het nie "note" gevat nie. Hy het gesê hy [dit] kan nie wees nie, dit was maar net 'n "one-night stand" gewees*. [I told him, but he did not give much attention. He said it could not be, it was only a one-night stand.]

Emily never even considered trying to claim child maintenance from him, because she did not think it worth the effort or trouble (Theme 7, Availability of services and a need for more services). Her motivation for this decision, which relates to that of Drika, was:

> *Ek het nie eintlik geworry daaroor nie, want in elk geval, gaan kla jy hulle, is dit suggeld. Dis meer sugte wat hulle vir jou gee … Toe sê ek nee, ek gaan nie worry nie. Ek maak maar my eie kind groot.* [I did not really care about it because in any way, if you lay a claim, it is for "sigh money". They mostly give you sighs … So, I said, no, I am not going to worry about that. I will raise my own child.]

By this time, her mother was a sober woman and took over almost all of Emily's responsibilities towards her child (Theme 2). This allowed Emily to drink excessively (Theme 2). She now admits that not having a responsibility towards her child other than working to provide for her, enabled her alcohol abuse. Over the next 12 years, Emily was a serious weekend drinker. When she realised she was pregnant again at more or less six weeks gestation, her usual drinking consisted of 26 standard drinks once or twice a week and 29 drinks once a month (FC). Her alcohol intake was thus above the median for high-risk mothers in CM as described by May et al. (2013), as well as compared to some other study participants. Although Emily cut down on her drinking after the confirmation of her pregnancy, she only stopped completely when she was three months pregnant and entered the CM programme (Theme 7). This pattern is in keeping with literature (De Vries et al., 2015) that women normally decrease their drinking when they realise they are pregnant, but only significantly cut down in the second or third trimester of pregnancy. During Emily's screening interview for participation in CM she admitted to drinking four to five drinks on two drinking occasions in the previous week. With her next interview a week later, she had stopped drinking and never drank again during her pregnancy (FC). This brings to mind the importance of pregnancy as a "teachable moment" and FASD as a "spark topic" (May & Moran, 1995) as discussed in chapter four.

Emily was also a heavy smoker who smoked 20 cigarettes per day and managed to cut down on her smoking too. The detrimental effect of smoking during pregnancy, its

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influence on intra-uterine growth and the added possibility of pre-term labour, especially when coupled with alcohol use, is fully described in literature (May et al., 2008; Odendaal et al., 2020). Emily states that she was aware that both alcohol and tobacco use in pregnancy is detrimental for the development of the baby. She knew this from her previous pregnancy, pamphlets she received and FASD awareness programmes presented in the local primary health care clinic (Theme 7). A study by Odendaal et al. (2020) confirmed that the mere availability of information and even specific information to pregnant women is not enough to change their drinking and smoking habits during pregnancy. Emily made a conscious decision to stop drinking and claimed that the support she received in CM fuelled her motivation to stay sober. Emily's experience confirms the successful use of Motivational Interviewing (MI) in CM to guide, support and strengthen women's motivation to abstain in pregnancy, as well as the fact that knowledge about the detrimental effects of alcohol and smoking alone is not enough to change behaviour (May et al., 2013; Odendaal et al., 2020).

Another factor that made it easier for her to stop drinking, was her partner's joy about her pregnancy (Theme 4). He fully supported her decision to stop drinking and even apprehended friends who tried to influence her to drink (Theme 4). His actions relate to the view of Richter and Morrell (Sonke Gender Justice, 2018) that men who are involved with their partners' pregnancies are often deeply involved and attached to their children. Emily's drinking friends, however, did not always respect her decision and tried to influence her to drink with them. During the Christmas season shortly before her baby's birth, some friends kept nagging her to drink with them. The influence of friends and the importance of the social environment on continued drinking, is in keeping with the evidence supplied in literature (De Vries et al., 2015; Osterman, 2011). Even in this situation where she was really tempted to drink, she decided to rather buy a non-alcoholic beer to satisfy her craving for the taste of beer (Theme 5, Pregnancy and children).

Except for small discomforts, Emily had a healthy pregnancy, during which especially her high blood sugar was closely monitored by the clinic (Theme 7). Shortly before the birth of the baby it was discovered that she had too much amniotic fluid. She was hospitalised and had a caesarean section. Emily stayed sober for six months after the birth of her child before she started drinking heavily again, even while she was

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breastfeeding (Theme 5). May et al. (2016) links drinking whilst breastfeeding to a six-fold increase in the likelihood of an FASD diagnosis and advises that prevention services should be continued while women are breastfeeding to limit the damage caused by alcohol exposure. Emily's mother stepped in again and took over most of her responsibilities, causing the child to spend more and more time at her grandmother's house (Theme 2). Emily said:

> *Naweke dan wil sy nie by my wees nie want ek suip, sien mevrou.* [Over weekends she did not want to be with me because I was boozing, you see.]

After Emily's mother died, she and her partner who were both drinking heavily, lived in her mother's home. Their drinking led to regular verbal fights but never physical violence (Theme 4). Emily told how she became increasingly unhappy with her own life:

> *Ek het gedrink … ek het nie gedrink nie, ek het gesuip soos 'n vis mevrou. Ek sal nie omgee om dit te sê nie. Ek het gesuip. En dit was ek gewees.* [I drank … No, I did not drink, I drank like a sailor. I do not mind saying that. I boozed. And it was me.]

Emily's discomfort with her drinking reminds of one of the key principles of MI, whereby the negative impact of drinking is brought to a person's attention causing discrepancy and discomfort with their situation, stimulating a desire for change (May et al., 2013). While Emily was drinking with friends more than a year ago, she announced out of the blue that she was done drinking. She now describes her motivation for this decision as:

> *En ek het so gevoel, as ek so dronk lê, wat kan gebeur met my kind, sien mevrou. As ek miskien so 'n paar biere gedrink het, dan tiep ek, los ek die kind, dan speel die kind daar buite. Ek weet nie wat kan gebeur met haar nie … Dis wat my baie ongelukkig gemaak het, te veel drink en ek worry nie hoe ek lyk nie, my hare staan soos hy wil staan, so. Toe het ek eendag in die spieël gekyk en gedink ek kan nog nooit so lyk nie. Die mense het altyd gesê ek lyk soos 'n weet-nie-wat-nie. "Aerial-drade" wat hier staan! Toe sê ek "Oh no!"* [And I felt, if I am lying so drunk, what can happen to my child, you see. When I had a few beers, I passed out. I would leave the child without supervision while she played outside. I did not know what could happen to her … That is what made me so unhappy, too much drinking and

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> then I did not care how I looked. My hair was unkept. Then one day I looked in the mirror and thought I cannot look like this. The people always said I look like a "what-not". Aerial wires in all directions. Then I said: "Oh no!"]

After Emily had stopped drinking, she started praying again and found support with a small group of Christian believers who became her support system (Theme 7). Literature describes low religiosity as a risk factor for high-risk drinking (May et al., 2013, Olivier, 2017). It can thus be reasoned that practising religion will decrease risk and serve as a protective factor against high-risk drinking. This was also true for Celia, who was supported by her church during her pregnancy. Emily still relies on this group and describes a special bond between them:

> *Ons moedig mekaar aan, gee vir mekaar drukkies, so ... Ons het daai liefdesband tussen ons.* [We encourage each other, give each other hugs … We have that bond of love between us.]

Changing her drinking behaviour has changed Emily's life. She has regained her self-respect and revels in the recognition she receives for her changed life and appearance (Theme 7). This is in correlation with findings that drinking lowers women's levels of happiness and that happiness increases when they drink less or stop (De Vries et al., 2015). Emily describes the changes in her life as follows:

> *My huishouding het verander mevrou. My lewe is anderste … En baie het respek ook vir my nou wat ek nie meer drink nie en … Noudat jy nie meer drink nie, het jy niks vriende nie. Dis nou net jy en die Here. Dis nou net julle twee alleen.* [My household has changed. My life is different ... And many people have respect for me too now that I am not drinking anymore … Now that you do not drink anymore, you do not have friends. It now is you and the Lord only. It now is the two of you alone.]

She recognises a change in her relationship with her children and tells with pride how her younger daughter boasts that her mother does not drink anymore (Theme 2). However, the realisation of the damage done especially to her oldest daughter by her emotional absence during years of alcohol abuse, caught up with her when she discovered her 18-year-old daughter was pregnant (Theme 2). Literature (Loudermilk et al., 2018; Mchunu et al., 2012; Pilowsky, Keys & Hasin, 2009) has repeatedly shown the connection between dysfunctional households, parental alcohol abuse and the

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risks it poses to children from these households. Realising her part in her child's decisions, Emily explain her feelings as follows:

> *Weet mevrou, as ek nou 'n beter ma gewees het, sou dit miskien nou ook nie gebeur het nie, sien mevrou. As ek nou nie meer miskien gedrink het of so nie.* [You know, had I been a better mother, it might not have happened, you see. If I maybe did not drink or so anymore.]

However, her changed lifestyle had a positive influence on this daughter who stopped drinking and smoking in her pregnancy (Theme 2). Despite her partner still drinking, Emily has not given up hope that he might change his ways too and states that she prays for him daily. About the possibility of drinking again, she was quite clear, saying:

> … *daai is nie meer in my gene nie. Ek wil nie eers meer daar wees waar ek gewees het nie … Huh-uh … ek sal nie weer daarnatoe gaan waar ek gewas het nie*. […that is not in my genes anymore. I do not even want to be there where I was before … Oh no, … I will not go back to where I was before.]

After many years of heavy drinking and irresponsible living centred around her drinking, Emily now sees herself as living in accordance with the education her grandmother gave her and being able to pass it on to her children. Despite living with a heavy drinking partner, she stays sober by reminding herself of the way things were when she drank and leaning heavily on her faith and the small group of believers supporting her. A very interesting factor is the change in Emily's self-esteem as she started experiencing respect and recognition from her community for her sobriety. This experience can be linked to the opinion of Fletcher et al. (2018) that, to change drinking behaviour, interventions changing non-drinking support systems are needed as well as that of Van Schalkwyk and Naidoo (2021a) indicating the need for both peer and community support for mothers.

### 6.3.6 Study participant 6 (Flora*)

At the time of the interviews, Flora was 35 years old and the mother of four children ranging between 19 and two years old. She had five pregnancies, of which one ended in miscarriage (Theme 5, Pregnancies and children). This is in keeping with findings that mothers who drink and smoke in pregnancy have an increased risk for stillbirths,

miscarriage, and placenta abruptio (Odendaal et al., 2020). Flora participated in the CM programme during her fourth pregnancy when she was 28 years old (FC).

Flora is the youngest of five children her mother had from three different relationships. She lived with both her parents in Cape Town when she was very young. At the time, her father was unemployed and a stay-at-home dad who took care of the children while their mother worked (Theme 1, Childhood). He abused alcohol and even sold their belongings to fund his drinking habit (Theme 2, Intergenerational patters). After her father assaulted her mother with a panga during a fight, Flora's mother sent her to live with her grandparents in the Langeberg area (Theme 1). Her father disappeared, and they only found out years later that he had a wife and two children in another province to whom he returned. Flora's early years can thus be linked to several adverse and traumatic events as described by Loudermilk et al. (2018).

When Flora's mother moved back in with her parents and found a permanent job in the Langeberg area later, the family lived in the township. Similar to Emily, Flora thus grew up moving between the care of her mother and grandmother and at times with both, thereby demonstrating the diversity and fluidity of families in SA (Hall & Mokomane, 2018). Flora attended an Afrikaans school in another residential area but struggled at school (Theme 3, Level of education and work circumstances). She had a strong bond with both her mother and grandmother (Theme 2). Although her grandmother never drank, she sold wine and marijuana from their home (Theme 2). This provided Flora with the opportunity to start experimenting with alcohol at an early age (Theme 1). This is in correlation with literature (Englund et al., 2018) stating that factors such as parenting practices and parental alcohol use contribute to behaviour problems in childhood and early onset of drinking in teens. Flora explained her experience as follows:

> *En soos, kan ek nou sê met my ouma wat wyn verkoop het, raak ons nou eintlik groot in daai huis wat sy verkoop wyn. Dis amper om te sê laat ons ook nou maar toetsproe hoe proe wyn want ouma het dit verkoop … Want al die mense het daar gekom wat wyn drink, wat daar sit en drink.* [And can I say that with my grandmother who sold wine, we grew up in that house where she sold wine. It is almost as if we had to try how the wine tasted because grandma sold it. … All the people who drank came to sit and drink there.]

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Flora was only 12 years old when she started taking wine from her grandmother's stock to drink with a friend (Theme 1). The two of them developed innovative ways to prevent her grandmother from finding out that they took her wine as well as getting hold of more alcohol. Flora told how her friend encouraged her to take her grandmother's wine saying:

> "… *steel daarso 'n bietjie wyn. Ouma sal nie weet nie, gooi water in," so.* ["… steal a little wine there. Your grandmother will not know, add water to fill up the wine," like that.]

Flora's behaviour become more daring over the years, and she would lie to her mother to get money to fund her drinking with friends. This correlates with Englund et al. (2018) stating that externalising problems of conduct in childhood are linked to drinking early in adolescence. This behaviour of Flora is contradictory to that of Bella, Drika, and Emily who all drank at a young age, but only started drinking heavily after they earned their own money. Only Celia admitted that she too was part of a group that stole wine and harassed others, confirming the role of social connections in drinking behaviour (Fletcher et al., 2018; May et al, 2008). Flora stated:

> *As my ma vir my sente gegee het, moes ek nou nog gelieg het vir haar die skool soek geld… Dan gee ek dit nou vir my vriende. … en, soos ons dronk geraak het, dan besluit hulle nou hulle gaan nou die mense se geld afvat of hulle gaan nou iemand seermaak.* [If my mother gave me money, I had to lie to her and tell her that the school wants money … I would then give it to my friends... And as we got drunk, they would decide to take people's money or to assault someone.]

Flora was 15 when she got pregnant (Theme 1) and just turned 16 when her first child was born (Theme 5, Pregnancies and children). Not long after her baby's birth, her mother died. Flora's whole life changed because she had no support system left. She reflected:

> … *maar toe my ma afsterwe toe "change" alles. Toe het als verander*. [… but when my mother died, everything changed. That was when everything changed.]

At the time, there was no family who could assist Flora and her brother. Both Flora and her brother, who was in his final year in high school, left school to support themselves (Theme 3). Flora's boyfriend also left school to earn an income to support her and the

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baby (Theme 4, The role of the father). This relates to the experiences of Ansa, Drika and Emily, who also left school to either support themselves or contribute to the household income. After Flora moved in with her boyfriend and his family, abuse at the hands of her boyfriend started (Theme 4). The accumulative effect of Flora's economical and emotional dependency on her partner combined with their alcohol abuse, correlates with findings about the complex connections between dependency and domestic violence (Bornstein, 2006, Matsika, 2021, Slabbert, 2016). Flora's second pregnancy ended in a miscarriage after her boyfriend beat her up with a knobkierie (club) and kicked her in the stomach. This correlates with research that has shown that there is an elevated risk of domestic violence between pregnant women and their partners (Eaton et al., 2012; Matsika, 2021), as well as with research indicating that mothers with children on the FASD spectrum more often reported physical assault (May et al., 2008).

Despite their relationship problems, the ongoing abuse, and the fact that Flora knew that he had affairs with other women, the couple got married (Theme 4). Around three years after their civilian marriage, the couple had a traditional wedding ceremony too. Flora was not happy in the relationship, but felt trapped because she had nowhere to go and nobody else to support her (Theme 6, Psychological factors), linking her situation and feelings to that of women in abusive relationships (Matsika, 2021; Slabbert, 2017). About her wedding day, she said:

> *Toe gaan ek eers na my ma se graf toe, toe gaan huil ek daarso. Toe sak hy nou vir sy familie af: "Ag as sy nie wil nie, ek kan beter kry ..." Maar in my gedagte voel ek, as hy nou 'n ander vrou gaan vat, dan waarnatoe gaan ek met my kinders?* [I then went to my mother's grave first and cried there. He then said to his family: "If she does not want to; I can get better …" But then I thought, if he takes another wife, where will I go with my children?]

During the ceremony, her husband's family made it clear that she was not accepted by the family (Theme 7). Flora said:

> *Hulle het my "getreat" soos 'n hond daai dag daar … maar ek weet in hulle "culture treat" hulle die vrou soos 'n prinses … Maar hulle het nie dit gedoen aan my nie.* [They treated me like a dog that day… in their culture, I know that they treat the wife like a princess … But they did not do that for me.]

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She still feels that the family still does not value her and treats her as unworthy (Theme 4). This is in keeping with literature (Matsika, 2021; Slabbert, 2010; Slabbert et al., 2020) stating that women in some cultures are still seen as inferior to men. Flora stated:

> *Die verskil, soos hy het my getrou, hy het nie vir my gaan betaal nie … Soos hulle dit noem in hulle "culture", ek was maar net 'n hoender. 'n "Spring chicken" gekoop.* [The difference is, when he married me, he did not pay for me … As they call it in their culture, I was just a chicken. He bought a spring chicken.]

When Flora was pregnant again, she thought that giving him another child after their traditional wedding would change things for the better (Theme 5). Unfortunately, not only did the abuse continue, but he also started an affair (Theme 4). Though she knew that he had previous affairs, his actions this time hurt her more than it did in the past because they were married (Theme 5). Flora's feelings at the time are in keeping with literature describing affairs as a form of emotional abuse (Matsika, 2021; Slabbert & Green, 2013). As Flora said:

> *Hy het my emosioneel seergemaak. So, dis met als het hy my seergemaak.* [He hurt me emotionally. So, he hurt me in every way.]

When Flora entered the CM programme at around 12 weeks' gestation, she admitted to drinking 23.6 drinks per drinking occasion three to four times per week in the first trimester and 36.3 drinks once or twice a week when she drank more than usual. This heavy drinking correlates with findings of May et al. (2013) that the mean number of drinks for women in CM was 20 per week in the three months prior to pregnancy and 19.3 during the first trimester. During CM Flora claimed that she stopped drinking, except for a few special occasions such as her birthday, Christmas, and New Year's Day (FC). During the research interviews, she now admitted that she drank heavily throughout her pregnancy, confirming findings about the effect of the environment, unstable relationships and drinking fathers on a pregnant woman's drinking behaviour (May et al., 2008; Symons et al., 2018). Thus, Flora voiced her feelings (Theme 5):

> *Vir my het dit gevoel hier's niemand wat omgee vir my nie, so ek drink maar. Vir my het dit gevoel, al kom ek iets oor of die kind iets oor, ek worry nie. So het ek gevoel.* [To me it felt as if there is no-one who cares about me, so I drink. To me it felt that, even if something would happen to me or the child, I do not care. That is how I felt.]

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The support she received from her case manager made her realise that she needed to change (Theme 7, Availability of services and a need for more services). Except for her case manager, she had no-one to talk to (Theme 6). Flora shared this experience with Bella who also relied on her case manager to listen to her and to feel heard. As described in literature (Pallito, Garcia-Moreno, Jansen, Heise, Ellsberg& Watts, 2013), both Flora's mental and physical health were affected by her circumstances. She suffered from hypertension attributed to stress and used medication for both conditions (Theme 7). Flora reflected:

> *… ek het ook berading geloop maar ek, ek dink ek het net mevrou, twee of drie maal gesien daai tyd en toe het ek dit gekanselleer. Toe het die dokter my mos reeds op strespille gesit want hy is nie van nou af so nie. Hy is van daai tyd af wat ons begin saamleef is hy so.* [I also went for counselling, but I think I only went two or three times before I cancelled it. At that time the doctor already had me on medication for stress because my husband is not like this since yesterday. He is this way since we started living together.]

The birth of their daughter did not change anything in their lives. The ongoing abuse was not limited to Flora only. Especially her second child was abused physically and emotionally. This is in keeping with findings that children in homes where there is domestic violence are at high risk for abuse (Slabbert, 2010). Flora said:

> *Hy het haar baie geslaan of hy vat haar, hy gooi haar sommer teen die muur, so. Maar ek het maar nou stilgebly want ek weet nou nie watter kant toe om te gaan nie*. [He would beat her a lot or he would pick her up and throw her against the wall. But I kept quiet because I did not know where to go.]

Flora's reaction to the abuse of her child corresponds with that of Bella's mother who did nothing to protect her from abuse for fear of her own life. This life of abuse and violence had a serious effect on all the children in Flora's household. A few years ago, Flora's oldest son reached breaking point and tried to beat up his father (Theme 3). The accumulative effect of adverse childhood events (ACE) such as exposure to domestic violence as a potential confounder to psychiatric disorders, is recognised in literature (Machisa, Christofides & Jewkes, 2016; Matsika, 2021). The child's distress is clear from Flora's account:

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> *… toe lig hy sy hande op vir sy pa. Toe sê hy vir sy pa: "Ek is moeg wat jy doen aan my ma. Jy 'abuse' haar." Hy was daai tyd 15 ...* [… he then lifted his hands against his father, and he told him: "I am tired of what you are doing to my mother. You abuse her." He was 15 at the time …]

Flora regrets the effect of her drinking on the child she expected when she was in CM (Theme 3):

> *Soos nou voel ek baie spyt, want ek kan sien dit het haar breins "getouch." Sy is baie stadig op skool en sy praat die woorde bietjie swak ... Maar die tyd wat sy nou gebore raak, toe begin ek nou eers lief raak vir haar. Maar die tyd wat ek gedrink het, ek was swanger met haar, toe worry ek eers nie. Maar nou voel ek dit raak nogals aan my.* [Like now I feel very sorry because I can see that it "touched" (affected) her brain. She is very slow in school and her speech is poor ... I only started loving her after she was born, but during the time when I drank while I was pregnant with her, I did not even care. But now I feel that it affects me.]

About the effect the domestic violence has on herself, Flora's response was:

> *Dit breek my*. [It breaks me.]

Flora finds herself in a powerless and hopeless situation. Years of abuse, humiliation, and poor decisions stripped her of her dignity, and her physical and mental health. Yet, similar to Emily, she decided to not go back to the same circumstances she came from. However, other than Emily, Flora needs a variety of services and interventions including social work, mental health, health and legal services to support and guide her to rebuild her life and that of her children (Matsika, 2021; Slabbert & Green, 2013; Slabbert et al., 2020).

## 6.4 THEMES

The stories and responses of the study participants to the questions were categorised into the seven themes identified in table 6.2. Each theme was verified against literature and further broken down into sub-themes and categories. The themes were identified from narratives repeated by the study participants and against the backdrop of the biopsychosocial model as described in discussed in chapter three, allowing discussion

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of biological, psychological, and social factors, which influenced the lives and experiences of the study participants.

Theme 1, "Childhood", was divided into three sub-themes, each with two or three categories. Theme 2, "Intergenerational patters", has two sub-themes, one with one category and the second with three categories. Theme 3, "Level of education and work circumstances," has three sub-themes, each with two or three categories. Theme 4, "The role of partners" consists of two sub-themes, of which the first has seven categories and the second three. The fifth theme was broken down into three categories, whereas theme six "Psychological factors," has two sub-themes with two and three categories respectively. Theme seven was divided into five sub-themes with one, two or three categories each. These themes, sub-themes and categories are presented in Table 6.3 below.

**Table 6.3: Themes, sub-themes, and categories**

| THEMES | SUB-THEMES | CATEGORIES |
|---|---|---|
| 1. Childhood | 1.1 Instability | a. Single mothers |
| | | b. Different caretakers |
| | 1.2 Childhood trauma | a. Death of a caretaker |
| | | b. Abuse and/or rejection |
| | | c. Poverty |
| | 1.3 High risk behaviour | a. Early onset of drinking |
| | | b. Influence of friends |
| | | c. Teenage pregnancies |
| 2. Intergenerational patterns | 2.1 Drinking patterns | a. Weekend binge drinking |
| | 2.2 The role of mothers or grandmothers | a. Influence on drinking behaviour |
| | | b. Support or a lack thereof |
| | | c. Support in caring for the children |
| 3. Level of education and work circumstances | 3.1 Early termination of schooling | a. Financial reasons or school fees |
| | | b. Parents' attitude towards schooling |
| | 3.2 Permanent jobs or incomes | a. Unemployment |
| | | b. Seasonal jobs |
| | | c. Farm work |
| | 3.3 The circle of poverty | a. Children with learning or behavioural difficulties |

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| THEMES | SUB-THEMES | CATEGORIES |
|---|---|---|
| | | b. Hope to break the cycle |
| 4. The role of partners | 4.1 Support or a lack thereof | a. Partners' reaction to pregnancy |
| | | b. Abandonment / Breaking off relationships |
| | | c. Affairs |
| | | d. Emotional support |
| | | e. Financial support |
| | | f. Alcohol and/or drug abuse by partners |
| | | g. Cultural differences |
| | 4.2 Domestic violence | a. Physical violence |
| | | b. Emotional violence |
| | | c. Financial violence |
| 5. Pregnancies and children | 5.1 Unplanned pregnancies | |
| | 5.2 Drinking in pregnancy | |
| | 5.3 Drinking whilst breastfeeding | |
| 6. Psychological factors | 6.1 Depression | a. Defaulting on treatment |
| | | b. Views of psychological services |
| | 6.2 Hopelessness | a. Nowhere to go |
| | | b. Circumstances stay the same |
| | | c. Nobody cares |
| 7. Availability of services and a need for more services | 7.1 Health services | a. Primary health care services |
| | | b. A need for communication |
| | 7.2 Mental health services | a. A need for interventions |
| | 7.3 Legal services | a. SAPD |
| | | b. Protection orders |
| | 7.4 Social services | a. Perceptions of social work services |
| | | b. A need for practical help |
| | | c. A need for counselling for children |
| | 7.5 Community support | a. Family support |
| | | b. Disposition of the community and its resources |

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### 6.4.1 Theme 1: Childhood

Borrell-Carriò et al. (2004:578) state that a person's story is simultaneously a testimony of their lives, "the here-and-now enactment of their life trajectory" and information that can be used to formulate a treatment plan. For this reason, the importance of childhood experiences as part of the life trajectory of the study participants and the influence thereof on their later choices, will be presented and argued below.

#### *6.4.1.1 Theme 1- Sub-theme 1: Instability*

Although information about their childhood was not collected as a specific theme in the semi-structured interviews, all the study participants talked about their childhoods when asked to tell the researcher more about themselves in the introduction, as well as in their descriptions of the kind of household, its knowledge, attitude, and beliefs about alcohol use, they grew up in. Four of the six study participants grew up with single mothers and also had different caretakers during their childhood. These factors, and dysfunctional households, can result in risky drinking behaviour in adults (Loudermilk et al., 2018). Subtheme 1.1 was divided into two categories, namely single mothers, and different caretakers.

***a) Category: Single mothers***

The following table contains quotations of study participants about being raised by single mothers.

**Table 6.4: Single mothers**

| Theme 1: Childhood | | |
|---|---|---|
| **Sub-theme 1** | **Category** | **Quotes from interviews** |
| Instability | Single mothers | Drika: *…hulle was al vir 15 jaar geskei.* [They were already divorced for 15 years.]<br>Bella: *… ek kan maar sê ek was my ouma se kind. Ek het by haar grootgeword, my ma het gaan werk…* [I can say I was my grandmother's child. I grew up with her, my mother left to work.]<br>Emily: *My ma het maar jonk gewees op die ouderdom, sy was jonk. Op 20 het my ma my broer gekry ja. En toe het my ma gaan werk in die Kaap.* [My mother was at a young age; she was 20 years old when she had my brother. And then she went to work in Cape Town.] |

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These quotes from the interviews show that several of the study participants' mothers were single mothers, either by divorce, or were unmarried and forced to leave their children in their mothers' care to earn a living wherever they could find jobs. This correlates with findings of the Human Sciences Research Council, stating that most South African children do not grow up in nuclear families (Sonke Gender Justice, 2018). Furthermore, this report states that only 20% of children in SA grow up in nuclear families, 7% grow up in households where only one parent lives with their children and 70% grow up in extended households with a parent or parents and other members of the family.

Two of the study participants were left in the care of grandmothers while their mothers lived elsewhere to earn an income. Hall and Mokomane (2018) state that many grandparents accept the responsibility to take care of grandchildren to enable parents to earn an income. Van Schalkwyk and Naidoo (2021a) are, however, of the opinion that a healthy mother-child relationship is never established in many of these cases because grandmothers tend to take over the mother's responsibility to raise her children. This was true in the cases of Bella and Emily who grew up with their grandmothers who took over all parental responsibilities for them as children and provided them with care and stability. Moving from their grandmother's care back to their mothers disrupted their lives. This will be discussed and explored in greater detail in the second category of this sub-theme "different caregivers", following below.

***b) Category – Different caretakers***

Some study participants were moved between their mothers and grandmothers or were left with family members to raise them. This was due to working conditions, because their mothers had started new relationships or even to protect the children against domestic violence as in the case of Flora, who said:

> *Gelukkig het my ouma nog gelewe … En toe het my ma ons gevat daar na [my ouma] toe.* [Fortunately, my grandmother was still alive … My mother then took us to my grandmother.]

Hall and Mokomane (2018) state that, although the perception of family may differ, children need functional families to prosper. The dynamic nature of families these authors further refer to, is demonstrated by the fact that Flora, Emily, and Bella were

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primarily raised by their grandmothers and later moved back to their mothers' care. Drika's mother, on the contrary, took care of her children during the week but left them in the care of family over weekends to be with her boyfriend.

Hall and Mokomane (2018) state that households are not static and that parents, especially migrant worker mothers, may move in and out of households and stay an integral part of their children's lives by contributing financially and participating in the decision-making about the child. These authors further describe it as a normal occurrence in SA communities that children are left behind by their mothers or sent to be cared for elsewhere. It can, however, be reasoned that despite this practice being normal in SA, it still had disruptive and, in some cases, even traumatic results for the participants in this study. The different impacts such arrangements can have, is shown in Flora and Emily having good relationships with their mothers, while Bella was severely traumatised by her grandmother's death and being moved back to her mother and her abusive husband. She felt that nobody cared about her anymore and later on attributed her depression to this traumatic move*:*

> *Die dag wat my ouma oorlede is toe het ek maar net gevoel ag, niemand gee om nie ...* [The day my grandmother died I just felt that nobody cares anymore…]

In the next section, childhood trauma as a second sub-theme will be analysed and discussed.

#### *6.4.1.2 Theme 1 – Subtheme 2: Childhood trauma*

ACEs and psychological stress are proven risk factors for alcohol abuse in adulthood (Machisa et al., 2016; Strine, Dube, Edwards, Prehn, Rasmussen, Wagenfeld, Dhingra & Croft, 2012). Other studies showed an increased risk for alcohol dependence in persons who experienced two or more childhood traumas (Pilowsky et al., 2009). The sub-theme of childhood trauma is further divided into three categories: death of a caretaker, abuse and/or rejection and poverty as discussed below.

#### *a) Category – Death of a caretaker*

Several study participants experienced the death of their primary caretakers. Bella's feelings when her grandmother, whom she accepted and loved as a mother, died, can be described as abandonment and feeling lost. She said:

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> *Toe my ouma oorlede is, … was daar is nie iemand waarnatoe ek kan gaan nie.* [When my grandmother died, … there was no-one I could go to.]

Flora, who first lost her grandmother and later on also her mother, experienced her mother's death as the time where her whole life changed for the worst, and described her feelings as follows:

> *… maar toe my ma afsterwe toe "change" alles. Toe het als verander.* [… but when my mother died, everything changed. Then everything changed.]

As indicated in the previous sub-theme, both Bella and Flora's circumstances changed completely after the death of their primary caretakers. Bella was moved to a household where alcohol abuse and domestic violence was rife, and Flora had to leave school and became a victim of inter-partner violence herself. Despite their loss, none of the study participants received any form of therapy or counselling.

The death of a parent is viewed in literature (Machisa et al., 2018; Pilowsky et al., 2009) as an ACE increasing the risk for mental health problems. Ntuli, Sebola and Medeba (2020) agree when stating that maternal death impacts on the psychological wellness of children and may result in continuous pain and sorrow, resentment towards their mothers for passing on and feelings of hopelessness after their mothers' deaths. These authors recommend that grief counselling should be offered to all orphans. The scope of children orphaned by the death of their mothers is contextualised by Hall and Mokomane (2018) saying that in 2017, 5% of SA children were orphaned by the loss of their mothers. Findings in literature (Berg, Rostila & Hjern, 2016; Machisa et al., 2016), showing an increased risk for depression following maternal death, could offer some insight in Flora and Bella's experiences. It also extends the role of social workers from merely providing alternative placement to orphaned children to also providing grief counselling or finding suitable support services.

#### *b) Category – Abuse and/or rejection*

Research (De Jong et al., 2021) confirms the role of childhood trauma as a contributing factor in the drinking behaviour of pregnant women, correlating with the experiences of study participants who described traumatic childhood experiences:

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Bella: *… my ma het ’n man gevat en getrou daar. Hy was ook maar baie stief met my.* […my mother married a man there. He was very hard on me.]

Flora*: En daar het hulle aangegaan en gestry en daar het my pa toe my ma gekap met die panga.”* [They were fighting and arguing, and then my father assaulted my mother with a panga.]

Of particular concern was that these traumatic experiences were shared very matter-of-factly as unpleasant experiences in their childhood. Violence and abuse were normalised as evident in Drika’s words:

> *… my ma toe ’n ander kêrel ontmoet. Hy was ook partykeer … hy het ook ’n drinker maar hy het ons versorg en hy was partykeers … Hy het aan my geslaan.* [… my mother then met another boyfriend. He was also sometimes … he was a drinker too, but he took care of us, and he sometimes was … He beat me.]

Pilowsky et al. (2009) state that the risk for depression and anxiety is increased by the level of exposure to ACEs. These authors add that two or more such events create an augmented risk for alcohol dependence. ACEs are further associated with binge-drinking and post-traumatic stress disorder (Loudermilk et al., 2018; Machisa et al., 2016). This rings true in the cases of Bella, Drika and Flora who continued binge-drinking in pregnancy despite interventions to change their drinking behaviour. The category, “poverty,” is discussed next.

***c) Category – Poverty***

Poverty is a stark reality in SA with half of the population living in poverty and the situation deteriorating (Francis & Webster, 2019). According to De Jong et al. (2021) poverty exacerbates social problems such as substance abuse, inter-partner violence, the stress of unwanted pregnancies and stressful life experiences in general. Van Schalkwyk and Naidoo (2021a) add to this when stating that poverty is one of the meaningful obstacles complicating the task of parents. Not only does poverty undermine parenting, but it prevents parents from providing in the basic needs of their children and ensuring their access to a good education (Van Schalkwyk & Naidoo, 2021b). Poverty in childhood, as well as current poverty were part of the narratives of participants in this study:

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Ansa: *Maandae as hulle moet werk toe gaan en die kinders moet skool toe gaan, my oudste broers en suster, dan is daar nie kos nie.* [On Mondays when they had to go to work and the children had to go to school, my older brothers and sisters, there was no food.]

About her current situation, Ansa said the following:

> *Oor die kinders is so mevrou, hulle wil mos altyd brood en so hê. Nou as daar nie is nie, dan huil die kinders … Soms is daar en soms is daar nie*. [The children are such, they always want bread and things. Now if there is not, the children cry … sometimes there is and other times there is not.]

Bella described similar experiences in her childhood:

> *Ek moes maar in die reën, winterreën en somer so skool toe loop en sy ander seun ry die bus. So daar was nie geld vir my nie.* [I had to walk to school in the rain, winter rain and summer, walking to school while his other son took the bus. So, there was no money for me.]

Bella's situation differed from Ansa's in the sense that Ansa's parents did not have more to give while Bella was denied some of her basic needs, thus qualifying her experience as abuse (Slabbert & Green, 2013). Her current life circumstances are not much better as she is dependent on her partner to provide for her and again subjected to financial violence as also described in literature (Machisa, 2016; Matsika, 2021; Slabbert; 2016). This aspect will be described in more detail in theme four. Bella expressed her experience as follows:

> … *ek is maar 'n seisoenwerker so ek moet maar aanvaar wat hy gee want praat ek nou, dan vat hy nog daai bietjie dan kry ek glad niks*. [… I am only a seasonal worker, so I have to accept whatever he gives because if I say anything, he takes even that little bit and then I get nothing at all.]

As previously discussed in the category "death of a caretaker", Flora experienced similar problems after her mother had died:

> … *daar was nie mense wat kan help nie. Ons het die skool gelos.* [… there was nobody who could help. We left school.]

Their financial situation while she was with her husband was equally difficult. She said:

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*Hy werk en hy pay R800, maar hy bring vir my R400 en vir drie maande het hy nie gewerk nie dan werk ek in die winter.* [He works and he pays R800, but he only gives me R400 and for three months he did not work and then I worked during the winter.]

These experiences correlate with findings in literature stating that mothers of children with FASD are in even worse socio-economic circumstances than mothers of control children in poor socio-economic circumstances themselves, stressing the importance of social work and other services to families living in poverty (May et al., 2008; May et al., 2021; Slabbert et al., 2020). The third sub-theme, high-risk behaviour, will be analysed and discussed below.

#### *6.4.1.3 Theme 1 – Sub-theme 3: High-risk behaviour*

ACEs impact on various factors such as substance abuse disorder, anti-social personality, conduct disorder, other mood disorders and inter-partner violence later on in life (Machisa et al., 2016; Pilowsky et al., 2009). Research has also shown that children who externalise behavioural difficulties are prone to start drinking earlier in adolescence (Englund et al., 2008). Study participants' narratives included a variety of examples of externalising behaviour challenges, which will be analysed and discussed in this section. The sub-theme high-risk behaviour is further divided into three categories namely, early onset of drinking, influence of friends and teenage pregnancies.

#### *a) Category – Early onset of drinking*

Englund et al. (2008) state that understanding childhood and adolescent substance abuse patterns is crucial to understanding those patterns in adulthood. When asked, several study participants in this study admitted that they started drinking at a young age. This correlates with findings (May et al., 2008) that heavy drinking women frequently started drinking at a young age. These findings were confirmed by the following narratives of participants:

Celia: *Ek skat my seker so 13. Ja, ek skat my daar rond.* [I guess I was about 13. Yes, I estimate around that age.

Flora: *Ek was 12 jaar oud.* [I was 12 years old.]

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Emily: *Ek was 17 … Nee, ek het sommer vas begin drink.* [I was 17 … No, I started drinking regularly immediately.]

May et al. (2008) explain that mothers of children with FASD in SA are younger than in developed countries. This is, however, not contributed to earlier onset of drinking but to the extent and consistency of binge-drinking paired with the number of pregnancies at a young age. In most instances, this early onset drinking can be linked to the influence of friends. This corresponds with the findings of Englund et al. (2008) who state that peer factors are an important ingredient of adolescent alcohol use. The influence of friends will be discussed in the next category.

***b) Category – Influence of friends***

Friends played an indisputable role in study participants' initiation into drinking. Adolescent drinking decisions are influenced by friends' alcohol use, peer competence, defiance, and personality traits such as hyperactivity, conduct disorder and impulsivity (Englund et al., 2008; Longmore, Sevareid, Manning, Giordano, Clemens & Taylor, 2022). Englund et al. (2008) elaborate on peer competence by saying that adolescents who feel more competent between peers tend to drink more versus those who feel less competent. In this study, some participants saw drinking as being daring by doing the things grown-ups do while others thought they were just having fun with friends. This is depicted in the narratives of study participants in Table 6.5 below.

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**Table 6.5: The influence of friends**

| Theme 1: Childhood | | |
|---|---|---|
| **Sub-theme 3** | **Category** | **Quotes from interviews** |
| High-risk behaviour | Influence of friends | Celia: *… die mense wat langsaan ons gebly het… en toe het ek ook gesien die meisietjie drink want ek het nie gedrink nie. Die meisietjie drink, nou ek gaan ook nou drink…* [The people who lived next to us… and I saw the girl drank and I did not drink. The girl drank, so now I am going to drink too…]<br>Flora: *Ja, daar was 'n maatjie... Nou, dan sê ek vir haar ek wil nou probeer hoe die mense dit doen. Dan sê sy "Kom ons doen dit."* [Yes, there was a friend… Now I would say to her I want to try doing what the other people do. Then she would say: "Let's do it!"]<br>Drika: *Ons vriendekring begin te drink en, hoe kan ek nou sê… lekker tye tesaam het ons gehad*. [Our circle of friends started drinking and, how can I say… we had good times together.]<br>Emily: *Dit was mos nou agter vriende aan. Vriende drink, jy wil mos nou inpas by vriende*. [It was because of friends. Your friends drink, so you want to fit in with your friends.] |

These quotes mirror the narratives of the drinking experiences of adolescents in a study by Van Schalkwyk (2021). Women in this study described adolescent behaviour and decisions they now thought "stupid". This included alcohol use and smoking, leaving school and risky sexual behaviour leading to teenage pregnancies. This correlates with Falletisch's (2008) statement that adolescent drinkers look for instant gratification, which easily develops into a drinking culture in a peer group. Mchunu et al. (2012) emphasise the extent of this problem when they point out that almost one in five adolescents use alcohol at hazardous levels. This highlights the importance of interventions at an early age and the fact that peer influence could be utilised as a positive tool in prevention and intervention efforts. In the next category, teenage pregnancies will be addressed.

### *c) Category – Teenage pregnancies*

Mchunu et al. (2012) define teenage pregnancies as pregnancies occurring between the ages of 10 and 19 years old. Although a matter of concern worldwide, it is especially a problem in sub-Saharan Africa where various risk factors endanger the lives and futures of pregnant teenagers and about one-third of these pregnancies end in unsafe

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abortions (Mchunu et al., 2012). Several of the participants in this study had teenage pregnancies. Their experiences were:

> Flora: *En daai tyd toe kan ek nog nie werk nie want ek was nog op skool.* [And at that time, I could not work yet because I was still in school.]

> Emily: … *ek was 19 gewees ja toe kry ek haar*. [… I was 19 when I had her.]

> Celia: *Toe was ek 17 gewees, toe was ek in 'n ongeluk gewees … Toe het die hospitaal uitgevind ek is swanger gewees.* [When I was 17, I was in an accident … They found out in hospital that I was pregnant.]

Celia and Emily were both already working when they got pregnant, while Flora and Drika were still attending school. For both Flora and Drika it also meant the end of their schooling and limitations to future job opportunities. In correlation with the realities of participants in this study, Mchunu et al. (2012) state that alcohol and other drug use along with poverty and low education levels are widely recognised as risk factors for teenage pregnancies. Englund et al. (2008) also describe unintended pregnancies such as teenage pregnancies as part of the societal cost of alcohol abuse, correlating with the realities of the participants in this study. Theme two, "Intergenerational patterns," will be analysed and discussed below.

### 6.4.2 Theme 2: Intergenerational patterns

Information pertaining to this theme was mostly derived from the discussions on cultural aspects on the semi-structured interview schedule. From these discussions it was clear that, additional to the cultural beliefs, knowledge, and attitudes of their communities about alcohol use, the drinking patterns of their extended families influence how women perceive alcohol use (Parry et al., 2012). This correlates with findings that mothers of children with FASD often have heavy drinking family, partners, and friends (May et al., 2008; Olivier, 2017; Van Schalkwyk & Naidoo, 2021a). This theme is further divided into two sub-themes, drinking patters and the role of mothers and grandmothers, which will be analysed and discussed below.

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#### *6.4.2.1 Theme 2 - Sub-theme 1: Drinking patterns*

Englund et al. (2008) state that drinking patterns in adulthood is best understood by identifying childhood and adolescence predictors of alcohol use patterns. Parenting factors such as parents' alcohol use, parenting styles and relationships with their children are identified as factors influencing adolescent alcohol use (Englund et al, 2008; Longmore et al., 2022). This corresponds with the information collected from participants in this study. The sub-theme "drinking patterns" has one category that is extremely relevant in a South African context, namely "weekend binge-drinking".

##### *a) Category – Weekend binge-drinking*

Studies have shown that binge-drinking has a profound effect on the development of the fetus (Hoyme et al., 2016; May et al., 2016, Popova et al., 2021). In the WCP, weekend binge-drinking is an embedded lifestyle with much planning going into these drinking occasions (Le Roux, 2020). Binge-drinking as a drinking pattern also manifested in the stories of the participants in this study. Some participants would drink on their own, but drinking is mostly a social affair with friends or family members (De Vries et al., 2015). The embeddedness of weekend drinking as a lifestyle is clear from the following remark by Emily:

> *… vir my was dit maar net ons mòèt gedrink het naweke.* [… for me it was just that we had to drink over weekends.]

The social aspect of weekend drinking is further highlighted by study participants' anecdotes:

> Emily: *Dit was net ek, my niggie, haar man en dis nou my kêrel se broers… Ons het in die jaart het ons bymekaar gegooi, dan koop ons nou vir ons drank*. [It was me, my cousin, her husband, and my boyfriend's brothers ... We who were living on the same premises all gave money and then we would buy alcohol for all the money.]

> Drika: *Ek drink net Saterdae en Sondae in die aand, maar ek drink nie in die week nie … Nee, maar as ons nou nie Maandae werk nie, dan drink ek 'n bier. Ek en my tjommies … ons is altyd drie of vier.* [I only drink Saturday and Sunday nights but I do not drink during the week. No, but if we do not work

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on a Monday, then I drink a beer. My friends and I … We are always three or four.]

Only one study participant said that she mostly drank on her own. This study participant also recognised that her drinking is problematic and to the detriment of herself and her family.

Celia: *Ek drink seker so 6 biere op 'n Saterdag uit mevrou. Alleen*. [I drink about six beers on a Saturday. Alone.]

To fully understand the extend of drinking described, it must be understood that "a beer" is a colloquial term mostly used for a 750 ml bottle of beer, which constitutes 2.2 standard drinks. Drinking "a beer" further does not necessarily mean that a person had only one beer. Binge-drinking as a lifestyle and weekend activity is discussed in chapter three where the impact of binge-drinking as a risk factor is described in more detail. Thus, these narratives clearly show the same lifestyle of weekend binge-drinking as a part of their social lives as it was in earlier generations of communities in the WCP. Weekend binge-drinking already surfaced in the description of the early drinking of all six study participants as depicted in their "stories" under heading 6.3. Whereas Flora lied to get money from her mother for their weekend drinking, Celia and her friends bought beer for their weekend drinking and Emily attended parties where she drank. It can thus be concluded that the "weekend ritual" of binge-drinking, often until intoxication, already started at a young age for these study participants (Falletisch, 2008; Le Roux, 2020). The intergenerational theme is further discussed in the second sub-theme where the role of mothers and grandmothers in the lives and drinking behaviour of study participants will be further explored.

#### *6.4.2.2 Theme 2 – Sub-theme 2: The role of mothers and grandmothers*

With single-parent and female-headed households the norm in SA as opposed to nuclear families, the role and influence of mothers and grandmothers in parenting and educating children is of the utmost importance (Van Schalkwyk & Naidoo, 2021a). Childhood factors such as instability due to changing caretakers and the influence thereof on the study participants was discussed in detail in theme one. Van Schalkwyk (2021) explains that mothers, especially in single-parent households, are responsible to provide as well as physically and emotionally care for their children. This was clearly

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demonstrated in the narratives of the study participants. This sub-theme is divided into three categories highlighting the areas of influence study participants most often emphasised. The categories are influence on drinking behaviour, support, or a lack thereof and support in caring for the children.

#### *a) Category - Influence on drinking behaviour*

According to literature (Englund et al., 2008; Le Roux, 2020), parental alcohol use can be associated with early onset of drinking in adolescence and problems with alcohol abuse. Englund et al. (2008) further found that the offspring of parents with higher levels of alcohol use, also drink at higher levels. This correlates with the finding of May et al. (2008) that FASD often clusters in family groups, speaking to the intergenerational transfer of drinking behaviour and patterns. Participants in this study confirmed these findings with their narratives about the influence their mothers and/or grandmothers had on their perceptions about drinking.

Flora, who grew up with her grandmother, felt that she received mixed messages from her mother and grandmother about drinking. Neither her mother nor her grandmother drank, but her grandmother ran a shebeen from her home. Flora said:

> S*oos ek grootgeraak het voor haar het sy nooit gedrink nie, maar sy het altyd wyn verkoop.* [As I grew up with her, she never drank but <u>she always sold wine</u>.]

Although Flora was raised with the idea that women should not drink, she described the example her grandmother set by selling alcohol, as the trigger for her to start experimenting with alcohol. The accessibility of alcohol, especially in drinking households and communities where parents often pass out while they are drinking, enables children to experiment with alcohol (Falletisch, 2008; Le Roux, 2020). For Flora this was certainly the case:

> *Dis amper om te sê laat ons ook nou maar toetsproe hoe proe wyn, want ouma het dit verkoop. So, … dis eintlik nie reg dat 'n vroumens moet drink nie.* [It was <u>almost if we had to try and taste</u> the wine because grandma sold it. So, … it is not actually right for a woman to drink.]

Celia had a different experience with a mother who drank, but always made sure that her family and household were cared for before she started drinking. The message

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she internalised was that, if a woman drinks, she should first see to it that her house and children are cared for before she starts drinking. Falletisch (2008) found a similar view of the importance of a mother fulfilling her household tasks in her interviews with children on a wine farm. Celia explained her view:

> *My ma het ook haar doppie gedrink, maar sy was ook 'n een … Syt als uitgesort, daars kos op die tafel voor sy gedrink het. As sy klaar kos gemaak het, … dan begin sy te drink*. [My mother also drank, but she was one … She sorted everything out, there was food on the table before she started drinking. After she prepared the food … then she would start drinking.]

Celia, despite being a heavy weekend drinker, upholds these same practices:

> *As die koskas eers vol is, dan weet ek, as daar een bier of twee biere se geldjies is vir my gaan ek vir my 'n biertjie koop.* [Once there is enough food in the cupboard, then I know, if there is money left for one or two beers for me, then I will I buy myself a beer.]

Ansa, Celia, Drika and Emily shared experiences where their mothers addressed their alcohol use and either told them to slow down or to stop drinking and take better care of their children. Even though they did not follow their mothers' advice, they all respected their mothers' input, acknowledging that their drinking could risk the safety of their children and households, correlating with findings in literature (Van Schalkwyk, 2019). Drika, whose mother never drank but still drinks herself, voiced her opinion about her mother's example with the following words:

> *Ek kan nou self sê van my ma, sy is baie goed vir ander en ek wil ook soos sy wees. So wil ek wees. Dis al wat ek maar kan sê.* [This I can say about my mother myself; she is very good to other people, and I want to be like her. That is how I want to be. That is all I can say.]

This remark by Drika summarises the important role of mothers or grandmothers as primary caretakers and correlates with the research of Englund et al. (2008) who argued that there might be a developmental pathway between parenting and alcohol abuse in their offspring. These authors reason that, to understand drinking patterns in adulthood, it is crucial to understand childhood and adolescent predictors thereof. Parenting factors such as parental alcohol use, rejection or a lack of support are noted

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as influential in decisions regarding alcohol use. It is reasoned that maternal alcohol use creates the perception that alcohol use is acceptable (Englund et al., 2008). Social workers are well positioned to address parenting and especially mothering to ensure the future of children. This opinion is in keeping with the view of Van Schalkwyk (2021:299) who stresses the importance of addressing parenting as a means of safeguarding children's future, by stating that "children do better when their families are strong, and families do better when they live in communities that help them to succeed." This confirms the role of the social worker in the prevention and intervention efforts strengthening individuals, families, and communities.

***b) Category - Support or a lack thereof***

Van Schalkwyk & Naidoo (2021a), state that parenting is a long-term responsibility, in which the mother's ability to cope efficiently and to be warm and responsive towards her children, are imperative. These authors further state that mothers who grew up in dysfunctional families, often display similar destructive ways of parenting. This in in accordance with the finding of Englund et al. (2008) as described in the previous category, that parental support influences alcohol use perceptions. In this study, every participant either longed for the support of her mother where it was not available or depended on her mother and the various forms of support she provided. Drika did not have an income during her pregnancy and depended on her mother's income. She said:

> *My ma het gewerk vir die huis* … ["My mother worked to provide for the household.]

Ansa still depends on her mother to help her out financially when they do not have an income, stating:

> *My ma kry mos nou toelae elke eerste. So halfmaand het jy en die ander 2 weke gaan dit nou 'n bietjie sukkelrig.* [My mother receives her grant on the first day of the month. So, for the first half of the month you have what you need and the other two weeks we are struggling.]

Both Drika and Ansa's situation relate to the plight of female-headed households where the bulk of the responsibility to maintain the household, take care of the children and to provide financially, rests on the woman (Hall & Mokomane, 2018). With Drika still living in her mother's house, her mother is the head of the household responsible to

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manage the household income, while Ansa's mother is her back-up when her own finances fall short. This is in keeping with Hall and Mokomane's (2018) opinion that female-headed households are financially vulnerable.

Bella, who grew up with her grandmother during her early childhood, felt that she was not important, that her mother could not protect her and was not really interested in her. When she had her first child, her mother did not attend the birth as she did with her other daughters. Bella explained:

> … *toe ek gaan kraam het, toe was my ma nie daar nie so daai het vir my vertel ek kom laaste*. [… when I gave birth, my mother was not there so that told me I am the least important.]

When asked what she felt she needed most during her pregnancy, she answered:

> *My ma se liefde is nommer een.* [My mother's love is number one.]

Bella's experience and needs correlates with the research of Van Schalkwyk & Naidoo (2021a:12) who state that "the impact of mothers' suffering, past and present, showed their being depleted of a sense of mattering." These authors further state the tendency of mothers to repeat the poor parenting practices of their parents, has disastrous effects on children. This emphasises the need for support pregnant women and young mothers experience in communities where few resources are available to see to those needs and points to a door wide open for collaboration between social workers, health care workers and other community support services to use this opportunity as a means of FASD prevention (Rehner, Brazael & Doty, 2017).

#### *c) Category - Support in caring for the children*

Hall and Mokomane (2018) state that grandparents are the primary caregivers of more than seven million children in SA. Although, according to these authors, one or two of the child's parents live in the same household in more than 50% of these cases, the researcher's experience is that it also is common practise in some communities in SA for grandmothers to take over the sole responsibility of caring for especially their daughters' firstborn children. This practise is also described by Van Schalkwyk and Naidoo (2021a) and relates to childhood experiences as discussed in theme one. A good example thereof is found in the case of Bella who grew up with her grandmother

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and described herself as a "grandmother's child" ('n oumakind). Grandmothers still play an important role in caring for children as proved by the following narratives:

> Ansa: *Hy't mos by my ma gebly…* [He lived with my mother.]
>
> Emily: *Ek kan half gesê het ek het nie 'n kind gehad nie, want die kind was meestal by my ma.* [I can almost say I did not have a child because the child was mostly with my mother.]

After Bella's mother left her husband and moved to the same property where Bella lives, they have restored their relationship. This situation demonstrates research findings (Van Schalkwyk & Naidoo, 2021a) stating that mothers' own well-being suffers due to the elevated risks and needs of their circumstances. Mending their relationship means a lot to Bella, and she expressed being especially grateful that her mother can now fulfil her role as a grandmother to Bella's children. Bella said:

> *En wat my hart so gelukkig maak is dat my ma is nou daar as 'n ouma vir hulle, vir dit wat sy nie vir my kon gewees het nie.* [And what makes my heart feel so happy, is that my mother is now there as a grandmother for them, being for them what she could not be for me.]

Although the support of their mothers is mostly positive, some situations raised questions about their mothers' roles in enabling drinking behaviour as well as the study participants' leaving their responsibility towards their children to their mothers. Vernig (2011) describes the role of the enabler as the person in a household who prevents another person from facing the negative consequences of their own actions and, by protecting them, enables such a person to maintain his/her behaviour. Although it may seem as if the enabler is doing everything possible to prevent the unwanted behaviour, the constant acceptance of the other person's responsibilities averts the need to change. A good example of this is found in Emily's story under heading 6.3. Emily admits that her drinking was enabled by her mother taking over her role to care for her children and not expecting of her to contribute anything more than just financial support. This matter corresponds with the view of Van Schalkwyk and Naidoo (2021a) who state that many grandmothers are inclined to take over the mother's role. Although well intended, these authors express their concern about the influence this has on healthy mother-child relationships. Emily described her experience:

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> *Ek het nie naweke 'n kind gehad dat ek weet ek het 'n kind gehad nie, dis hoekom ek so gedrink het*. [I did not have a child over weekends that I knew of. That is why I drank so much.]

Although Drika lives with her mother and brother and the whole family are involved in raising the children, it was evident that her mother takes the brunt of the responsibility. What further raised questions about whether her mother's role is supportive as discussed in the previous category, or that of an enabler, is that her brother, a marijuana dealer, deals from their home with their mother's approval. The following anecdote Drika shared highlights the importance her mother assigned to her own role as caretaker:

> *Sy sê altyd vir my: "O jinne, ek weet nie wat gaan van julle raak nie en my kleinkinders*." [She always tells me: "Oh my goodness, I do not know what is going to happen to you and my grandchildren."]

In Drika's case it might be said that her mother's well-intentioned support is still preventing her from taking responsibility for herself and her children. Family structures are, however, dynamic and roles shift according to the demands of the circumstances (Hall & Makomane, 2018; Vernig, 2011). This offers social workers the opportunity to promote social change by strengthening the abilities of mothers as individuals, family, and community members to break the cycle of poor parenting (Department of Social Services, 2006). The third theme, level of education and work circumstances, will be analysed and discussed below.

### 6.4.3 Theme 3: Level of education and work circumstances

Studies worldwide and especially in SA, have shown that drinking during pregnancy is linked with lower socio-economic circumstances, lower levels of education and a low income (May et al., 2008; May et al., 2021; Urban, Olivier, Louw, Lombard, Viljoen, Scorgie & Chersich, 2016). According to De Jong et al. (2021), this indicates that the need for information about drinking during pregnancy is not only a need for health education, but a systemic need for improved education. Information about the level of educational and work circumstances of study participants in this study, were divided into three sub-themes, which will be analysed and discussed henceforth.

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#### *6.4.3.1 Theme 3 – Sub-theme 1: Early termination of schooling*

Urban et al. (2016) found that almost half of the mothers of children with FASD in their study, did not complete their primary school education. May et al. (2008) had similar findings earlier, indicating that mothers of children with FAS had a mean number of 4.6 years schooling, the lowest of all the groups on the FASD spectrum and the mothers of control children. The findings of this study where Ansa completed grade 7, Bella grade 11, Celia grade 5, Drika, grade 11, Emily grade 10 and Flora grade 10, correlates with the above literature. Two main reasons stood out as factors influencing study participants to abort their school careers early. These two reasons will be discussed as the two categories in this sub-theme, namely financial reasons or school fees and parents' attitude towards schooling.

#### *a) Category – Financial reasons or school fees*

Four participants in this study left school due to financial reasons. Three study participants explicitly stated that, during a time where school fees were still compulsory, their parents could not afford their school fees any longer as displayed in Table 6.6.

**Table 6.6: Financial reasons for early termination of schooling**

| **Theme 3: Level of education and work circumstances** | | | |
|---|---|---|---|
| **Sub-theme 1** | **Category** | **Quotes from interviews** | |
| Early termination of schooling | Financial reasons or school fees | Emily: | *As jy op "Skool A" was, moes jy mos vir twee kinders betaal het…* [If you attended "School A", you had to pay for two children…] |
| | | Celia: | *Toe kan my pa en my ma nou nie meer skoolfondgeld betaal nie.* [Then my father and mother could not pay the school fees anymore.] |
| | | Flora: | … *daai tyd, toe betaal ons nog skoolfonds. En daar was nie mense wat kan help nie.* [… during that time, we still paid school fees. And there was no-one who could help.] |

Another study participant left school because she did not have the supplies she needed in school, no shoes, and no warm clothes in winter. These accounts indicate that the study participants are not only currently in low socio-economic circumstances but that they also grew up in poor households where their basic needs, especially with regard to schooling, were not fulfilled. This left them vulnerable to continued poverty and

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everything it encompasses. Francis and Webster (2019) state that inequality in SA is worse than in most parts of the world. This affects access to education from basic to tertiary education, having the most pronounced effect on poor citizens by confining them to insecure, low-income jobs, thus reinforcing the cycle of poverty and inequity as portrayed in the lives of Ansa, Celia, Emily, and Flora (Francis & Webster, 2019). In the next section, parents' attitudes towards their children's schooling will be analysed and discussed.

#### *b) Category – Parents' attitude towards schooling*

As social worker in the Langeberg area, this researcher often came across parents or caretakers expressing the view that it is shameful for school going children to be sexually active, use alcohol or drugs or act as if they are adults in any other way. The view was also expressed that such children do not belong at school. This experience correlates with findings by Matabese, Macleod and Tsetse (2021) that conceiving at an early age is one of several factors regarded as "shameful" in SA. Although this perception has changed somewhat in the Langeberg area, the participants in this study grew up in an era when this was the notion. Some participants'experiences portray exactly what the researcher encountered:

> Drika: "… *as jy 'n grootmens wil wees, dan moet jy maar uit die skool want 'n grootmens kan nie op 'n skool nie.* [… if you want to be an adult, you have to leave school because <u>an adult cannot be in school</u>.]
>
> Celia: *"Jy is dan 'n groot vrou. Jy suip en rook dan!"* [You <u>act as if you are a grown-up</u>. You drink and smoke!]

It can also be reasoned that several study participants' parents did not value their children's' schooling. This is in keeping with findings that, for farmworkers, spending money on schooling and school related needs, is impalpable (Falletisch, 2008). Parents choose to rather spend their money on items that provide instant gratification than making a long-term investment in schooling. Emily's mother, who allowed her to leave school to supplement the household income and Bella's stepfather who refused to contribute to the expenses for her schooling, serve as examples. Boyden and James (2014) state that schooling has an important role in shaping children's futures. Fransman and Yu (2019) add to this when they state that poverty is multi-dimensional

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and that years of schooling is one of the most important factors contributing to poverty. Early termination of schooling or what they refer to as educational deprivation, can thus, according to these authors, be linked directly to a future of financial deprivation. The second sub-theme, permanent jobs or incomes, and its connection to education will be evaluated and discussed under the next heading.

#### *6.4.3.2 Theme 3 – Subtheme 2: Permanent jobs or incomes*

Fransman and Yu (2019) state that unemployment and years of schooling are the two most significant drivers of poverty. This corresponds with the earlier work of Boyden and James (2014) who stated that educational advancement is requisite for poverty reduction. Some participants in this study were already exposed to poverty as children as discussed in theme one, sub-theme two. However, they are continuing the cycle of poverty as all the study participants are limited in their careers and work opportunities due to their limited education and the fact that permanent jobs are hard to come by. The continuing cycle of poverty will be described in more detail in sub-theme three of theme three. The current sub-theme “permanent jobs or incomes,” is divided into three categories: unemployment, seasonal jobs, and farm work.

##### *a) Category – Unemployment*

According to Francis and Webster (2019) the high rate of unemployment in the rural areas of SA is connected to a lack of economic opportunities in those areas. The Langeberg area, well-known for its deciduous fruit and wine production, is no exception. Although many job opportunities have been developed due to an expansion of the export fruit and wine trade, many of these opportunities are seasonal and involve farm labour, correlating with findings in another farming community (Falletisch, 2008). The range of opportunities, especially for women with low educational levels are, therefore, limited. Unemployment or temporary employment is a reality for many women. Study participants have expressed their experiences as follows:

> Ansa: *Omdat ons nie eintlik 'n werk het nie mevrou, sukkel ons 'n bietjie.* [Because we do not really have jobs, we struggle a bit.]
>
> Bella: *Ek is maar net hier want ek werk nie.* [I am just here because I do not work.]

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These narratives correspond with literature that found mothers of children with FASD to have lower education and a lower weekly income (May et al., 2008; May et al., 2021). Le Roux (2020) postulates that the farming sector has been hit hard by droughts, farm murders and Covid-19, adding to more job insecurity and the risk of further job losses. This leaves women with low levels of education no choice but to work seasonal jobs with minimum payment when it is available. This will be discussed in more detail in the next category.

***b) Category – Seasonal jobs***

As discussed in the previous category, the seasonal nature of farming activities, which is the main source of job opportunities for unskilled workers in the Langeberg area, limits the income of many workers in this area to a seasonal income. Although the season has been lengthened considerably over the past years due to an expansion in the range of produce from the area, it still leaves many workers with limited time per annum to earn an income (Le Roux, 2020). Especially women are often only employed as seasonal workers during the peak season, leaving them in an even more vulnerable situation than their male counterparts (Le Roux, 2020). Farming activities are also closely linked to jobs in canning factories and packing sheds where jobs are also of a seasonal nature, leaving several of the study participants without an income for months on end. This was evident in the accounts of study participants:

> Bella: … *kyk ek werk net seisoentyd*… [… I only work <u>during the season</u>…]
>
> Ansa: … *ons werk seisoentye op die plaas. Ons het nou wingerd gesny … maar nou is ons klaar met daai werk.* [… we work on the farm <u>during the season</u>. We pruned the vineyards … but we are done with that work now.]

Globalisation has led to changed patterns of employment leading to a decline in permanent jobs and a greater emphasis on informal work (De Vries, 2012; Kritzinger, 2005). Adding to the plight of seasonal workers on farms is the fact that they seldom have written contracts and are only paid for the days they work (Le Roux, 2020). Farm work as a third category in this sub-theme, will be discussed next.

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#### *c) Category – Farm work*

Le Roux (2020) states that farm workers are both positively and negatively affected by a range of factors impacting on their well-being. Although Le Roux's study focussed on farm workers living and working on wine farms, it must be kept in mind that many modern-day farm workers live in towns and are transported between the farms where they work and the towns where they live. A significant number of these farm workers are not employed by the farmers but are contracted by labour brokers. Although this has financial benefits for the farm owner, it leaves the workers without benefits or job security (Visser & Ferrer, 2015). Being a farm worker is also seen as a social risk factor for having a child with FASD (De Vries, 2012).

Study participants were asked about their jobs and sources of income. Four of the study participants work on farms, one as a permanent worker living on a farm and the other three as seasonal workers. The two who do not currently work on farms, have both worked on farms before.

> *Emily: Ek het vir haar gewerk op die plaas ... Daar het ek wingerd geknip, wingerd gesuier* … [I worked for her <u>on the farm</u> … There I pruned the vineyards, thinned excess leaves …]
>
> Celia: … *daai selle Maandag toe val ek ook in by die plaas, dat ek nou nog daar werk*. [… that same Monday I started <u>working on the farm</u> and I am still working there.]

The connection between farm work and drinking patterns leading to a higher risk of having a child of FASD, can thus be confirmed with this small cohort of study participants. This connection also indicates a clear gap for social workers and other organisations involved in FASD prevention, for targeted interventions to farm workers. Le Roux (2020) links this gap in services to employee wellness programmes providing counselling, support and information, while simultaneously ensuring social justice and providing services that are mutually beneficial to farmers and workers. The next sub-theme, the circle of poverty, will be discussed below.

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#### *6.4.3.3 Theme 3 – Sub-theme 3: The circle of poverty*

According to Francis and Webster (2019), SA has a history of studying poverty stretching back to the first Carnegie commission in 1932. Several other studies were later undertaken, amongst which Carnegie Two in the nineteen eighties. This commission maintained that poverty is a substantial issue for four reasons, namely the harm caused to those in poverty, the wastefulness in economic terms, the effects of inequality on a community and the fact that poverty is an indicator of deeply rooted problems (Wilson & Ramphele, 1994). Francis and Webster (2019) add that poverty reveals itself in different ways and forms. As Wilson and Ramphele (1994:4) stated: “Hungry children cannot study properly; malnourished adults cannot be fully productive as workers …” However, despite much research and many efforts to address this problem, poverty is rampant in SA with children from poor families still excluded from higher education, keeping the cycle of poverty going (Francis & Webster, 2019). Participants in this study serve as examples of children who have experienced poverty as described in theme one, were limited in educational opportunities as discussed in theme three, sub-theme one and are still impoverished due to a lack of permanent jobs or incomes as described in theme three, sub-theme two.

The information in the current sub-theme was derived from information obtained about the background of the study participants, as well as questions about the children born from their pregnancy during CM, their progress in school, behaviour, and general development. The information pertaining to this sub-theme was divided into two categories, children with learning or behavioural difficulties and hope to break the cycle.

##### *a) Category – Children with learning or behavioural difficulties*

When asked about their children born from the pregnancy while they were in CM, study participants’ responses varied between the belief that their children were normal and do not show any educational or behavioural difficulties, and the recognition that their children were harmed by alcohol use in pregnancy. Despite the belief that their children were unharmed by their alcohol use, some described hyperactivity or behavioural problems, which can be associated with alcohol use in pregnancy (Dörrie et al., 2014; Kalberg & Buckley, 2006; Wozniak et al., 2019).

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Drika: *... ek was bang ek kry 'n alkoholsindroom baby of so, maar hy is vandag normaal. Hy is baie besig, hy is 'n baie besig kind. Hy hou nie van rus nie. Hy is baie besig, hou nie van staan nie.* [… I was afraid that I would have an alcohol syndrome baby or so, but today he is normal. He is very busy; he is a very busy child. He does not like resting. He is very busy, he does not like standing still.]

Celia: *Peter* doen die wonderlikste goed in die skool. Peter slaan die kinders ... Peter ruk die kinders se ore. Peter gaan agtertoe dan klap hy teen die kinders se kop ... Peter is 'n probleem en Peter vloek sê sy in die klas.* [Peter does the most unbelievable things in school. Peter beats the children … Peter pulls the children's' ears. Peter goes to the back of the class and slaps the children's heads … Peter is a problem, and the teacher says Peter swears in class.]

Emily: *Sy hou nie van lank stilsit op 'n plek nie. Sy is so. Ek weet nie of sy "hyper" is of wat nie mevrou. Sy kry nie rus nie mevrou. Sy is heeldag op die pad.* [She does not like sitting still in one place for long. That is how she is. I do not know if she is "hyper" or something. She does not calm down. She is out and busy all day.]

Hyperactivity and socially inappropriate behaviour are widely described in literature and these narratives fall within the boundaries of such behaviour (Carpenter, 2011; Hoyme et al., 2016; Kalberg & Buckley, 2006; Riley et al., 2011). The fact that parents and teachers do not recognise these behaviours as connected to alcohol use in pregnancy and influencing children's educational needs, limit the possibility that these children will receive any educational or behavioural interventions to enhance their chances of completing their schooling (Carpenter, 2011; Kalberg & Buckley, 2006; Kambeitz et al., 2019). Study participants who recognised the consequences of their own drinking behaviour on their children's development and realised the impact thereof, showed intense feelings of guilt, remorse, and sadness. These feelings are in correlation with findings that alcohol use in pregnancy is regarded as "shameful" and that mothers who drink are "bad mothers" (Matabese et al., 2021). Study participants said:

Flora: *Soos nou voel ek baie spyt, want ek kan sien dit het haar breins "getouch". Sy is baie stadig op skool en sy praat die woorde bietjie swak.* [Now I feel

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very sorry because I can see it affected her brain. She is very slow in school, and she pronounces words poorly.]

Bella: *Sy sukkel nou nog met die manier hoe sy woorde uitdruk. Maar ek sê vir myself ek het te laat opgehou met drink ... Sy praat, sy leer maar baie stadig.* [She is still struggling with the way she pronounces words. But I tell myself that I stopped drinking too late … She talks, but she learns very slowly.]

For children to grow into independent adults, it is essential to address their specific learning needs and provide the support they need (Kalberg & Buckley, 2006; Wozniak et al., 2019). Therefore, interventions with a focus on both academical and functional abilities must be implemented early. Mainstream education in SA, however, does not allow much focus on individual learning needs and children with special needs often fall through the cracks. Unless these children are properly assessed to determine their educational needs and receive the needed interventions, many of them may not be able to receive a proper education and will repeat the cycle of low education, job insecurity and poverty (Boyden & James, 2014, Fransman & Yu, 2019). The mothers who participated in this study still hope that they and their children will be able to break this cycle. This will be discussed in the next category.

***b) Category – Hope to break the cycle***

One of the principles of MI applied in CM, was to support study participants' self-efficacy by allowing them to express hope for change and to lead them to understand that the responsibility to bring about change, is their own (May et al., 2013). This principle was also applied in this study where study participants were asked if they had hope for the future of their children and what it entailed. Despite their hardships, depression, and bleak circumstances, they articulated hope for a better future for their children. Many of the hopes they expressed, reflected the dreams they could not accomplish themselves.

Bella: *Dit is 'n lewe van hoop ja ... As ek na haar kyk, dan sien ek vir myself in haar in. Sy is baie sport-aktief. Ek het haar in 'n stadium toegelaat in netbal. Ek laat speel hulle nou al netbal en sy is maar nou eers ses jaar.* [Yes, it is a life of hope … When I look at her, I see myself in her. She is very sporty.

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> I allowed her to start playing netball. I let them play netball already and she is only six years old.]

Ansa, who's view of education as the only way out of poverty relates to the opinions of Fransman and Yu (2009), has just one wish for her children:

> *… dat hulle moet skool loop.* [... that they should attend school.]

These narratives suggest that, despite their own feelings of hopelessness, the mothers in this study hoped for a better future for their children. They could see what was needed to break the cycle, but need support to make the right decisions and take the right steps, emphasising the role of the social worker in supporting and advocating for the vulnerable. This finding is supported by research in a high-risk community where social workers identified a need for peer support, community support and skills development for mothers in challenging circumstances (Van Schalkwyk & Naidoo, 2021b). These authors stressed the need for added support and reinforcement of mothers to cope amidst their continuous struggles. In the next theme, the role of partners in the lives and struggles of the study participants will be analysed and discussed.

### 6.4.4 Theme 4: The role of partners

The role of partners and how they contribute to a pregnant woman's health and lifestyle decisions, is a neglected area of study (De Vries, 2012; Olivier, 2017). Participants in this study were asked several questions regarding the role their partners played during their pregnancy in CM. These questions aimed to explore the reaction of the fathers to the news of the pregnancy, if they supported the women and in what way, and how their alcohol or drug abuse influenced the women's own drinking habits. Reactions to these questions are divided into two sub-themes namely, support or a lack thereof and domestic violence.

#### *6.4.4.1 Theme 4 – Sub-theme 1: Support or a lack thereof*

The reactions of participants in this study regarding the role of their partners in either supporting them or not, correlates with literature regarding partners as a social risk factor for drinking during pregnancy (May et al., 2013; May et al., 2020). For this sub-

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theme, study participant's experiences were allocated to seven categories as deliberated below.

### *a) Category - Partners' reaction to pregnancy*

At the time of their pregnancy in CM, five of the six study participants were in long-term relationships with their partners. One was married, one had a third pregnancy from the same partner and two others were in relationships for three years or more at the time of their pregnancy. Only one was in a new relationship. Two of the study participants feared that their partners might leave them because they were pregnant. Four study participants claimed that their partners were excited because it would be their first children. Emily said the following:

> ... *hy was eintlik bly gewees omdat dit sy eerste een gewees het. Hy het mos nou nie kinders gehad nie.* [He was <u>very glad</u> because it was his first child. He did not have other children.]

Despite Drika's fear of being abandoned as in her previous pregnancy, she had a similar experience as Emily:

> *Hy was baie ordentlik want ... ek dink ek is sy eerste meisie en wat hy nou gehad* het. [He was <u>very decent</u> because … I think I was his first girlfriend.]

These initial positive reactions had a positive effect on the study participants and strengthened their relationships. The same conclusion can be made about more permanent relationships like that of Ansa and Celia who described being happy in pregnancy. This finding is supported by research (Sonke Gender Justice, 2018) showing that father involvement during pregnancy has a positive effect on their partners, encouraging them to make better lifestyle choices. The research further shows that supportive fathers increase pregnant women's happiness, physical and mental well-being. Early bonding of fathers with their children, starting in pregnancy, is encouraged to strengthen their emotional connection (Sonke Gender Justice, 2018). Where the partners' reaction in this study was negative or relationships were tense, it led to much stress for the study participants. As Flora said:

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> *Ek was bly vir myself, gesê jinne, hier kry ek nog 'n babatjie, maar hoe gaan die man nou weer optree*. [I was glad for my own sake. I said, here I am getting another baby, but how is my husband going to act again?]

These experiences of the study participants correlate with literature stressing the importance of father involvement during pregnancy to limit maternal stress and avoid harmful choices (Sonke Gender Justice, 2018). It can also be argued that these first reactions determined the support the women received during the remainder of their pregnancies, as well as emphasising the biopsychosocial nature of the needs of pregnant women. It can also be linked to the psychological and social risk factors for having a child with FASD as discussed in chapter three (May et al., 2013; May et al., 2020; May et al., 2021). Study participants' experiences of abandonment in pregnancy will be analysed and discussed next.

#### *b) Category - Abandonment / Breaking off relationships*

Hall and Mokomane (2018) state that nearly ten million South African children do not live in the same household as their fathers. Of these children, 25% never see their fathers and a significant number of fathers are not involved in their children's lives, which according to these authors, is partly due to abandonment. Some participants in this study had first-hand experience of abandonment or breaking off of relationships once they informed their partners about their pregnancy. Although none of them were abandoned during their pregnancy in CM, some experienced it in previous pregnancies. Drika said:

> *Andrew* se pa het my gelos* … [Andrew's father dumped me …]

Emily's first partner with whom she said she did not have a relationship, refused to be held responsible saying:

> … *dit was maar net 'n "one-night stand" gewees* ... [… it was only a one-night stand …]

Ansa, in her story, also referred to men who leave women the moment they are pregnant and shared the fear she had of being left again to raise a child on her own. These experiences correlate with literature (Sonke Gender Justice, 2018) stating that especially in teenage pregnancies, unplanned and out-of-wedlock pregnancies, fathers

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tend to be unprepared, refuse to take responsibility or become involved. This is also in correlation with findings (May et al., 2008, May et al., 2021) that mothers of children with FASD are seldom married. In addition, several study participants were affected by their partners' infidelity during their pregnancies. This is described and discussed in the next category.

### *c) Category – Affairs*

When asked about their relationships during their pregnancy in CM, several study participants indicated that their partners had had affairs. They experienced this as extremely hurtful and saw it as the ultimate betrayal. According to literature (Slabbert & Green, 2013), affairs might be seen as a form of emotional abuse. Kleine (2019) adds that partners affected by affairs want the transgressor to acknowledge the pain they caused and need them to show remorse. In this study it was clear that affairs contributed to the study participants' continued drinking in pregnancy. Flora, who was deeply hurt by her husband's affair stated:

> ... *die keer was ons mos nou getroud so dit het my nog meer seergemaak*. [... this time we were married, so it was even more hurtful.]

Bella's partner had several affairs over time. She said:

> *Hy het buite-verhoudings gehad ... klomp*. [He had affairs ... several.]

These experiences correlate with the findings of several studies linking unstable relationships to an increased risk for having a child with FASD as discussed in chapter three (May et al., 2008; May, 2011; May et al., 2013). Affairs and infidelity are indicative of a lack of emotional support as discussed in the next category.

### *d) Category - Emotional support*

Lemola et al. (2009) state that sufficient emotional support from a pregnant woman's partner is a protective barrier against stressful life events. These authors further state that partners' emotional support reduces the possibility of maternal depression as well as long-term effects on the irritability of the baby. The experiences of the study participants reflect these findings. Four study participants felt that they had good support from their partners, one felt that she was supported in some ways, but not in

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the ways she needed, and one had no support from her partner. When asked how her partner supported her, Ansa said:

> *Hyt ook opgehou drink... tot ek nou vir haar gekry het. Om vir my te help dat ons kan kleertjies en als kry vir haar.* [He also stopped drinking… until I had her. To help me that we could get clothes and everything for her.]

Drika's explanation of her partner's support was:

> *Hy was elke dag by my. Hy het saans as hy uit die werk uit kom dan kom sit hy, hy praat en hy en my ma-hulle praat.* [He came to me every day. When he came from work he would come and sit, he talks and he and my family talks.]

Flora, who already suffered from depression and high levels of stress at the time, hoped for support, but did not receive any:

> *Ek het gedink die swangerskap gaan hom verander. Jy weet mos, as party vrouens swanger is dan troetel die man hulle ... ek het vir hom gewys ek is swanger maar hy het net sy kop geskud ... en as hy somtyds dronk gewees het, dan sê hy sommer: "Dis nie my kind die nie. Jy moet die kind se pa gaan soek."* [I thought the pregnancy would change him. You know, when some women are pregnant, the men pamper them … I told him I am pregnant, but he just shook his head … and sometimes when he was drunk, he would say: "This is not my child. You must go and find the child's father."]

Three of the study participants who felt emotionally supported, managed to stop drinking during their pregnancies. The two who did not feel fully supported or not supported at all, drank heavily either throughout or until late in pregnancy. This notion that paternal support influences drinking during pregnancy, is supported in literature (Sonke Gender Justice, 2018).

> Bella: *Ek het sommer nie gemaaind hoeveel biere ek drink nie, ek het net wou drink.* [I did not even care how many beers I drank, I just wanted to drink.]
>
> Flora: *Maar in [my] swangerskap het ek mos baie gedrink ook. Ook van die stresprobleme.* [But in my pregnancy, I drank a lot too. Also due to the stress problems.]

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Only one study participant who felt she had enough support did not stop drinking during her pregnancy. This finding stresses the importance of the emotional support and involvement of fathers in their partners' pregnancies and eventually, the health of their children as supported by findings in literature (Sonke Gender Justice, 2018).

***e) Category - Financial support***

Women, and especially low-skilled women, still earn less than men, leaving them in a very vulnerable position if there is no financial support from their partners (Hall & Mokomane, 2018). To support financially, is seen as a gender role of fathers (Sonke Gender Justice, 2018). Participants in this study supported this view and expressed clear expectations pertaining to financial contributions. In some respects, it was considered one of the most, if not the most important form, of support they needed and expected. Ansa, who feared to be left without financial support and to live off the Child Care grant, expressed her gratitude that her partner not only stopped drinking to contribute financially, but also borrowed money to buy everything she and the baby would need.

Emily's partner not only provided what she needed, but also encouraged her to buy herself treats:

> *Baie kere dan bel ek hom dan bel ek hom werk toe dan vra ek vir hom: "Kan ek vir my dit koop, kan ek vir my dit koop?" So. Dan sê hy vir my "Jy sit met die geld. Koop vir jou dit'."* [Sometimes I would call him at work and ask him: "Can I buy this; can I buy that?" Then he would say to me: "You have the money, you can buy it."]

As described in their stories, Drika and Emily had previous experiences where their partners did not take responsibility for their children and made no financial contributions. This experience is supported by literature (Sonke Gender Justice, 2018) stating that the maternal family usually take financial responsibility for a child's care. Both Drika and Emily felt it was not worth their while to claim maintenance through the court system, believing it would be an ongoing struggle with little to show for it. Although they took pride in the fact that they cared for their children alone, they made no secret of their disdain for the fathers' shortcomings as financial providers. Drika had the following reaction when she felt her son idolised his father:

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> *O jy bly vir ons vermaak van jou pa maar hy beteken niks vir jou nie.* [Oh, you are spiteful to us about your father, but <u>he does not do anything for you</u>.]

This reaction is in concurrence with literature regarding the perception of fatherhood as that of financial provider, excluding other roles and responsibilities of fathers (Sonke Gender Justice, 2018). These authors further state that some fathers will rather break the ties with their children than being shamed by their inability to provide financially. The narratives above demonstrate the strong feelings elicited when women who need financial contributions to take proper care of their children, are left to fend on their own for their survival and that of their children. These women's psychological well-being is affected by their feelings which, consequently, affect the physical and emotional well-being of their children. A lack of financial support, which can be seen as a social problem, thus has biological, psychological as well as social consequences for the women and their children. It further contributes to the limited opportunities for their children and eventually, the continuation of the cycle of poverty as discussed in theme three. Alcohol and drug abuse by partners as an influential factor in a woman's pregnancy, is deliberated next.

#### *f) Category - Alcohol and/or drug abuse by partners*

McBride and Johnson (2016) state that pregnancy and the well-being of the fetus, was traditionally regarded the responsibility of women. Over recent years, the influence of drinking partners as a social determinant contributing to women's drinking during pregnancy, was confirmed by several studies (McQuire et al., 2019; Olivier, 2017; Sonke Gender Justice, 2018). These studies provided proof that pregnant women frequently live with their heavy drinking partners who often initiate drinking and coerce them to drink. The role of the partner as social risk factor and determinant of drinking behaviour as indicated in chapter three, was also the narrative of women in this study. The partners of two study participants stopped drinking to support them during their pregnancy. Not only did this motivate the study participants to stay sober, but it also strengthened their relationships with their partners, correlating with literature (Sonke Gender Justice, 2018) about the positive effects of paternal support. About their life during her pregnancy and the way her partner offered support, Celia said:

> *Nee, toe het hy opgehou drink saam met my. Hy het vir my daai tyd baie ondersteuning gegee. Ek kon gevra het, want hy het my baie gehelp met als...Hy*

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> *het my baie ondersteun met als, als.* [… he stopped drinking with me. He gave me a lot of support during that time. I could ask and he would help me with anything … He supported me a lot with everything, everything.]

On the contrary, Flora was so disheartened by the humiliation and violence she experienced as a result of her husband's alcohol abuse, that she did not feel it would be possible for her to stop drinking as long as they lived together. Although she wants to change her own drinking, she feels stuck in a situation that does not change. This is in keeping with findings that some women in difficult circumstances drink to cope or as a means of self-care (De Jong et al., 2021; Van Schalkwyk, 2021). Flora said:

> *... dan is als weer dieselfde en dan koop hy biere ... Ek wil graag so minder drink, ek wil graag die drank los maar hoe sal ek die drank kan los as ek in die huwelik nog is?* [Then everything is the same again and then he buys beers …I want to drink less so badly; I want to stop drinking but how can I stop as long as I am in this marriage?]

Bella's partner abused alcohol and marijuana. She suffered physical abuse, felt emotionally neglected, financially marginalised and that she was the last on his priority list. Although Celia, Flora and Bella were in completely different situations, it is clear from each of their stories that their own drinking behaviour was influenced by their partners' drinking because in their eyes, their partners' behaviour reflected their value and the importance of their pregnancies. This, again, emphasises the importance of interventions and prevention efforts to involve fathers and improve their awareness of the important role they have in the physical, emotional, and social well-being of both their partners and their offspring as described in literature (Sonke Gender Justice, 2018). It also connects the three components of the biopsychological model as discussed in chapter three with the three levels of prevention as discussed in chapter four to ensure inclusion of all the elements of well-being on all three levels of prevention. This also urges social workers to consider, address, and place more emphasis on the importance of the role of fathers in social work services. The role of cultural differences in perceptions about the roles of fathers, is examined and discussed in the next category.

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### g) *Category - Cultural differences*

Three of the six study participants' partners were from different cultural backgrounds than the study participants. Although none of them felt that cultural differences alone were the cause of problems in their relationships, they all felt that their partners' cultural backgrounds influence the way they are treated. This correlates with the opinion of Khunou (Sonke Gender Justice, 2018:39) who states that "fatherhood is dynamic and multi-layered in terms of race, class, ethnicity, and culture." The influence of cultural factors in their relationships was reflected in several statements by the study participants as depicted in Table 6.7 below.

**Table 6.7: Cultural differences**

| Theme 4: The role of partners | | |
|---|---|---|
| **Sub-theme 1** | **Category** | **Quotes from interviews** |
| Support or a lack thereof | Cultural differences | Bella: *Ek dink dit is die kultuur, want as hy vir my so vertel van wat daar anderkant by hulle huis is, dan, die man het meer sê as die vrou... die man bring die geld so die vrou met maar net dans soos die man sê.* [I think it is the culture because when he tells me how things are at their home, then the man has more of a say than the woman… the man brings in the money so the woman has to dance to his beat.]<br>Flora: *... in hulle "culture", ek was maar net 'n hoender... [ek] beteken nie veel nie.* [... in their culture, I was just a chicken… I am not worth much.]<br>Ansa: *Hy is nie eintlik een wat baie praat nie. Saam met my nou nie. Hy is meer by sy mense. Hy is meer aan Xhosa praat*. [He is not one who talks a lot… at least not with me. He is more with his own people. He enjoys Xhosa company.] |

Culture and traditions are important aspects of fatherhood and fathers' perceptions of their roles (Sonke Gender Justice, 2018). From the narratives of the study participants, it was clear that there were different expectations concerning the roles of the men as fathers, but also the role and importance of the study participants as women and their perception of how they should be treated by their partners. This finding underlines the importance of shaping FASD prevention efforts and interventions to include cultural aspects as described by Baydala et al. (2011).

In the next section the second sub-theme, domestic violence, study participants' experiences of abuse will be deliberated.

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#### *6.4.4.2 Theme 4 – Sub-theme 2: Domestic violence*

The vicious circle of alcohol use and domestic or gender-based violence is well described in literature (Gibbs, Jewkes, Willan & Washington, 2018; De Jong et al, 2021). According to Eaton et al. (2012) pregnancy in itself leads to increased levels of domestic violence. De Jong et al. (2021) state that domestic violence increases drinking during pregnancy. These statements correlate with the accounts of the study participants exposed to domestic violence. This sub-theme was further divided into three categories, physical, emotional, and financial violence as discussed below.

***a) Category - Physical violence***

Fletcher et al. (2018) found a significant correlation between harmful attitudes about drinking during pregnancy and physical abuse. These authors state that some women continue drinking during pregnancy to cope with the stress of violence, amongst other factors. From Flora's description of the ongoing abuse by her husband, it was clear that she lived in constant fear of her husband. Physical violence often followed on drinking episodes.

> Flora: *Net as hy alkohol in sy liggaam het dan wil hy baklei met iemand. Hy's nie net met my alleen so nie, hys met almal so. Hy het my geslaan ook met so 'n ysterdingetjie oor my kop ... Toe is ek reeds swanger.* [As soon as he has alcohol in his body, he wants to fight with someone. He is not only that way with me, he is like that with everybody. He beat me with a piece of iron over my head … I was pregnant at the time."]

In some cases, the level of abuse these women suffered was horrific and left them traumatised and, in some cases, possibly with permanent emotional scars. More concerning than their physical scars are the feelings of hate, loss of respect and emotional blunting caused by the violence. This finding is supported by literature (Joyner & Mash, 2014; Matsika, 2021; Slabbert & Green, 2013) describing feelings of immobilisation, absence of emotion, self-blame, helplessness as well as the existence of physical and emotional scars.

> Flora: *Dis 'n haat wat ek het teen hom.* ["It is hatred I feel for him.]

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Bella: *Daar is nie respek nie, daar is nie liefde nie. So, hoekom moet ons nou nog saam wees?* ["There is no respect, there is no love. So, why should we still be together?]

The effect of physical violence on the children who often witnessed the abuse, is equally disturbing.

Flora: *Hulle is kwaad. Hulle het so 'n woede in hulle. Die een sê altyd vir my: "Daai goete wat my pa aan jou doen. Dis nie mooi om dit so te staan en kyk nie."* ["They are mad. They carry an anger in them… The one always tells me: 'Those things my father are doing to you. It is not nice to have to stand and watch it."]

Slabbert and Green (2013) postulate that children exposed to domestic violence feel betrayed, suspicions and fearful. They exhibit numerous behavioural and emotional problems including aggression, suicidal thoughts, a lack of self-appreciation, withdrawal and suffer anxiety attacks. In this study, several of the children from the homes where there is domestic violence already display problem behaviour, which can be associated with the trauma they experience in their homes.

Celia: *My kinders… daar my oudste seun nie gerook het en gedrink nie, hy drink. My meisiekind van 11 jaar oud, sy rook ... Die mense skel my, die [jongste] kind het nie meer maniere nie.* ["My children … my oldest son did not smoke or drink, he now drinks. My 11-year-old daughter smokes. The people scold me, the youngest child does not have manners anymore.]

Gibbs et al. (2018) state that preventing childhood trauma is imperative for the prevention of domestic violence in adulthood. However, as is clear from the stories of the participants in this study, their own childhood traumas as discussed in theme one, went unattended. This cycle is continued in their children who, despite being traumatised in their homes, were not receiving any form of help or counselling at the time of the interviews, potentially creating another cycle of alcohol abuse, domestic violence, and poverty in the next generation. This correlates with Van Schalkwyk and Naidoo (2021a) stating that exposure to disempowering contexts, influences the functioning of children and families. The role of social workers where domestic violence occurs, should thus consider that not only the women in violent relationships need support, but that the resulting trauma to the children should be addressed too. This is

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especially true in households where this trauma repeats itself, creating multiple adverse childhood events and possibly a repeated cycle of future alcohol dependence (Machisa et al., 2016; Pilowsky et al., 2009; Van Schalkwyk, 2021). Domestic violence also includes emotional violence. This aspect of violence will be investigated and argued below.

### *b) Category – Emotional violence*

Slabbert (2016) states that physical violence often goes hand in hand with emotional violence. Emotional violence can take the form of negative feedback regarding character, appearance, personality or even placing the blame for physical violence on the victim of abuse, as well as infidelity as stated in theme four, sub-theme one under the category "affairs". The experiences of the participants in this study reflected the findings of this study. Study participants' narratives included humiliating statements about their worth, blame, and breaching the trust placed in them when sensitive information was shared.

> Flora: *Weet hy waar kry ek jou? Ek het jou in 'n vullisdrom opgetel.* [Do you know where I got you? <u>I picked you up in a rubbish bin</u>.]

> Bella: *Maar ek kan ook gesien het hy het my blameer vir dit.* [But I could see he <u>blamed me</u> for it.]

> Bella: *Ek kan nie met hom dinge deel soos, ek het nou 'n probleem en ... praat ek die probleem saam met hom, as hy dronk is dan praat hy die goed wat ek net met hom deel.* [I <u>cannot share things</u> with him. If I have a problem and talk to him about the problem, <u>he will talk about the things I shared with him</u> when he is drunk.]

Flora and Bella experienced direct emotional violence in the sense that they were told by their partners that they are useless or to blame for things that happened, but Celia experiences a more subtle form of blame. When she tries to lay a complaint with the police after her partner had beaten her up, he makes sure that he presents himself respectably and tells them that she is intoxicated. Celia said:

> *Hy sê vir die polisie: "Sy het dan nou net voordat sy na julle toe gekom het, gesuip." ... Nou toe ek by die huis kom, ek en die polisie, toe het daai man gou gewas, aangetrek, als is klaar. Hy is nou soos 'n mooi nugter man, 'n man wat nie 'n vrou*

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> *geslaan het nie, 'n man wat nie 'n strykyster gegooi het nie.* [He told the police: "She drank right before she came to you." … Now, when I got home, the police and I, that man has washed himself, he dressed, everything is done. He looks like a completely sober man, a man who did not beat up a woman, a man who did not throw a flat iron.]

This experience is in correlation with the findings of Slabbert (2010:25) that the police sometimes arrive at a scene and find the man accused of violence sitting peacefully and "the picture of innocence", making it hard for them to know what to do. The belief that women must have provoked their partners or did something to deserve abuse, is still prevailing (Retief & Green, 2015). This contributes to the police treating domestic violence as personal matters and nothing being done to protect the woman and her children. Additionally, stereotypical views that men should be unemotional, detached, and tough contributes to emotional detachment and uncaring behaviour that manifests as emotional abuse (Sonke Gender Justice, 2018). In the next section, the third category of violence, financial violence, will be discussed.

#### ***c) Category – Financial violence***

Financial violence, along with physical violence and emotional violence, is a component of domestic violence. Financial violence includes withholding financial support, controlling financial decisions and wasteful expenditures. The perception that women are responsible for all household tasks while working full-time to provide for their families, adds to the impact of financial violence (Matsika, 2021; Slabbert & Green, 2013). The narratives of the women in this study included all these components and was clearly connected to both physical and emotional violence. Flora's experience with her husband who, at times, does not work and then expects her to hand him her money to uphold his drinking habits, correlates with previous findings (Davhana-Maselesele, Myburgh & Poggenpoel, 2009; Matsika, 2021). Flora says:

> *Hy raak kwaad en hy slaan my oor my oor my eie pay, oor my eie geld.* [He gets mad, and he beats me because of my own pay, because of my own money.]

Bella, in contrast with Flora, has a partner with a good, full-time job but he limits his financial contribution to the household as he pleases. This, to Bella, is worse than the

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physical violence because it affects her and her children's food security. Bella explained:

> *... die hande lig is niks, maar nou die geld. Die kosgeëry. Hy gee sommer een week R100, die ander week R170.* [… raising his hands to beat me, is nothing, but the money is a problem. Giving food. He might one week give me R100 and then R170 the next week.]

This, once again, emphasises the role and importance of the father or partner as financial provider as discussed in theme 4. Talking about this problem does not have any effect in Bella's case, because her partner uses his importance as breadwinner to emphasise her dependency from him and the fact that he has power over her. This is in correlation with literature (Bornstein, 2006; Matsika, 2021; Slabbert & Green, 2013) which argues that the more financially dependent a person is on his or her partner, the more power such partner has over him or her. As Bella stated:

> *So ek moet maar elke keer die goed hoor. Dis my geld, dis my kos.* [So, I have to hear these things time and again. "It is my money; it is my food."]

Flora's husband takes this attitude even further by refusing to do anything to help her unless she pays him.

> Flora*: Ek moet vir hom betaal, want ek wil gou dorp toe gaan of gou oor die pad gaan.* [I have to pay him if I want to go to town quickly or have to go to someone.]

These narratives indicate how trapped women are when they are held financially hostage by their partners. Along with the belief instilled by physical and emotional violence that they are powerless, financial violence further ensures that these women are imprisoned in abusive relationships (Slabbert & Green, 2013). Financial abuse is linked to economic dependency with the level of economic dependence determining the risk of abuse (Bornstein, 2006; Matsika, 2021). Economic dependency is associated with a higher risk for abuse than emotional dependency and severely impairs the woman's ability to leave an abusive partner (Bornstein, 2006; Matsika, 2021; Slabbert, 2016). The combination of elevated economic dependency in the women and high levels of emotional dependency in the man, however, increases the likelihood of physical abuse, adding to the complexity of domestic violence.

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Theme five, “pregnancies and children”, will be analysed and discussed next.

### 6.4.5 Theme 5: Pregnancies and children

Information for this theme was derived from the biographical information obtained from the study participants’ CM files as well as questions asked during the semi-structured interviews. Study participants were asked if their pregnancies were planned, what their own feelings about their pregnancies were at the time, if and when they stopped drinking during pregnancy, when they resumed their drinking after their babies were born and if they drank while they breastfed. All of the study participants had previous pregnancies and five of the six study participants already had children before this pregnancy. Only Bella, who had two miscarriages prior to the pregnancy in CM, did not have live children to take care of. The sub-themes that evolved from the information obtained, are unplanned pregnancies, drinking in pregnancy and drinking whilst breastfeeding.

#### *6.4.5.1 Theme 5 – Sub-theme 1: Unplanned pregnancies*

The role of unplanned or unwanted pregnancies and their association with an increase in drinking during pregnancy, is described in detail in literature (De Jong et al., 2021; Fletcher et al., 2018; Urban et al., 2016). Unplanned pregnancies are, as discussed in chapter three, further seen as a risk factor for having a child with FASD. This is to a great extent because unplanned pregnancies often lead to late pregnancy recognition, which is strongly associated with prolonged alcohol exposure of the fetus (Burd, 2016; May et al., 2020). With drinking before pregnancy seen as the best predictor of alcohol use in the first trimester, unplanned pregnancies are a major risk factor for having a child with FASD in the WCP with its culture of weekend binge-drinking (May et al., 2020).

Not one of the six participants in this study planned their pregnancies. Only Bella and Emily have previously discussed the possibility of having a baby with their partners, but neither of the couples planned the pregnancy at the time. The study participants said the following:

> Drika: *... ons was vrinne ek en hy, maar ons het nou nie dit beplan nie ...* [… we were friends he, and I, but <u>we did not plan it</u> …]

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Flora: *Ons het dit nie beplan nie ... En waar vind ek toe uit? Toe is ek al klaar vier maande, toe vind ek uit.* [We did not plan it … And when did I realise it? I was already four months pregnant when I found out.]

Ansa: *Dit het net gebeur ...* [It just happened ...]

These narratives emphasise the importance of the correct use of contraception and the need for education in this regard as a means of FASD prevention. It further raises the matter of taking active steps to include FASD prevention as a topic of importance in family planning clinics. In chapter four, FASD as a perfect "spark topic" is discussed. FASD as a "spark topic" could be employed in family planning clinics to create "teachable moments" whereby the opportunity for women to make responsible decisions regarding the health of their future children can be created even before they are pregnant.

#### *6.4.5.2 Theme 5 – Sub-theme 2: Drinking in pregnancy*

The study participants' CM files offered extensive information regarding their drinking in the three months prior to pregnancy, and during each trimester of pregnancy. The semi-structured interviews further explored this topic by asking open-ended, non-threatening questions about their drinking during their pregnancy and their knowledge about the harmful effects of alcohol on the fetus prior to their pregnancies. All the study participants knew that pregnant women should not drink. This correlates with the findings of Fletcher et al. (2018) that all the women in their study had some knowledge about the detrimental effects of alcohol during pregnancy, but that they did not have detailed knowledge about FASD or all possible effects. Odendaal et al. (2020) further state that even though women may have knowledge about the harmful effects of drinking during pregnancy, they do not always apply their knowledge in their pregnancies. Emily's answer sums up what most study participants said:

> *... ek geweet ek moet ophou drink, want dit is nie goed vir die baba nie en dit het ons by die kliniek ook [gehoor], mense het vir ons pamflette gegee ...* [... I knew I should stop drinking because it is not good for the baby and we heard it at the clinic too, there were people who gave us pamphlets.]

However, despite this knowledge, all but one of the study participants drank after they knew they were pregnant. Bella, Drika and Flora now had the courage to admit that

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they drank long after they started the CM process despite them telling their case managers that they had stopped drinking. The following narratives reflect their experiences:

> Flora: *Ja, ek het meer gedrink. Ek het baie gedrink met haar.* [Yes, I drank more. I drank a lot with her.]

> Bella: *Ek het na vyf maande beginne ophou met drink.* [I stopped drinking after I was five months pregnant.]

> Drika: *Ek dink maar seker … sewe of ag maande het ek ophou drink.* [I think round about … seven or eight months I stopped drinking.]

Fletcher et al. (2018) state that harmful attitudes about drinking in pregnancy significantly correlates with abuse, depression, alcohol use during a previous pregnancy and unintended pregnancies. Both Bella and Flora had to deal with domestic violence, were receiving treatment for depression before pregnancy, drank during previous pregnancies and had unplanned pregnancies. In contrast, Ansa, Celia, and Emily who also had unplanned pregnancies but were supported by their partners and family, managed to stop drinking earlier and could maintain their sobriety throughout the remainder of their pregnancies. This emphasises the role of partner and family support, as well as the fact that knowledge alone is not enough to change behaviour as was discussed in more detail in chapter three. (Fletcher et al., 2018; Odendaal et al., 2020). In the next sub-theme, drinking while breastfeeding will be analysed and discussed.

#### *6.4.5.3 Theme 5 – Sub-theme 3: Drinking whilst breastfeeding*

As described in chapter three, drinking during breastfeeding adds to the damage done by drinking during pregnancy (May et al., 2016). Information about drinking whilst breastfeeding formed part of the CM programme and study participants were encouraged not to drink whilst breastfeeding. Yet, several of the study participants admitted that they started drinking again while they were still breastfeeding. Some waited until their children were stronger, as Ansa explained:

> *… as my babatjie nog klein is, drink ek ook nie. Ek sal altyd wag tot hy sterk is.* [… when my baby is still small, I do not drink. I will always wait until he is strong.]

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This was, however, not the general perception of drinking whilst breastfeeding.

Flora: *Ek het altyd gehoor by die susters 'n bietjie rooibostee ... sal meer melk gee maar ek het gedrink. Ek het nie geworry eers nie.* [I always heard from the nursing sisters that a little rooibos tea … will help with milk production, but I drank. I did not even care.]

Emily: [*Ek] ... het gedrink. Daar is mos nou nie nog tyd om uit te melk nie, want die bier raak weg!* [I drank. There is no time to pump out breastmilk because the beer will disappear!]

This correlates with the findings of May et al. (2016) that 71% of the mothers in their study in the WCP drank whilst breastfeeding. This study further found that women who drink whilst breastfeeding, generally more often drank prenatally too. This finding relates to the Canadian four-step prevention programme which includes the breastfeeding period as a part of their extended prevention programme where prevention and support is actively continued during the postnatal period as discussed in chapter four (CanFASD, 2013). From a biopsychosocial view, this can also be seen as an important biological factor that needs to be included in FASD prevention and interventions given the influence on a child's physical and neurological development (May et al., 2016).

### 6.4.6 Theme 6: Psychological factors

As discussed in chapter three, psychological factors such as stress, depression, inter-partner violence and traumatic life experiences, are considered risk factors for having a child with an FASD (Coriale et al., 2019; May et al., 2008; May et al., 2016). Stress and trauma influence drinking behaviour and can lead to an increase in alcohol use (Garland et al., 2011). May et al. (2021) state that SA women's stressful lives contribute to heavy drinking in pregnancy. Two sub-themes emerged from questions regarding their feelings about their pregnancies and factors that influenced their psychological well-being, namely depression and hopelessness. The two sub-themes will be discussed below.

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#### *6.4.6.1 Theme 6 -Sub-theme 1: Depression*

Several of the study participants had traumatic life experiences that left them struggling with depression. As was described in Bella's story under heading 6.3, her depression started after the death of her grandmother when she moved in with her mother and felt that nobody cared about her anymore. Flora ascribed her depression to her stressful life and the abuse she suffers at the hands of her husband, while Celia, who had never received mental health services and had not been diagnosed with depression, described feelings of hopelessness and desperation because of her partner's cheating and ongoing physical and emotional abuse. This was described in detail in Celia's story (heading 6.3). Some study participants were diagnosed and treated for depression at some point and others, though never diagnosed with depression, described feelings associated with depression. This is in keeping with the findings of Fletcher et al. (2018) that there is a connection between pregnant women's attitudes about drinking during pregnancy and depression. Depression as a sub-theme is further divided into two categories, defaulting on treatment, and views of psychological services.

#### ***a) Category – Defaulting on treatment***

Both Bella and Flora received mental health services, including medication and visits to a psychologist at the clinic at some point during their lives. They both defaulted on their treatment, stopped using anti-depressants and did not go back to the psychologist for follow-up appointments. Bella felt that she did not benefit from seeing the psychologist because they did not develop a therapeutic relationship. She said:

> *Daar by die kliniek is … Hulle gee net vir sekere mense berading en daar is nie nog een dat jy kan sê nee maar ek wil met haar gesels want ek voel gelukkig met haar. Nee, jy kom net vir medikasie en sekeres word uitgekies om te gaan gesels*. [At the clinic … They only choose some people for <u>counselling</u>, and you cannot say that you want to talk to a certain person because you feel at ease with her. No, <u>you only come for medication</u>, and <u>some are chosen for consultations</u>.]

Flora, on the contrary, felt that she benefitted from her visits to the psychologist in some ways, but reasoned that it did not change her circumstances at home and, therefore, did not change anything in her life. She said she stopped her medication due to her pregnancy:

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> *En ek het stresspille ook gebruik maar toe raak ek mos nou swanger met my babatjie. Toe haal die dokter maar die strespilletjies af van my af. [And I used medication for stress too but then I got pregnant with my baby. The doctor then stopped my medication.]*

Flora and Bella's experiences are in keeping with literature (De Jong et al., 2021) that mental health factors such as depression, suicidal thoughts and stress are contributing to alcohol use in pregnancy. What is especially concerning about Flora's depression, is the fact that she has contemplated suicide on several occasions. She made several remarks about thinking about either suicide or wishing she was dead:

> *Want ek het sommer beplan om myself dood te maak ook al. Ek het nou laas amper weer pille gedrink wat 'n vriend my gekeer het en sê dink aan jou kinders want jy gaan nou vandag hier dood en wat van jou kinders? En wat van jou babatjie?* [Because I have planned to kill myself. A while ago I almost took pills, but my friend stopped me saying I must think about my children because, if you die today, what will happen to your children. And what about your baby?]

Flora also said:

> *Vir my het dit gevoel Flora, hoekom gaan jy maar nie dood nie. Dan voel ek "Ai Here, hoekom laat U my nie gaan nie?* [To me it felt, Flora why don't you just die. Then I feel: "Lord, why do You not let me go?]

Of particular concern about Flora's suicidal thoughts is the fact that she is not receiving any form of mental health services, social work interventions or professional support to support and guide her. The experiences of Bella and Flora who defaulted on their treatment, as well as that of Celia who was never evaluated for receiving treatment, not only underscores the role of depression in drinking behaviour as described in literature (Coriale et al., 2019; De Jong et al., 2021; Fletcher et al., 2018), but also suggests that monitoring of mental health treatment should be prioritised as part of the antenatal care of pregnant women. This too fits into the framework of the biopsychosocial model (Engel, 1980) underscoring the interaction between biological and environmental factors (Burns et al., 2019; Spedding et al., 2020). The following category will explore study participants' views of psychological services.

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#### *b) Category – Views of psychological services*

De Jong et al. (2021) state that mental health issues such as depression, low self-esteem, and psychological distress, play an important part in drinking during pregnancy. These authors further argue that stigma sometimes influences women's willingness to make use of these services, but also that women often see drinking during stressful and difficult times, as a form of self-care. This was true for some of the study participants who stated that they either drank or contemplated drinking to cope with their lives:

> Celia: *Dink ek wat, as jy so bedonnerd is en jy kom heeltyd so skel-skel hier in die huis in, … gaan ek daar af, koop ek vir my 'n bier, kom ek daar om met die een bier… Ja, as ek gedrink is ook mevrou, dan loop ek. Ek sal nie loop as ek nie gedrink is nie. Dan cope ek maar en ek hou alles in.* [Then I think, if you are so cussed and you come home raving … then <u>I go and buy myself a beer</u> and go home with the beer … Yes, when I drink, I walk about. I will not walk about when I am not intoxicated. Then I must cope and keep everything bottled up.]
>
> Bella: *Daar was dae wat ek voel, kom, laat ek maar weer aan die drink raak, want as gevolg van die drukking wat hy op my plaas.* [There were days I <u>felt to start drinking again</u> because of the pressure he puts on me.]

Although none of the study participants mentioned stigma as a reason for not making use of psychological services, two matters were evident in their experiences and views of these services. Both Bella and Flora who made use of psychological services at some point, felt that they did not really benefit from these services. Bella felt that she did not develop a relationship of trust with the psychologist and seeing her did not help her:

> *Want ek het sielkundige geloop by die hospitaal maar dit het vir my gevoel dit help nie*. [Because I saw a psychologist at the hospital, but <u>I did not feel that it helped me</u>.]

Flora, however, said she felt better, but that seeing a psychologist did not change her reality at home:

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> *Ek het die berader gaan sien. Ek dink ons het twee, drie dae, keer mekaar gesien maar toe kanselleer ek dit self, want toe voel ek, toe voel ek dan nog altyd as ek uitstap by haar en ek gaan nou huis toe is alles dan nog weer dieselfde. Daar is 'n bietjie, ek voel in my in dan voel ek 'n verligting in my hart, maar kom ek by die huis dan is dit dieselfde*. [I went to see a counsellor. I think we met twice, three times but then I cancelled it because I felt that when I walk away from her and I go home, everything is still the same. There was a little, I felt a bit of relief in my heart, but when I got home, everything was still the same.]

These experiences indicate unrealistic expectations on the side of the study participants about the role of the psychologist, but also points out a need for counselling accompanied by practical interventions to help them change their circumstances. In an environment where social factors, health services and sometimes the lack of these are part of the community's reality, the importance of the role of the social worker to counsel, support and intervene on a practical level is underscored by the experiences and expressed needs of these study participants and the positive experiences they had with their case workers' support, empathy, reflective listening, and non-judgemental attitude. Literature (Rehner et al., 2017:S40) supports the notion of addressing the "psychosocial dimensions of health with an emphasis on the role [of] behavioural health" by involving social workers. The importance of mental health services to address depression amongst other mental health needs, is in keeping with literature stating that depression often precedes alcohol exposed pregnancies (McQuire, Daniel, Hurt, Kemp & Paranjothy, 2020). The sub-theme, "hopelessness", will be discussed below.

#### *6.4.6.2 Theme 6 – Sub-theme 2: Hopelessness*

Hopelessness, whether it be due to marginalisation, poor living conditions, poverty, inter-partner violence or even being stuck in addiction, can be immobilising, overwhelming and keep a person stuck in a situation (Le Roux, 2020). In this study, hopelessness was experienced mainly due to three reasons. Firstly, study participants felt that they had nowhere else to go, secondly, their circumstances stayed unchanged and thirdly, they felt that nobody cared. These three reasons will be discussed as the three categories of this sub-theme.

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### a) Category – Nowhere to go

Falletish (2008), describes the practise of tied housing on farms where the provision of housing forms part of the benefits of most farm workers. However, housing is normally tied to the contract of the male head of the household. This means that, especially women on farms, are trapped as far as housing is concerned, since they are unable to secure housing for themselves. Due to the general shortage of housing in SA, this is a much more widespread problem than on farms only (Le Roux, 2020; Matsika, 2021). Many women do not have alternative housing and are stuck in relationships because they have nowhere else to go (Slabbert, 2016). This was also true in the case of some study participants.

> Celia: *Naweke dan maak hy die deur toe, dan moet ek agter die huis slaap*. [Over weekends he closes the door and then I have to sleep outside.]

> Flora: *Ek is daar uit sy huis uit middel nag en ek het begin blyplek soek ... Maar soos ons nou aan lewe daar, daar is nie 'n toekoms eintlik nie.* [I left his house in the middle of the night and started looking for a place to stay … but the way we live there now, there is no future for us there either.]

Not having access to housing for themselves and their children, traps many women in a cycle of violence, poverty, and alcohol abuse because they have no way out of their situation, creating feelings of hopelessness and powerlessness (Falletisch, 2008; Le Roux, 2020). Bornstein (2006) also describes difficulty obtaining alternative accommodation as a form of economic dependency preventing women from leaving their partners. This finding is also reflected in literature with regard to inter-partner violence, a matter that formed an integral part of the lives of some study participants (Matsika, 2021; Slabbert & Green, 2013).

### b) Category – Circumstances stay the same

In the biopsychosocial model as discussed in chapter three, it is reasoned that the biological, psychological, and social realities of an individual are constantly in interaction. These interactions influence each other's functionality as well as the functionality of the individual and his/her environment as a whole (Davidson & Strauss, 1995; Engel, 1980). Some participants in this study experienced that, while they felt a need to change and made efforts to change, the lack of reaction from their

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environments and the people close to them, made it impossible for them to follow through.

> Flora: *Hy's maar net dieselfde, want hy het nooit verander nie.* [Hy is still the same because he never changed.]

> Bella: *... ek moet maar my sakkies vat en gaan want praat help nou nie meer nie.* [...I will have to pack my bags and go because talking does not change anything.]

> Celia: *Kan dit nie Maandag raak dat ons kan gaan werk dat dit rustig is, want ek weet in die week is jy nie so nie ... vir wat moet ek dan nou stilsit en net luister na jou stront en jou goed. Dan kan ek ook mos maar suip*. [Can it not be Monday that we can go to work and have peace because I know you are not like that during the week … why should I sit still and listen to you. Then I might as well drink too.]

These anecdotes not only confirm the important influence of the environment on the mental disposition of women, but also refers back to the role of partners as facilitators of drinking in pregnant women as discussed in theme four. It further emphasises the role of the social determinants of drinking on women's ability to stop drinking in pregnancy (McBride & Johnson, 2016). This, once again, emphasises the role of social workers as agents of social change, as well as the benefits of empowering women through the use of MI to be the agents of change in their own lives (Department of Social Services, 2006; May et al., 2013).

#### ***c) Category – Nobody cares***

Van Schalkwyk and Naidoo (2021a) state that a woman's mental health influences her parenting abilities and skills. According to these authors, mothers must be able to effectively cope themselves and reflect warmth and responsiveness to be successful parents. However, mothers often tend to practise the same parenting styles they were exposed to. This, in combination with absent or uncaring partners and family, often leave women feeling unsupported, alone and stressed (Van Schalkwyk & Naidoo, 2021a). Feelings of abandonment, that nobody cares, and that nobody will extend a helping hand, was common amongst the study participants. Bella experienced the lack

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of interest in her and her pregnancy as proof that she is unworthy and not important enough to care about. She said:

> *Ja, want ek het gedink toe ek swanger was, ag man, hulle gee nie om nie ... so ek is maar nou 'n niks nie.* [Yes, because when I was pregnant, I thought they do not care … so I am a nobody.]

For Flora, the feeling that nobody cares, made her feel that she had no reason to care either and that fuelled her drinking. She said:

> *Vir my het dit gevoel hier's niemand wat omgee vir my nie, so ek drink maar*. [To me it felt there is nobody who cares about me, so I drink.]

Ansa, too, felt nobody in her community cared about her when she said:

> ... *die mense gee nie vir mens om nie*. [... the people do not care about you.]

For Celia the feeling of not being cared about was extended to not even expecting any kind of support from anybody, not even from her children. She felt:

> *Niemand gaan my help nie, nie eers my kinders nie, niemand nie*. [Nobody is going to help me, not even my children, nobody.]

Despite these women's needs for support, the lack thereof convinced them that they did not matter and should not expect anything more, correlating with the findings of Van Schalkwyk and Naidoo (2021a). It further confirms the opinion of Spedding et al. (2020), that psychological distress is intensified by social factors, indicating a need for a combination of social work and psychological services in the lives of high-risk drinking women.

### 6.4.7 Theme 7: Availability of services and a need for more services

Adebiyi et al. (2021) describe services for FASD prevention and intervention in SA as "fragmented". This correlates with the findings of De Vries (2012) that there is a lack of coordination and collaboration between role players in this field. From a biopsychosocial point of view, services regarding FASD prevention and interventions should address biological needs such as health needs, psychological services such as mental health needs as well as social services including legal services, social work

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interventions and community support as described in chapter three (Garland et al., 2011). Health services, mental health services, legal services, social services, and community support are, therefore, used as the five sub-themes of this theme.

#### *6.4.7.1 Theme 7 – Sub-theme 1: Health services*

Study participants were asked about the nature of the services they received in the primary health care system, their satisfaction with antenatal services in both primary health care and high-risk clinics and what information they received concerning health care as well as alcohol and other substance use in pregnancy. The responses of the study participants are divided into two categories: primary health care services and a need for communication.

#### *a) Category – Primary health care services*

All six study participants made use of primary health care services. They all visited primary health care clinics in the Langeberg Municipal area where they received antenatal services and gave birth in the district or regional hospitals. Some of the study participants did not have any health issues during their pregnancy and only had routine visits to the antenatal clinics during their pregnancy, while some had high risk pregnancies requiring regular visits to the high-risk clinic at the regional hospital in Worcester. The study participants' accounts of the health care service they received, did not reflect the importance of detecting alcohol use in pregnant women as a priority in health care as described in literature (Dozet, Burd & Popova, 2021).

In general, they had mostly positive experiences in the clinics and were satisfied with the service provided to them. Drika, who felt that everything health wise was done for her, described the process in the clinic as follows:

> *… gaan jy mos nou, jy moet mos nou elke keer jou "pee" staan en doen. Dan kyk hulle jou suiker, groei en bloeddruk … en dan kyk hulle na my gewig en groei die baba of is hy nou baie klein …* [… when you go to the clinic, you must give urine for a test every time. Then they check your blood sugar, growth, and blood pressure … They then checked my weight and the baby's growth to see if it is very small …]

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Flora agreed, stating that her hypertension was regularly monitored during her pregnancy and that she also received medication to help her cope with her stressful life before her pregnancy:

> *Hulle het vir my op hoë bloed pille gesit en op die strespilletjie en so twee of drie dae weer my hoë bloed vat om te kyk hoe hoog is my hoë bloed. Ja, daar was hulp gewees.* [They gave me tablets for <u>high blood pressure</u> and a tablet for <u>stress</u> and, every two or three days, my blood pressure was taken again to monitor it. Yes, there was help.]

Although the study participants accepted that there was limited time available in the clinics, it was also clear that they avoided the clinics unless they had more serious problems and had no choice but to go to a clinic. This correlates with findings stating that the long waiting times in primary health care clinics have been a cause of concern over many years (Karat, McCreesh, Baisley, Govender, Kallon, Kielman, MacGregor, Vassal, Yates & Grant, 2021). This study indicates that the general waiting time in clinics are around 2.5 hours, but the reality is that this can be much longer in smaller, underserviced clinics. As Ansa explained:

> *Omdat, om vir mevrou die waarheid te sê, mens sit lank by die kliniek en … as dit miskien nou nie te erg is nie dan gaan jy nie, maar ... as jy nou daar moet wees dan moet jy maar geduldig [wag] tot jy gehelp word*. [Because, to tell you the truth, one has to sit and <u>wait for long</u> at the clinic and … if it is not too bad, then you do not go but when you have to be there, you have to <u>wait patiently</u> until you are helped.]

When asked if they received any information regarding alcohol use in pregnancy at the antenatal clinics, the following responses were given:

> Drika: *Ek dink nie so nie. Daar is mos 'n plakkaat wat wys*. [I do not think so, but there is <u>a poster</u> that shows it.]

> Flora: *Want ons het mos altyd boekies gekry by die kliniek om te wys swanger moeders mag nie drink nie.* [We always <u>received pamphlets</u> from the clinic that showed that pregnant mothers should not drink.]

> Emily: [*By] die kliniek ook, mense het ook vir ons pamflette gegee*. [At the clinic too, there were people who <u>gave us pamphlets</u>.]

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From these responses it can be concluded that, although there is some effort on the part of the primary health care clinics to convey information regarding alcohol use in pregnancy via posters and pamphlets, none of the study participants could recall a personal conversation in the clinics informing them about the dangers of alcohol use during pregnancy. One of the procedural steps required for a first antenatal visit is taking a full history about alcohol use and other drug use (Department of Health, 2016). Additionally, the First 1 000 days programme of the Western Cape Department of Health, has education, screening and referral for alcohol use disorders listed as part of their Maternal and Child Health care programmes in antenatal clinics (Western Cape Government, 2021). This finding implies that primary health care clinics are not yet following the advice of literature regarding the integration of alcohol use information in pre-natal screening, the application of multifaceted healthcare interventions or even brief interventions to prevent alcohol use in pregnancy (May et al., 2008; Odendaal et al., 2020).

The services received at the high-risk clinic and the regional hospital in Worcester, were commended by the study participants. They felt they were treated as human beings and were satisfied with the quality of service they were provided with. Emily had a very positive experience with her attendance of the high-risk clinic and her week-long stay in Worcester Hospital during the birth of her baby:

> *… ek het vir al die scans gegaan mevrou. Op 38 weke toe is dit die laaste wat ek gegaan het. Toe bly ek nou sommer in Worcester. En voor daai, ek het elke tweede, derde maand dan gaan ek op … toe ek vir die laaste scan Worcester toe gaan, toe tel hulle dit op dat ek te veel vrugwater het … Worcester se dokters is baie goed mevrou. Ja baie goed. Jy voel eintlik lekker as jy daar gewees het mevrou… Hulle het nie jou stief behandel of so nie. Jou goed het nooit weggeraak of so nie.* [… I went for all the scans. At 38 weeks I went for the last time. I had to stay in Worcester that time. And before that, I went every second or third month … Worcester's <u>doctors are very good</u>. Yes, very good. <u>You feel good</u> when you were there … They <u>did not ill treat you</u> or anything. Your <u>things never got lost</u> or nothing.]

Odendaal et al. (2020) postulate that much can be done to educate pregnant women to accept responsibility for the health of their unborn children and that the Department of Health has an important role to play in this regard. The First 1 000 Days programme already offers the opportunity to carry out the mandate of the Department of Health in

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this regard (Western Cape Government, 2021). This points to a need for better communication within health services but also between health providers and patients. This aspect will be deliberated in the next category.

***b) Category – A need for communication***

Despite a general satisfaction with the health services received in both the primary health care and high-risk antenatal clinics, there were aspects of the health services that were pointed out as unsatisfactory. Especially communication and the transfer of information seemed to be problematic. Several study participants felt they did not receive the information they needed to understand why their pregnancies were seen as high risk or given guidance on how to take better care of themselves as indicated by Odendaal et al. (2020).

> Drika: *Nee, ek het nie vrae gevra ... nie... Daar is nie nog vrae gevra vir ons nie*. [No, I did not ask questions ... We were not asked any questions either.]

> Bella: *Hulle kon my meer gehelp het. Die ding is, ek het gegaan toe het hulle gesê ek is 'n hoë risiko, maar hulle het my nooit verder verwys nie… Daar is net gesê: "Daar is jou datum vir Worcester. Jy's op high risk, gaan net daar sonar." Dis al. Ek het nie geweet hoekom is ek "high risk" nie. Ek het vrae gevra, maar hulle het my nie geantwoord nie.* [They could have done more to help me. The thing is, I went when they said I am high-risk, but they never referred me any further... They only said: "There is your date to go to Worcester. You are high risk, go for an ultra-sound there." That is all. I did not know why I am high risk. I asked questions but they *did not answer* me.]

It can thus be concluded from the study participants' remarks that the primary health care clinics provided the basic health care services when they were most needed. Though most services were delivered effectively in the clinics, the lack of time available discouraged study participants to ask questions or to gather information that could help them understand their medical conditions and take better care of themselves. They mostly did as they were told without a clear understanding of what their situation was or why they had to do things in certain ways. This is in contrast with the opinion of Rehner et al. (2017) that primary care clinics are important resources for the integration of care and interventions focussing on behavioural health changes to improve individual well-being. This, again, places emphasis on the importance of the role of the

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Department of Health to clearly communicate information that can lead to lifestyle changes improving the health of unborn children (Odendaal et al., 2020).

#### *6.4.7.2 Theme 7 – Sub-theme 2: Mental health services*

Garland et al. (2011) describe stress as a key-factor in the development of alcohol dependence. These authors further acknowledge the contribution of interpersonal, individual, and environmental factors in alcohol abuse. May et al. (2008) emphasised the fact that SA women who drank excessively in pregnancy were often exposed to severely stressful situations. As described in chapter three, alcohol abuse goes hand in hand with mental health problems including depression, anxiety, and other psychiatric conditions (Coriale et al., 2019; McLafferty et al., 2016). This is a clear indication that mental health services should be an essential part of the services to alcohol using pregnant women.

As described in theme six, some of the study participants suffered from depression and at some point, made use of mental health services. The narratives indicated a need for psychologists and counselling services as discussed below.

#### *a) Category – A need for interventions*

Only two of the study participants, Bella, and Flora, received services from psychologists during their lifetime. Bella felt that this service did not help her much:

> *Want ek het sielkundige geloop by die hospitaal, maar dit het vir my gevoel dit help nie.* [Because I saw the psychologist at the hospital, but I did not feel that it helped me.]

Flora, on the contrary, felt that she benefitted from her visits to the psychologist, but had the unrealistic expectation that it should change her circumstances at home. The need for social interventions in the environment of alcohol abusing women is acknowledged in literature (Eaton et al., 2012). Flora's expectation of change in her social environment, would better fit the role and task of a social worker. Collaboration between social workers and health care providers have been proven to be beneficial to patients in need of multidimensional services (Rehner et al., 2017). In Flora's case, such collaboration would undoubtedly benefit her and her family who need both social work and mental health services. Flora now acknowledges that she felt better after her

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sessions with the psychologist and that talking about her feelings, might help her feel better again, help her to drink less and to improve her relationship with her children:

> *Ek het 'n bietjie verligting gevoel maar ek weet nie hoekom het ek dit gekanselleer het vanself nie. En agterna toe voel ek tog spyt ... Maar ek het 'n bietjie beter gevoel by die sielkundige ... Vir my is dit, as ek die sielkundige gaan sien, sal ek minder kan drink en dan sal ek 'n goeie verhouding hê met [my kinders].* [I felt a bit of relief, but I do not know why I cancelled it myself. Afterwards, I felt sorry … But I felt a bit better going to the psychologist … I feel that, if I go and see a psychologist, I will be able to drink less and then I will have a better relationship with my children.]

Flora's referral to the damage her emotional suffering is causing her children, is a confirmation of the view of Van Schalkwyk and Naidoo (2021a) that a mother's mental health affects her capacity for parenting as discussed in theme two. This confirms the importance of collaboration, the coordination of services and referrals between health and social work services (De Vries, 2012).

Due to the difficulty accessing professional mental health services, some study participants devised their own, mostly unhealthy, ways to cope with their circumstances. In accordance with the findings of Van Schalkwyk and Naidoo (2021a) Celia and Flora admit that they drink to cope with circumstances at home:

> Celia: *Toe die probleme kom toe het ek ook begin drink.* [When the problems began, I started drinking too.]
>
> Flora: *Of die stress tyd kom, dan vat ek daai glas* ... [When stressful times come, I take that glass …]

Although Bella was still contemplating the option of seeing a psychologist again, she acknowledged her need for support and came up with the idea of a support group for women:

> *Ek het gedink ek moet maar vir my by 'n groep gaan aansluit waar dat ek net kan praat as ek stress vat maar ek weet nie waarnatoe nie.* [I thought I should join a group where I can talk when I am stressed, but I do not know where to go.]

The need for peer support and stronger support networks to strengthen women in high-risk communities is confirmed by Van Schalkwyk (2021). The need to talk to someone

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who understands and listens without judgement, will be further discussed in sub-theme four of theme seven. It should, in conclusion, be kept in mind that the study participants had difficulty expressing their mental health needs because, in their view, the solutions for their problems lie in practical actions and changes in their social environments.

#### *6.4.7.3 Theme 7 – Sub-theme 3: Legal services*

Study participants' encounters with law enforcement services was often due to domestic violence and mostly included contact with the police and magistrate's court concerning protection orders. The extent of domestic violence in SA is such that the state president, Mr. Cyril Ramaphosa, in his 10 February 2022 State of the Nation Address, described domestic violence as SA's "second pandemic" (State of the nation address by President Cyril Ramaphosa, 2022). Despite the intension of The Domestic Violence Act, Act No. 16 of 1999 to decrease the prevalence of domestic violence, the problem prevails with severe and often lifelong effects for women (Slabbert, 2010). The stories of women in this study, reflect the difficulties they encountered getting help and protection as well as their lack of trust in the willingness and ability of the police to assist them. Their experiences and narratives are summarised in two categories, the South African Police Service and protection orders.

##### *a) Category – The South African Police Service*

South African studies (Retief & Green, 2015; Slabbert, 2010) indicate that victims of domestic violence do not trust the police or the interventions they are capable of and feel their actions are in many cases insensitive and incompetent. This finding was confirmed with participants in this study who pointed fingers at the police and the way they handled matters regarding domestic violence. In several cases the police did not believe the women about the abuse or accused the women of being the perpetrators because they seemed intoxicated. Similar experiences of women who were further traumatised by the reaction of the police, is described by Retief and Green (2015) as well as Slabbert (2010).

The Domestic Violence Act (DVA) no. 118 of 1998, requires from the police to explain to victims of domestic violence that it is the responsibility of the police to assist them in whichever way they need and to find them the services they may require (Retief & Green, 2015; Vetten, 2005). As Celia shared, this is not what she experienced:

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> *Niemand wil my glo nie. Die polisie het my al kom laai. Hulle staan nie my kant nie. Hy het my geslaan, maar as ek hier ingaan, hulle wil niks weet nie van my saak nie. Ek bly net dronk, maar ek is nie eers dronk as daar inkom nie. Dan sê hy sommer klaar vir hulle: "Sy's gesuip."* [Nobody wants to believe me. The police have picked me up. They do not take my side. He beat me, but when I go in, they do not want to take my case. They just say I am drunk, but I am not even drunk when I go there. He tells them beforehand: "She is inebriated."]

Celia was desperate about her situation and the ongoing abuse she suffers:

> *Ek soek hulp! Niemand wil my help nie mevrou. Niemand het my gehelp nie.* [I am trying to find help!! Nobody wants to help me. Nobody helped me.]

Her plea resonates with that of many women who, in the researcher's experience as social worker over many years, have found especially the police service inaccessible and impassive in cases of domestic violence. These experiences further correlate with findings that the police often do not know how to act when a man presents himself respectably and pretends that nothing had happened (Slabbert, 2010; Retief & Green, 2015). This situation is described effectively by Celia's narrative under the heading "Emotional violence" in sub-theme two of theme four.

#### *b) Category – Protection orders*

Although the aim of the DVA in theory is to protect victims of domestic violence, there are still challenges and obstacles preventing its success (Slabbert, 2016). The withdrawal of applications for protection orders, is one of these challenges that was also highlighted by this study. Flora described a long history of applying for protection orders, being manipulated to withdraw them and the constant underlying hope that going to apply for a protection order will bring about the change she so desperately wants. However, even applying for a protection order can be challenging, especially for women who do not have a good comprehension of how the system works. In table 6.8 below, narratives of the study participants regarding their experiences with obtaining protection orders are given.

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**Table 6.8: Experiences obtaining protection orders**

| Theme 7: Availability of services and a need for more services | | |
|---|---|---|
| **Sub-theme 3** | **Category** | **Quotes from interviews** |
| Legal services | Protection orders | Flora: *Ek het hof toe gegaan maar as 'n vroumens mos lief is vir 'n man, jy's so verlief dat jy die sake loop terugtrek en so aan, maar hy doen weer dieselfde.* [I went to court but, when you love a man, you are so in love that you withdraw the case, but he does the same thing again.]<br>Celia: *Ek het al hof toe. Die mense sê vir my ek moet vir hom sê ... [hy] moet tot by hulle kom. Ek sê: "Hulle sal nie mevrou. Gaan tot by hulle dan gaan help mevrou vir my."* [I have been to court. The people told me to tell him to… come to them. I told them: "He will not. You must go to him if you want to help me.]<br>Flora: *Ons gaan hof toe soos hy my nou altyd soebat ek moet die sake terugtrek. Dan trek ek die sake terug. Kom ons by die huis dan is alles weer dieselfde. Dan het ek klaar die saak teruggetrek. Dan is hy maar net dieselfde*. [We go to court, but he always begs me to withdraw the case. I then withdraw it. When we get home, everything is the same again. Then he is just the same again.]<br>Bella: *Hy het nog ander sake ook gehad vir aanranding... Toe kom hy uit en toe elke keer moet ek hoor dis deur my dat hy sy werk verloor het.* [He had other cases of assault against him too... When he got out of jail, he told me time and again it was my fault that he lost his job.] |

These narratives indicate that, although the DVA sets out the possibility and process to obtain protection orders, there are underlying problems such as a lack of understanding of the system, a lack of practical help to follow through with the process of application and court appearance in addition to the lack of action by die police. In correspondence with literature (Matsika, 2021; Retief & Green, 2015; Slabbert, 2010), these findings indicate a need for practical assistance and support for women to navigate their way through obtaining protection orders. In the next sub-theme, social services will be deliberated.

#### *6.4.7.4 Theme 7 – Sub-theme 4: Social services*

The role and contribution of social factors in alcohol use behaviour causing FASD is well established (May et al., 2008; May et al., 2013; May et al., 2021; Olivier, 2017). The social determinants of health and its inter-connectedness with the health determinants of social well-being are increasingly acknowledged as of equal

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importance in an individual's general well-being (Adebiyi et al., 2019a; Berzoff & Drisco, 2015). This emphasises the important role of social work services in both prevention and intervention services with high-risk drinking women and adds to the view of Brekke (2012) that social workers should promote an understanding of the consequences of the exclusion and disregard of social factors in disease.

The sub-theme "social services" is discussed in three categories, namely, the influence of perceptions of social work services on the use of services, a need for practical help and a need for counselling for children.

#### *a) Perceptions of social work services*

Despite the growing notion of the role of social workers in interventions relating to FASD, none of the participants in this study were recipients of services by a social worker either at the time of their pregnancy or when interviewed, nor did they indicate that they have received social work services during their lifetime. Given the fact that these women were all high-risk drinkers at the time of their pregnancy, some lived in households where excessive violence was common, experienced trauma and loss during their lifetimes and had children who were exposed to abysmal social circumstances, the involvement of a social worker in their lives should have been non-negotiable. However, this is a clear indication of the shortage of and the need for comprehensive social work services in South African communities.

Although several of the study participants indicated that they had no-one to support them, they either did not think about the possibility of getting the help of a social worker or feared that a social worker's involvement might lead to the removal of their children. This fear was echoed by mothers in a study by Van Schalkwyk (2021) who realised that their alcohol abuse had negative implications for their children. Some verbalised being threatened with the removal of their children, while others described the shock following alternative placement of their children. Flora mentioned these matters as reasons why she did not seek help from a social worker.

> *Om eerlik te wees mevrou, ek het nog nooit aan dit gedink eers nie … Ek het nooit gaan hulp soek om my op te bou nie, want soek ek die hulp, ek bly dan nog in daai donker gat … Dis dit wat nou oor my gaan, want deel ek nou saam met hulle dan gaan hulle vir my so vat, OK, ek is 'n slegte ma en so en dan gaan hulle my kinders*

> *vat. Dis dit wat my bang laat voel. So, dis amper vir my bly maar met die probleme want kyk hoe groot is hulle klaar nou om hulle weg te vat van my af.* [To be honest, I never even thought about it … I have never looked for help to build me up because, even if I look for help, I am still living in that dark hole … That is what I am thinking of because if I share my life with them, they might think that I am a bad mother, and then they will take my children away. That makes me feel scared. So, for me it is almost better to rather deal with my problems because the children are so big already. It would be a shame to take them away from me now."]

Despite their hesitation to make use of the services of a social worker, all the study participants felt free to talk in the non-threatening, non-judgmental, emphatic environment created by MI as described in chapter four (Miller & Rollnick, 2009). Several study participants mentioned that they felt that they were listened to, that they were heard and that they could tell their project officer anything and still be supported and accepted despite their failures. This emphasises the role of the social worker as an emphatic listener, non-judgmental supporter, and a sounding-board for decision-making rather than an advisor and decision-maker. This view is supported by the successes of using MI in CM as described in chapter four (May et al., 2013; Miller & Rollnick, 2009).

Celia gave a clear description of how CM made her feel worthy and enabled her to stay sober in pregnancy:

> *"… dis net mevrou-hulle wat hier gekom het toe mevrou-hulle vir my so kom ontmoet het ... Toe hulle so baie kom na my toe en hulle maak hulle tuis by my huis. Dis amper hulle behoort daar. Ek het vir myself ook gesê: "Ek voel nie meer om te drink nie." Want dit wat ek loop soos hier by hulle. Hulle is goed. Hulle kom elke maand of so kom hulle. Hoekom wil ek drink?* [… it is only your team who came here when they met with me ... When they came to me so often and they made themselves at home in my house. It was almost as if they belonged there. I also told myself: "I don't feel like drinking anymore." Because of this I am attending with them. They are good. They come every month or so. Why would I want to drink?]

Bella echoed the same sentiments:

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> *Ja, en as ek so moedeloos binne raak … dan sit ek en gesels ek met haar dan praat sy vir my weer moed in. Dan het ek miskien besluit ek gaan nou drink, dan praat sy vir my weer moed in, dan sê ek vir myself nee man, los die wyn.* [Yes, when I felt so discouraged on the inside … then I would sit and talk to her, and she would encourage me. Then I have maybe already decided to drink, but she would encourage me, and I would tell myself to let go of the wine.]

Both Celia and Bella's stories indicate that the decision to stop drinking, was theirs. Once again, this indicates that the role of the social worker where high-risk drinking pregnant women are concerned, should rely more on the principles and techniques of MI, which aims to listen and reflect what was heard, create a non-judgmental, non-threatening environment where the woman feels safe to make her own decisions based on her own evaluation of where change is most needed (De Vries et al., 2015; May et al., 2013; Miller & Rollnick, 2009).

#### ***b) Category – A need for practical help***

According to De Vries et al. (2015) SA women are battling socio-economic needs and realities, poor living conditions and a culture of institutionalised drinking with few resources to aid them in this struggle. Van Schalkwyk and Naidoo (2021a) add that the context of life in high-risk communities must be understood to bring about change in the lives of women and children living in those communities. With limited resources and little support, many women do not know where to turn to, how to help themselves and are further disempowered by poverty, domestic violence, and a lack of information about resources. Study participants expressed different needs for help ranging from help with relationships, a need for food in tough times, to help with abusive partners in the following ways:

> Celia: *Toe gaan huil ek by meneer. Toe sê ek ek kan nie meer nie. As meneer nie 'n plan maak nie dan gaan ek maar liewerste die werk bedank.* [Then I went to my employer and cried. I told him I cannot take it anymore. If you do not make a plan, I will rather resign from my job.]

> Ansa: *As jy nou miskien nie iets het nie, moet jy maar vir jou iemand kry by wie jy kan geld leen en weer die persoon se geld teruggee*. [If there is something you do not have, you must get someone from whom you can borrow money and give it back later.]

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Celia and Ansa could both verbalise the kind of help they needed, but for Flora it was hard to even contemplate what kind of help she needed. She knew she needed change in her household and help with her abusive husband, but she felt too powerless to even think of what kind of help she would need to bring about those changes. Being a battered woman herself, her feelings of being powerless and left to fight her own battles, is similar to those of abused women as described in literature (Matsika, 2021) and also reflects the struggles of women in high-risk communities (Van Schalkwyk, 2021). In the next category, study participants' need for counselling for their children will be discussed.

#### *c) Category – A need for counselling for children*

Van Schalkwyk and Naidoo (2021a) state that raising and educating children is an integral part of motherhood but that effectively raising children can be compromised by the circumstances in which they grow up. This study further indicates that mothers may be aware of the physical and emotional dangers their children are exposed to but that the safety and well-being of children cannot be guaranteed in high-risk communities. This correlates with Hall and Mokomane (2018) stating that the growth, safety, and development of children is best served in functional families. Mothers in this study reflected similar concerns about their children:

> Flora: *Ek sal probeer veral vir John*. Hy is baie eensaam ... Hulle wil eintlik net 'n bietjie deel met hom. Wat gaan aan in sy lewe. Hoekom is hy so.* [I want to try, especially for John. He is very lonely … They should <u>just talk to him</u> a bit. <u>What is going on</u> in his life. <u>Why</u> he is the way he is.]

> Celia: *Maar dit lyk vir my die kind, die oudste kind ..., het klaar te ver … Maar ek sê ek gaan nie dat mense sê hys te ver nie. Ek kan nog my kind help.* [But it seems to me the child, the oldest child … is too far gone … But I am not going to allow other people to say he is too far gone. I can still <u>help my child.</u>]

> Bella: *By hom is dit, ag julle praat maar net maar ek weet hoe my kinders voel want ek sien hoe tree hulle op.* [He thinks we are just talking, but I <u>know how my children feel</u> because I <u>see the way they act.</u>]

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The researcher observed that, when these mothers talked about their children's needs and suffering, they were further traumatised by their own inability to know what to do or where to find the help they so desperately wanted for their children. This correlates with the findings of Van Schalkwyk (2021) that mothers in a high-risk community in the WCP realised that their children would become increasingly dependent on others or might even be removed from their care should they not take action to bring about change. This finding implies that the task of the social worker cannot only be seeing to the physical safety of children, but that their social, emotional, and psychological well-being should be considered too. This, again, demonstrates the applicability of the biopsychosocial model as discussed in chapter three, in dysfunctional families. In the next section, sub-theme five "community support," will be discussed.

#### *6.4.7.5 Theme 7 – Subtheme 5: Community support*

The role of community support in alcohol and substance abuse disorders, is highlighted by the CRA, an approach used in combination with MI during the CM process. The purpose of the CRA is to involve the woman's family, friends, and partner to support her and thereby enable her to bring about change in her lifestyle (May et al., 2013). This sub-theme is divided into two categories, family support and the disposition of the community and its resources.

##### *a) Category – Family support*

Van Schalkwyk (2021) states that mothers in high-risk communities often come from troubled families where they experienced broken relationships and financial hardship, themselves. As discussed in theme two, especially grandmothers play a pivotal role in supporting mothers in various ways, including financially, emotionally and in taking care of the children. In correlation with the findings of Hall and Mokomane (2018), some study participants had extended families on whose support they could count. When Bella's relationship with her partner was disintegrating, she called an aunt who intervened. Bella recounted:

> *... ek het my ma se oudste suster uit Worcester uit laat kom en sy het kom gesit en gesels met ons.* [I had <u>my mother's oldest sister</u> come from Worcester and she <u>sat down</u> with us and <u>talked</u> to us.]

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Maternal aunts were involved with the study participants or seen as family members willing to offer support despite providing little practical help. Flora said:

> *My ma se susters is almal in die Kaap en my antie ... hulle kan my net troos maar hulle kan niks maak nie*. [My mother's sisters are all in Cape Town and my aunt … they can only offer solace but there is nothing they can do.]

What was unexpected from the accounts of the study participants, was the fact that they could not always rely on their siblings for support. Ansa, who mostly interpreted support as financial support, said the following:

> *Nee wat. Hulle is ook maar net so ... Ons kan nie mekaar ondersteun nie mevrou*. [No. They are just like me ... We cannot support each other.]

In contrast to Ansa's view of support, Flora wanted her brother to care about her and listen to her. She explained his disappointing reaction:

> *Praat ek saam met my broer dit, hy lag my eerder uit*. [If I talk to my brother about that, he rather laughs at me.]

Celia is the only study participant with an older sister who took on a more maternal and protective role towards her and often assured her that she is available to help her. These experiences with family members as support systems again highlights the role of the women as support structures in families as discussed in theme two. However, none of the study participants mentioned a male member of the family as someone who supports them. Referring back to the role of partners as discussed in theme four, this observation reflects on the general lack of involvement of men in their families, not only as partners but also as fathers, brothers, and active members of households. This is in keeping with the opinion of Van den Berg and Makusha (Sonke Gender Justice, 2018) that some SA men are not only uninvolved in their children's lives but are overall indifferent and disengaged. These authors call for an improvement in "social fatherhood", which refers to men becoming involved with their families and children in the family who are not necessarily theirs biologically. This call is in keeping with Hall and Mokomane (2018) encouraging co-resident men in homes to engage in "social fathering." The second category of this sub-theme, disposition of the community and its resources, will be deliberated below.

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### b) *Category – Disposition of the community and its resources*

Van Schalkwyk and Naidoo (2021a) state that resilient families have support networks providing them with information, services, and a feeling of belonging. This opinion relates to the CRA and its function to obtain community involvement to support change as described in chapter four (May et al., 2013). Most study participants indicated that they did not receive any or very little support from the communities they live in. A few had a friend or family member who supported and encouraged them, but they mostly felt alone in their struggles. This correlates with Van Schalkwyk's (2019) statement that the strength of families relates to their use of resources, even in low resourced communities. When asked how she felt knowing that she had no support from her community other than that of her mother and partner, Ansa answered:

> *Ek is al dit nou gewoond. Dit voel normaal*. [I am used to it by now. <u>It feels normal.</u>]

Flora shared her experience of being on her own and having no support from her community by saying:

> *Daar's nie iemand wat miskien nou vir my kan oplig nie, die een druk my eerder af.* [There is <u>no-one who can possibly lift me up</u>, they rather push me down.]

Bella, too, confirmed that she did not get any encouragement from her community when she said:

> *Aanmoediging, niks nie.* [<u>Encouragement, nothing.</u>]

Study participants were probed about the possible involvement of resources such as churches as support structures. This was done with the protective role of religiosity against having a child with FASD, in mind (May et al., 2008). Contrasting reactions were given. Bella, who grew up in a Christian household and regularly attended church activities when she was younger, at some point tried to join the church community again, because she thought she would be supported and welcomed back in their midst. She was very disappointed when the person she chose to share her struggles with, pushed her away and had excuses not to be seen with her at church. Matsika (2021) discusses similar experiences by women exposed to domestic violence. Bella's experience left her with a lack of trust in churchgoers, which she expressed as:

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> *Deesdae sal mense, ook die susters en broers as jy gesels, dra dit weer oor na 'n ander suster toe, [en nog] 'n ander suster. So, ek sê nee*. [Nowadays the people, the brothers, and sisters you talk to also tell it to another sister and another sister. So, I say no.]

However, belonging to a church community and being supported by the members of the congregation, is partly what kept Celia sober during her pregnancy, helped Flora stay sober for a period of 14 months and still supports Emily to maintain sobriety. Slabbert (2010) validates these experiences by stating that religiosity enables people to cope with the difficulties of life, gives hope for the future and a sense of purpose in life. The role of the church in offering support to women exposed to domestic violence and the unique opportunity it has to break the silence about domestic violence, is emphasised in literature (Zust, Opdahl, Moses, Schubert & Timmerman, 2021). From Bella's response it was clear that she too, longed to be accepted and welcomed into the church community. The difference the support and influence of the church can have, is clearly explained in Emily's experience:

> *Dit help my baie mevrou. Ons het gister … kerk gehad. Ons het nagmaal gehad en jy kan voel die Here was tussen ons, begenadigdes oor ons gewees. Ons is maar vyf wat saam kerk hou … Maar ons is baie gelukkig tussen mekaar mevoru. Ons moedig mekaar aan, gee vir mekaar drukkies, so. Ons is, vir ons is dit ons het nie COVID nie, daars nie COVID tussen ons nie. So is ons. Ons het daai liefdesband tussen ons.* [It helps me a lot. We had a church service yesterday. We shared Holy Communion and could feel that the Lord is amongst us, his mercy is over us. We are only five people who gather … But we are very happy to be together. We encourage each other, give each other hugs and so. For us it is as if there is no COVID, there is not COVID between us. That is how we are. We have that bond of love between us.]

The role of the church and religion to enable women to stay sober, is confirmed by May et al. (2008) who state that women who are more religious, are less prone to alcohol abuse and producing children with FASD. Zust et al. (2021) add to this by stating that the church, by often taking a conservative and patriarchal stance, may create the impression that domestic violence is condoned by encouraging women to be submissive to their husbands. To achieve the goal of reducing the prevalence of FASD and supporting women through tough times, a range of social services are needed to

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help women realise their inner strengths and enable them to use it. This can only be done in concurrence with improvement of the accessibility of all available resources including physical and mental health resources, social work services, and community resources (May et al., 2013).

## 6.5 CONCLUSION

One of the objectives of this study was to empirically investigate the realities and needs of women with high-risk drinking behaviour in pregnancy. Against the backdrop of the biopsychosocial perspective, this was achieved with the use of semi-structured interviews and accessing information from their file content while they were involved in a study assessing the efficacy of CM as a means of tertiary prevention of FASD. This aim is pursued further to portray the lives and lived realities of women with a high risk for having a child with FASD summarising their lives, experiences, challenges, and struggles in their "stories". The intention of telling their "stories" is not to portray the women as helpless victims of their circumstances, but to create a better understanding of the biological, psychological, and social needs of high-risk drinking pregnant women.

To plan and execute effective prevention services and interventions, it is imperative for social workers and all other role players to understand that FASD is a complex condition that cannot be prevented by single, uncoordinated efforts. The "stories" of these women tell us about the need for combined and coordinated efforts to educate, inform, support, and provide practical assistance. This cannot be achieved by the fragmented and haphazard way FASD prevention is dealt with in SA. To move forward, these women's "stories" tell us that we need to address the lack of strategy, services, community involvement and, especially, the need for government involvement to create policies and structures to ensure coordinated and collaborative interventions for the prevention of FASD.

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# CHAPTER 7
# CONCLUSIONS AND RECOMMENDATIONS

## 7.1 INTRODUCTION

The aim of this study was to gain an in-depth understanding of the lives, realities and needs of women with a high risk of having a child with FASD. This was done from an insider's perspective, telling the "story" of each participant to portray the realities of the daily lives of these high-risk women. In this chapter, the fifth objective of this study will be fulfilled by making conclusions and recommendations for more effective FASD prevention and support services. The recommendations seek to contribute to an understanding of the important roles of health care providers, social service professionals such as social workers, communities, organisations, and policy makers in shaping FASD prevention, intervention, and support services.

Furthermore, the study aimed to answer the following secondary research questions to help service providers, and especially social work professionals, to address the phenomenon of FASD in a more effective way:

1. What are the life experiences and realities of high risk drinking pregnant women?
2. How do these experiences and realities influence their choices, especially during pregnancy?
3. Why do some women succeed in changing their drinking behaviour, whilst others continue their lifestyle despite interventions to support changes to their drinking behaviour in pregnancy?

To reach conclusions regarding these questions, a literature review was done, the research methodology was described, and empirical findings were presented. Chapter two provided a detailed description of the effects of prenatal alcohol exposure on the developing fetus, as well as the long-term effects on the functioning and health of the affected individual. In chapter three, the biopsychosocial model was used as the theoretical framework to analyse the maternal risk factors for FASD, FASD prevention efforts, support services to high risk drinking pregnant women and FASD policy. Chapter four gave a description of the three levels of prevention, FASD prevention

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efforts around the world and information on what is currently being done in SA. Case management (CM) as a method of indicated or tertiary prevention was also described in this chapter. Since CM as a method of social work is well-known and regularly used by social workers, the use of this method is linked to FASD prevention with the social worker as part of the multi-disciplinary team. Chapter five described the research methodology and the research process followed according to the four phases and thirteen steps suggested by Fouché (2021). In chapter six the results of the empirical study were analysed and discussed. This chapter will focus on reaching conclusions and making recommendations to effectively prevent FASD and for social workers to render the support services pregnant women need to enable them to change their drinking behaviour.

## 7.2 CONCLUSIONS AND RECOMMENDATIONS

The conclusions and recommendations are presented according to the following seven themes identified in the data-analyses:

- Theme 1 – Childhood
- Theme 2 – Intergenerational patterns
- Theme 3 – Level of education and work circumstances
- Theme 4 – The role of partners
- Theme 5 – Pregnancies and children
- Theme 6 – Psychological factors
- Theme 7 – Availability of services and a need for more services

The conclusions and recommendations will be discussed below. This will be done according to the seven themes above.

### 7.2.1 Theme 1 – Childhood

#### *7.2.1.1 Findings and conclusions*

The **findings** of this study indicate that several childhood factors can be linked to high-risk alcohol use behaviour in pregnancy. These factors include instability in childhood. Growing up in single parent households and broken homes were contributing factors to childhood instability. Another **finding** was that the realities of migrant labour and

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grandmothers accepting full responsibility to raise their grandchildren, influenced the relationship between mothers and their children, leading to a disruption of their lives and sense of belonging when they had to move back to their mothers' care. Another **finding** was that there was no grief counselling or any other form of therapy for women who experienced childhood trauma. The traumas experienced by this cohort of women included the death of caretakers, having to adapt in a new household and to completely different circumstances that included abuse and rejection. The significance of poverty as a contributing factor to childhood instability was confirmed in this study. Another **finding** was that all of the study participants displayed high-risk behaviour as adolescents. This behaviour included the early onset of drinking in which they were influenced by their friends. In addition, they all had unplanned teenage pregnancies.

A **conclusion** drawn from these findings is that this cohort of high-risk pregnant women experienced instability and trauma in childhood. Another **conclusion** made is that all the participants in this study showed high-risk behaviour in adolescence. These behaviours include the early onset of drinking, giving in to peer pressure and teenage pregnancies. Given the fact that none of these women received any form of therapy, counselling or social work services, the **conclusion** is made that there is a need for trauma counselling and social work services to children at risk. It is further **concluded** that effective social work services and counselling can serve as a measure of FASD prevention.

#### *7.2.1.2 Recommendations for practice*

It is recommended that:

- Social workers are cognisant of the fact that childhood trauma can result in high-risk behaviour during adolescence.
- Social workers as part of the multi-disciplinary team provide counselling or are involved in arranging counselling for children who experienced trauma due to the death of a parent or caretaker, were moved to a new caring environment or were exposed to abuse or rejection in the home.
- Social work services to adolescents with high-risk behaviour include counselling and education addressing alcohol use, life skills to manage peer pressure and information on family planning to prevent unwanted, unplanned pregnancies.

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- Social workers acknowledge and fulfil their roles as part of the multi-disciplinary team in delivering services to children and adolescents affected by adverse childhood events.

#### *7.2.1.3 Recommendations for training*

Recommendations for training are:

- Training to social workers to enhance their ability to counsel children who have experienced traumatic events.
- Training to social workers to understand and address the psychological and social needs of at-risk adolescents.
- Training to social workers to understand the functioning of a multi-disciplinary team and the role of the social worker as a member of such a team.

### 7.2.2 Theme 2 – Intergenerational patterns

#### *7.2.2.1 Findings and conclusions*

The **findings** of this study show that drinking patterns, especially the embedded pattern of weekend binge-drinking in the Western Cape Province (WCP), are transferred from one generation to the next. Weekend binge-drinking is a lifestyle where social engagement is tied to alcohol use. The **findings** reflect that this lifestyle already starts early in adolescence and, in some cases, even before adolescence. The **findings** further indicate that the notion that one drinks because that is what you have to do to have fun with your friends, is firmly embedded by the time children reach adolescence.

**Findings** further indicate that mothers and grandmothers influence the view women have of what is acceptable drinking behaviour for women. Even when women did not always follow the example their sober mothers or grandmothers set, they internalised the messages they received about alcohol use. Another **finding** is that high-risk drinking women either lean heavily on the support of their mothers or have a deep desire to be supported by their mothers. Support entailed financial and emotional support as well as support in caring for their children.

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One **conclusion** drawn from this study is that alcohol use behaviour is repeated in intergenerational patterns and is, amongst other factors, influenced by the views and drinking behaviour of mothers and grandmothers. It can also be **concluded** that the view of weekend binge-drinking as a normal and accepted way of socialising, contributes to the early onset of drinking. What starts out as experimenting in early adolescence, often sets in motion a cycle of life events compromising the future of the adolescent.

Another **conclusion** made is that mothers and grandmothers of pregnant women and young mothers, can be utilised as a powerful tool to influence their drinking behaviour.

#### *7.2.2.2 Recommendations for practice*

It is recommended that:

- The positive influence of mothers is strengthened by parenting programmes and peer group support systems.
- Parenting programmes are extended to include grandmothers and extended family members to stress the significant role they have in an intergenerational transfer of attitudes, knowledge, and their experience regarding alcohol use behaviour.
- Children and adolescents from high-risk environments are engaged in life skills training with a focus on lifestyle choices, peer pressure, alcohol use and the prevention of teenage pregnancies.
- Special attention is paid to counselling and supporting children in alternative care as a vulnerable group already exposed to childhood trauma and in need of social work and psychological services.
- Parenting programmes, life skills training, counselling, and supporting the vulnerable are utilised as opportunities for FASD prevention.

#### *7.2.2.3 Recommendations for training*

It is recommended that:

- Training for social workers include the biopsychosocial perspective to enable social workers to link the biological, psychological, and social factors affecting

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individuals. Social factors should include the influence of environmental factors and the various influences of these on the individual, as well as the community.

- Training for social workers to use the group work method in social work to support children at risk and as a means to provide peer support to vulnerable children.

### 7.2.3 Theme 3 – Level of education and work circumstances

#### *7.2.3.1 Findings and conclusions*

One of the **findings** of this study was that none of the high-risk drinking pregnant women completed their high school education. In several cases this was due to financial reasons and parents' inability to provide in their children's physical needs. However, the **findings** also link early termination of schooling to parental attitudes about the importance of schooling. These attitudes included parents' perceptions of how school going children should behave, but also parents' priorities where their own drinking habits were concerned. A further **finding** was that**,** due to their lack of schooling, high-risk drinking women were vulnerable in the labour market. They were often unemployed and dependent on seasonal jobs for an income. This added to their stressful life circumstances. Another **finding** in this study highlights the previously identified link between high-risk drinking patters and farm work. Early termination of schooling not only limits income and job opportunities but enforces a cycle of poverty that is hard to break. It was **found** that the children of high-risk drinking pregnant mothers presented with learning and/or behavioural difficulties that might be attributed to prenatal alcohol exposure. Despite these difficulties and mothers' own feelings of hopelessness, it was found that they continued hoping for a better future and opportunities for their children.

It is **concluded** from the findings of this study that more support is needed for children from vulnerable and poor households to complete their schooling and ensure better opportunities in the labour market. A further **conclusion** drawn is that more focus should be placed on targeted interventions to farm workers addressing their biopsychosocial as well as financial well-being, which all affect future opportunities for their children. This should be done while keeping in mind that farm workers include those workers working on farms but living in the surrounding towns.

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#### *7.2.3.2 Recommendations for practice*

It is recommended that:

- Social workers become involved in employee wellness programmes providing counselling, support, and information to farm workers.
- Social workers form active collaborations with other stakeholders to ensure social justice and provide services that are mutually beneficial to farmers and farm workers.
- Social workers play an active role in ensuring that children complete their schooling.
- Social workers work together with parents, schools, and the Department of Education to enable children to complete their schooling.

#### *7.2.3.3 Recommendations to the Department of Education*

It is recommended that:

- The Department of Education considers employing social workers in all schools in impoverished communities, especially in areas where there is a high prevalence of early termination of schooling.
- The Department of Education and the Department of Social Services collaborate to formulate a plan of action to follow up children with poor school attendance and a high risk for early termination of schooling to prevent children from dropping out of school for social or financial reasons.

#### *7.2.3.4 Recommendations for training*

It is recommended that:

- Social work students receive training in employee wellness programmes and how they should be implemented.
- Social work students' knowledge of existing resources and how it can be utilised, is expanded.

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### 7.2.4 Theme 4 – The role of partners

#### *7.2.4.1 Findings and conclusions*

**Findings** from this study indicate that partners play an important role in the drinking behaviour of high-risk pregnant women. Partners' reactions to the news of pregnancy often set the tone for the support they offered to their pregnant partners. The **findings** show that high-risk pregnant women's drinking behaviour is negatively influenced by partners leaving them or having affairs. Abandonment and affairs add to the stress and pain women experience in their lives and fuel their drinking habits. **Findings** indicate that high-risk drinking pregnant women need both financial and emotional support from their partners. This study confirmed earlier **findings** that high-risk pregnant women's drinking behaviour is related to their partners' alcohol and drug abuse. It was further **found** that domestic violence presented itself in the form of physical violence, emotional violence, and financial violence in the lives of this group of high-risk drinking pregnant women.

It can, therefore, be **concluded** that the role of partners in the drinking behaviour of high-risk pregnant women is still understated and neglected. It can also be **concluded** that partner support is a crucial factor in changing the drinking behaviour of high-risk pregnant women. The **conclusion** was also drawn that financial and emotional support are equally important to these women who were already emotionally and financially vulnerable. A further **conclusion** made is that domestic violence has devastating results for both high-risk drinking women and their unborn children. Physical, emotional, and financial violence adds to these women's feelings of worthlessness and powerlessness. It adds more stress to their already challenging lives and causes serious emotional harm to children in these households.

#### *7.2.4.2 Recommendations for practice*

It is recommended that:

- The role and contribution of fathers is included as an integral part of FASD prevention and support services.
- FASD prevention programmes for men are designed and implemented to give attention to the importance of emotional and financial support, the role of

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partners in the drinking behaviour of women during their pregnancies and the devastating effects of domestic violence on the well-being of women and children.

- Education about FASD is not only focussed on girls but that boys are made aware of their role in FASD prevention from a young age.
- Men are involved in parental guidance programmes to improve education regarding the roles of fathers and men as husbands and partners in the physical, psychological, and social well-being of their families.
- Fathers are educated to take responsibility, to be held accountable for the financial and emotional needs of their children, and to become active role players in the lives and education of their children.

#### *7.2.4.3 Recommendations for the Department of Health*

It is recommended that:

- Fathers are encouraged to attend at least the ultra-sound scans of their partners to create an understanding that the baby is a reality and a person for whom they have a shared responsibility.
- Family planning is promoted as the responsibility of both men and women and that men are encouraged to become actively involved in family planning.

#### *7.2.4.4 Recommendations for training*

It is recommended that:

- Social work students are trained to understand different family structures and the importance of the role of the father in the family.
- Social work students receive training to understand the family as a system and the role of both parents in this system.
- Social work students receive training in the role and functions of the multi-disciplinary team and its different stakeholders, as well as the role and functions of social workers in this team to tend to the well-being of children.

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### 7.2.5 Theme 5 – Pregnancies and children

#### *7.2.5.1 Findings and conclusions*

One of the **findings** of this study is that not one of the women participating in the study had planned their pregnancies. It was further **found** that this led to late recognition of pregnancy and continued drinking in the first trimester of pregnancy. The **findings** of this study confirmed earlier findings that negative attitudes towards pregnancy and stressful life circumstances contributed to continued drinking beyond the first trimester of pregnancy. A further **finding** of this study was that high-risk drinking women continue drinking whilst breastfeeding or started drinking again before their babies were weaned.

It can, therefore, be **concluded** that unplanned pregnancies are a major risk factor in communities where weekend binge-drinking is the norm. The **conclusion** is made that unplanned pregnancies lead to negative attitudes towards the pregnancy and contributes to heavy drinking in at least the first trimester, but often beyond, due to late pregnancy recognition. It is further **concluded** that heavy drinking pregnant women resume their drinking while they are still breastfeeding, causing further damage to their already compromised babies.

#### *7.2.5.2 Recommendations for practice*

It is recommended that:

- Social workers implement the techniques of MI to inform and support all women to plan pregnancies and prevent FASD.
- Social workers make use of group work with adolescents with high-risk behaviour, foster children, foster parents, and parent support groups to inform and educate communities about the risks, realities, and challenges of FASD.
- Social workers make use of peer support groups for pregnant women to create an environment where pregnant women feel more supported and understood.

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#### *7.2.5.3 Recommendations for the Department of Health*

It is recommended that:

- FASD prevention is introduced in family planning clinics to make women more aware of the importance of using their contraceptives correctly, especially if they are using alcohol in any quantity.
- More emphasis is placed on the importance of abstinence from alcohol in pregnancy during first antenatal visits.
- Women are not only asked if they use alcohol in antenatal clinics, but that all pregnant women receive counselling in the form of brief interventions using the techniques of MI at their first antenatal visits.
- Men are involved as active role players in family planning.

#### *7.2.5.4 Recommendations for training*

It is recommended that:

- Current attempts to train social work students in FASD, are expanded to include more information about the biopsychosocial effects of alcohol exposure in pregnancy, as well as the health determinants of social well-being and the social determinants of health influencing women's ability to sustain alcohol free pregnancies.
- Social work students are trained to recognise the possibility that a child might be on the FASD spectrum. This is especially important in vulnerable populations such as neglected children, children in foster care and other alternative care and children of alcohol abusing parents.
- Social work students are trained in the use of MI as a tool in FASD prevention services to high-risk adolescents and women.
- Social work students are trained in the use of assessment tools such as the AUDIT, T-ACE, and CAGE to identify problematic drinking.
- Social work students are trained in the use of prevention and treatment models for FASD such as the CHOICES and SBIRT programmes.

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### 7.2.6 Theme 6 – Psychological factors

#### *7.2.6.1 Findings and conclusions*

One of the **findings** of this study is that several of the women suffered from depression. It was, however, **found** that even if they received medication and, in some cases counselling by the primary health care psychologists, they defaulted on their treatment. Another **finding** was that women have a need for counselling, but that counselling should be accompanied with practical interventions to address the factors causing stress and depression.

It was further **found** that high-risk drinking pregnant women experience feelings of hopelessness, which is related to feeling trapped in their situations because they had nowhere else to go, their circumstances stayed the same and they felt that nobody cares about them.

It can thus be **concluded** that mental health issues such as depression, feelings of hopelessness and powerlessness contribute to heavy drinking during pregnancy. Another **conclusion** made is that there is a need to follow up on patients defaulting on their psychiatric medication and visits to psychologists. It is further **concluded** that mental health services need to go hand-in-hand with social work services to address both the mental health problem and the social factors causing it.

#### *7.2.6.2 Recommendations for practice*

It is recommended that:

- Social workers are aware that high-risk drinking is associated with mental health issues such as depression.
- Social workers refer possible mental health issues for evaluation by psychologists.
- Social workers play an active role in the compilation and functioning of multi-disciplinary teams to ensure continuous services to mental health patients.

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#### *7.2.6.3 Recommendations for training*

It is recommended that:

- Social work students are acquainted with the signs of mental health problems such as depression.
- Training in mental health form a more important part of the syllabus of students in social work.
- Training for social workers include information regarding the link between mental health and drinking patterns.
- Social work students are trained to understand the functions of the multi-disciplinary team in mental health care, and the role and functions of the social worker in such a team.

### 7.2.7 Theme 7 – Availability of services and a need for more services

#### *7.2.7.1 Findings and conclusions*

The **findings** of this study indicate that high-risk drinking women were mostly satisfied with the services they received in the antenatal clinics, although the long waiting time discouraged them to go to the clinic when they had minor health issues. A second **finding** regarding the availability of services was that women in this study experienced a lack of communication, leaving them with uncertainties about their health and diffident to ask questions. Regarding mental health services the **findings** showed that high-risk drinking pregnant women had a need for mental health services coupled with more practical interventions in their social circumstances. These services included taking care of the emotional damage done to their children and counselling for their children. A further **finding** of this study is that high-risk drinking women exposed to domestic violence do not feel protected by the SAPS, experience that they are regarded as the perpetrators when they seek help and experience a need for practical assistance to obtain protection orders.

Regarding the availability and need for social services, it was **found** that there is a need for social work interventions, but that high-risk drinking women have the perception that social workers will remove their children. Women expressed their need

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for practical help, such as assistance handling their tough socio-economic circumstances, help to mend their relationships and counselling for their children.

With regard to community support, **findings** showed that high-risk drinking pregnant women have few support systems in their community. Although some women could rely on their mothers and maternal aunts, there was little involvement by the men in their families. It was further **found** that churches can play a significant role in supporting women, but that this supportive role does not always suffice.

It can thus be **concluded** that high-risk drinking pregnant women need support from a variety of community support systems, including health, mental health, social services, law enforcement and community groups. It can further be **concluded** that, although these services and support systems are available to some extent, the fragmented nature of FASD prevention and support services and the lack of coordination, collaboration, and policy regarding FASD, is failing those most in need of these services.

#### *7.2.7.2 Recommendations for practice*

It is recommended that:

- Given the extent of FASD prevalence in SA, coordination, and collaboration of services between the Departments of Health and Social Services are enhanced and formalised to improve the availability and quality of services rendered for FASD prevention and intervention.
- A formal approach to FASD prevention and intervention between the Departments of Health and Social Services is prioritised as both a health and social service responsibility.
- Social workers use the principles and techniques of Motivational Interviewing and the Community Reinforcement Approach in their support of high-risk drinking pregnant women.
- Social workers work from a biopsychosocial approach in FASD prevention and intervention services, acknowledging the biological, psychological, and social needs of high-risk drinking pregnant women.
- Although protection orders can be obtained directly from the Magistrate's Court, social workers assist women with a lack of understanding of the system and

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offer practical help to follow through with the process of application and court appearance where needed.

- The Department of Social Services and NGOs work with the South African Police Service to train police officials to implement and uphold the principles and instructions of the Domestic Violence Act (DVA) no. 118 of 1998.

#### *7.2.7.3 Recommendations for the Department of Health*

It is recommended that:

- The procedural steps required for a first antenatal visit to take a full history about alcohol use and other drug use as set out by the Department of Health, is followed in all antenatal clinics.
- Screening and referral for alcohol use disorders as suggested by the First 1 000 days programme as part of the Maternal and Child Health care programmes in the Western Cape Department of Health, is fully implemented.
- The National Department of Health become actively involved in FASD prevention programmes and plays a leading role in this regard.
- The Departments of Health and Social Services take the lead in formulating and implementing formal FASD policies mapping out the responsibilities of each sector, as well as the pathways for communication, coordination, and collaboration between all the role players involved.

#### *7.2.7.4 Recommendations for policy*

It is recommended that:

- A national policy for the prevention and management of FASD is developed and implemented.
- The Departments of Health, Social Services, Justice, and Education, assisted by knowledgeable academics and professionals involved in the field of FASD, work together towards developing and implementing such a policy.
- A national policy for the prevention and management of FASD:

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- is holistic,
- makes provision for the biological, psychological, and social factors contributing to the high prevalence of FASD,
- makes provision for prevention services on primary, secondary and tertiary levels of prevention,
- sets out clear pathways for referral between the Departments of Health, Social Services, Justice, and Education,
- addresses the accessibility of alcohol for minors,
- ensures the implementation of existing and new policies to inform women in family planning clinics, antenatal clinics, and all healthcare facilities about the harmful effects of alcohol on the fetus and to promote the use of contraceptives to prevent unplanned, unwanted pregnancies with a high risk for alcohol exposure,
- addresses the health, educational and social needs of alcohol exposed individuals.

### 7.2.8 Further research

This study provides some insight in understanding the complex answer to why women continue drinking during pregnancy, even in situations where they are aware of the detrimental effects of alcohol on the fetus. The research, however, focussed on a small number of women in a specific rural community in the Western Cape Province. Given the fact that these experiences might be different across the borders of culture and communities, it is recommended that further studies:

- explore the stories and realities of more women in different cultures and social environments,
- explore FASD prevention strategies specifically focussed on adolescents,
- investigate the stories and lived experiences of fathers of children with FASD.

### 7.2.9 Conclusion

This study aimed to tell the “stories” and describe the lived experiences of high-risk drinking pregnant women to create an understanding of the complex and intertwining factors contributing to FASD. It was explored how women’s experiences and realities

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influence their choices, especially during pregnancy. This study also sought to understand why some women succeed in changing their drinking behaviour in pregnancy while others are unable to. These questions were investigated through a qualitative research study using case studies to provide in-depth and thick descriptions of women's lived realities.

The study revealed that high-risk drinking behaviour in pregnancy is affected by various biological, psychological, and social factors. The "stories" of these women revealed instability in childhood, exposure to childhood trauma in the form of loss of caregivers, alcohol abusing parents, poverty, and abuse. The role of friends and peer pressure in the early onset of drinking and unplanned teenage pregnancies were described. Intergenerational patterns of drinking behaviour, which included the embeddedness of weekend binge-drinking and the strong influence of mothers and grandmothers on the lives of women in this study, were revealed. It was shown that none of the high-risk drinking women in this study completed their schooling, leaving them financially vulnerable and unable to secure viable permanent jobs.

The study showed that relationships with their partners were often volatile, there was a lack of emotional and financial support and domestic violence often occurred. These women's partners, in some cases, did not accept responsibility for their children in any way, had affairs during their partners' pregnancies and were heavy drinkers themselves. The study indicates that the partner's role in women's drinking behaviour is still understated and neglected and needs to be addressed in more effective and innovative ways.

It was found that, in this study, all the women's pregnancies were unplanned. This had a direct influence on alcohol exposure of the fetuses in at least the first trimester of pregnancy but also beyond that. It was confirmed that unplanned pregnancies coupled with a lack of paternal support contributes to negative attitudes towards pregnancy, causing an increased risk for continued alcohol use in pregnancy. Psychological factors such as depression, feelings of hopelessness and powerlessness, contributed to alcohol use in pregnancy.

The study further demonstrated a desperate need for services in the fields of health, mental health, social work, counselling for traumatised children, assistance with

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obtaining protection orders where domestic violence takes place and showed a lack of action and protection form the police service in cases of domestic violence.

In summary, this study confirms the complexity of the phenomenon of FASD and the need for a coordinated, collaborative effort to address the biological, psychological, and social factors contributing to continued alcohol use in pregnancy. Although there can be drawn upon the knowledge and skills of social workers as prevention specialists, interventionists, and sources of support to at risk individuals, the prevention of FASD cannot only be the responsibility of social workers and NGOs. To address FASD in all its complexities, to ensure FASD prevention on all three levels of prevention and to deliver prevention and intervention services addressing the biological, psychological, social, and educational needs of individuals with risky drinking behaviour as well as affected individuals, SA needs clear policies and strategies to lay out and implement a plan of action.

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# REFERENCE LIST

Aase, J.M., Jones, K.L. & Clarren, S.K. 1995. Do we need the term FAE? *Pediatrics,* 95(3):428-430.

Adebiyi, B.O., Mukumbang, F.C. & Beytell, A.M. 2019a. A guideline for the prevention and management of fetal alcohol spectrum disorder in South Africa. *BMC Health Services Research*, 19:809. [Online]. Available: https://search-proquest-com.ez.sun.ac.za/docview/2452069781?pq-origsite=primo. [Accessed 9 January 2021].

Adebiyi, B.O., Mukumbang, F.C. & Beytell, A.M. 2021. Policy requirements for the prevention and management of fetal alcohol spectrum disorders in South Africa: a policy brief. *Frontiers in Public Health*, 9(592726):1-5. [Online]. Available: https://www.frontiersin.org/articles/10.3389/fpubh.2021.592726/full. [Accessed 12 July 2021].

Adebiyi, B.O., Mukumbang, F.C. & Beytell, A.M. 2019b. To what extent is fetal alcohol spectrum disorders considered in policy-related documents in South Africa? A document review. *Health Research, Policy and Systems*, 17:46. [Online]. Available: https://link.gale.com/apps/doc/A586535834/AONE?u=27uos&sid=AONE&xid=afcb9b5e. [Accessed 2 March 2020].

Adebiyi, B.O., Mukumbang, F.C., Cloete, L.G. & Beytell, A.M. 2018. Exploring service providers' perspectives on the prevention and management of fetal alcohol spectrum disorders in South Africa: a qualitative study. *BMC Public Health*, 18:1238. [Online]. Available: https://doi.org/10.1186/s12889-018-6126-x. [Accessed 2 March 2020].

Adebiyi, B.O., Mukumbang, F.C. & Erasmus, C. 2019. The distribution of available prevention and management interventions for fetal alcohol spectrum disorder (2007 to 2017): implications for collaborative actions. *International Journal of Environmental Research and Public Health*, 16:2244.

Stellenbosch University https://scholar.sun.ac.za

Adebiyi, B.O., Mukumbang, F.C., Okop, K.J. & Beytell, A.M. 2018. A modified Delphi study towards developing a guideline to inform policy on fetal alcohol spectrum disorders in South Africa: a study protocol. *BMJ Open,* 8:e019907. [Online]. Available: https://bmjopen.bmj.com/content/bmjopen/8/4/e019907.full.pdf. [Accessed2 March 2020].

Adnams, C.M., Kodituwakku, P.W., Hay, A., Molteno, C.D., Viljoen, D. & May. P.A. 2001. Patterns of cognitive-motor development in children with fetal alcohol syndrome from a community in South Africa. *Alcoholism: Clinical and experimental research*, 25(4):557-562.

Anderson, A.E., Hure, A.J., Forder, P.M., Powers, J., Kay-Lambkin, F.J. & Loxton, D.J. 2014. Risky drinking patterns are being continued into pregnancy: a prospective cohort study. *Plos One*, 9(7):e86171. [Online]. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3893287/. [Accessed 18 November 2020].

Andrew, G. 2011. Diagnosis of FASD: an overview. In: Riley, E.P., Clarren, S., Weinberg, J. & Jonsson, E. (eds). *Fetal alcohol spectrum disorder: management and policy perspectives of FASD.* Weinheim, Germany: Wiley-Blackwell.

Agnihotri, S., Subramaniapillai, S., Keightley, M., Rasmussen, C., Cameron, D., Ryan, J. & Rovet, J. 2018. Everyday memory difficulties in children and adolescents with Fetal Alcohol Spectrum Disorder. [Online]. Available: http://www.tandfonline.com/loi/ipdr20. [Accessed 8 October 2020].

*Assessment of fetal alcohol syndrome disorders*. 2020. Washington, D.C.: Pan American Health Organization.

*AUDIT*. [Online]. [n.d.]. Available: https://nida.nih.gov/sites/default/files/audit.pdf. [Accessed 7 August 2022].

*Australian Government, Department of Health and Aged Care: National fetal alcohol spectrum disorder (FASD) strategic plan 2018-2028*. [Online]. 2018. Available: https://www.health.gov.au/resources/publications/national-fetal-alcohol-spectrum-disorder-fasd-strategic-action-plan-2018-2028. [Accessed 26 January 2021].

Stellenbosch University https://scholar.sun.ac.za

Babbie, E. 2014. *The practice of social research* (14th ed). Canada: Cengage Learning.

Babbie, E. & Mouton, J. 2001. *The practice of social research*. (South African edition). Cape Town, SA: Oxford University Press.

Babalda, E., Noel, P. & White, R. 2017. The biopsychosocial approach and global mental health: synergies and opportunities*. Indian journal of social psychiatry,* 33(4).

Barker D.J. 2004. Developmental origins of adult health and disease. *Journal of Epidemiology and Community Health*, 58:114–115.

Barker, D.J. 2006. Adult consequences of fetal growth restriction. *Clinical obstetrics and gynecology*, 49(2):270-283.

Barker, D.J.P. 2012. Developmental origins of chronic disease. *Public Health*, 126:185-189.

Barker, D.J.P. 1993. Fetal origins of coronary heart disease. *British heart journal*, 69:195-196.

Barkley, J. 2009. Biopsychosocial assessment: why the biopsycho and rarely the social? *Journal of the American academy of child and adolescent psychiatry*, 18(4):344-347.

Baydala, L, Worrell, S. & Fletcher, F. 2011. FASD: A preconception prevention initiative. In: Riley, E.P., Clarren, S., Weinberg, J. & Jonsson, E. (eds). *Fetal alcohol spectrum disorder, management and policy perspectives of FASD.* Weinheim: Wiley- VCH Verlag, GmbH & Co., KgaA, 151-158.

Berg, L., Rostila, M. & Hjern, A. 2016. Parental death during childhood and depression in young adults – a national cohort study. *Journal of Child Psychology and Psychiatry*, 57(9):1092–1098.

Berzoff, J. & Drisco, J. 2015. What clinical social workers need to know: bio-psycho-social knowledge and skills for the twenty-first century. *Journal of Clinical Social Work*, 43:263-273.

Beyers, N. & Moosa, A. 1978. The fetal alcohol syndrome. *South African Medical Journal*, 54(14):575-578.

Stellenbosch University https://scholar.sun.ac.za

Bornstein, R.F. 2006. The complex relationship between dependency and domestic violence: converging psychological factors and social forces. *American Psychologist,* 61(6):595-606.

Borrell-Carriò, F., Suchman, A.I. & Epstein, R.F. 2004. The biopsychosocial model 25 years later: principles, practice, and scientific inquiry. *Annals of family medicine,* Nov; 2(6): 576–582. doi: 10.1370/afm.245. PMCID: PMC1466742, PMID: 15576544.

*Boston Children's Hospital*: *Clinodactyly*. [Online]. 2021. Available: https://www.childrenshospital.org/conditions/clinodactyly. [Accessed 7 August 2022].

Boyden, J. & James, Z. 2014. Schooling, childhood poverty and international development: choices and challenges in a longitudinal study. *Oxford Review of Education*. [Online]. Available: http://www.tandfonline.com/doi/pdf/10.1080/03054985.2013.873524. [Accessed 5 May 2022].

Braun, V. & Clarke, V. 2006. Using thematic analyses in psychology. *Qualitative research in psychology*, 3(2):77-101. [Online]. Available: https://www.tandfonline.com/doi/abs/10.1191/1478088706qp063oa. [Accessed 28 March 2021].

Braun, V. & Clarke, V. 2021. *Thematic analyses: A practical guide*. Sage publications, London.

Brekke, J.S. 2012. Shaping a science of social work. *Research on social work practice,* 22(5):455-464.

Burd, L. 2016. Fetal alcohol spectrum disorder: complexity from comorbidity. *The Lancet (British edition),* 387(10022):926-927. [Online]. Available: https://www-sciencedirect-com.ez.sun.ac.za/science/article/pii/S014067361501346X. [Accessed 9 August 2020].

Stellenbosch University https://scholar.sun.ac.za

Burd, L. & Wilson, H. 2004. Fetal, infant and child mortality in a context of alcohol use. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, 1:51-58. [Online]. Available: https://onlinelibrary.wiley.com/doi/epdf/10.1002/ajmg.c.30016. [Accessed 16 May 2021].

Burns, A., Dannecker, E. and Austin, M.J. 2019. Revisiting the biological perspective in the use of biopsychosocial assessments in social work. *Journal of Human behaviour in the social environment*, 29(2):177-194. DOI: 10.1080/10911359.2018.1500505

*CanFASD: Prevention of fetal alcohol spectrum disorder (FASD. A multilevel model).* [Online}. 2013. Available: https://canfasd.ca/wp-content/uploads/2016/09/PREVENTION-of-Fetal-Alcohol-Spectrum-Disorder-FASD-A-multi-level-model.pdf. [Accessed 2 January 2021].

Carpenter, B. 2011. Pedagogically bereft! Improving learning outcomes for children with foetal alcohol syndrome. *British journal of special education,* 38(1):37-43.

Carter, R.C., Jacobsen, J.L., Molteno, C.D., Dodge, N.C., Meintjes, E.M. & Jacobsen, S.W. 2016. Fetal alcohol growth restriction and cognitive impairment. *Pediatrics*, 138(2): e20160775. [Online]. Available: http://pediatrics.aappublications.org/content/138/2/e20160775. [Accessed 25 May 2020].

Catterick, M. & Curran, L. 2014. *Understanding fetal alcohol spectrum disorder: a guide to FASD for parents, carers and professionals*. London and Philadelphia: Jessica Kingsley publishers.

Chang, C., Fisher, N.D.L., Hornstein, M.D., Jones, J.A. & Orev, E.J. 2010. Identification of Risk Drinking Women: T-ACE Screening Tool or the Medical Record. *Journal of Women's Health*, 10:1933-1939.

Chang, G., Wilkins-Haug, L., Berman, S. & Goetz, M. 1999. A brief intervention for alcohol use in pregnancy: a randomized trial. *Addiction*, 94:1499-1508.

Chasnoff, I.J., Wells, A.M. & King, L. 2015. Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics*, 135:264-270.

Stellenbosch University https://scholar.sun.ac.za

Chersich, M.F., Urban, M., Olivier, L., Davies, L.A., Chetty, C. & Viljoen, D. 2011. Universal prevention is associated with lower prevalence of fetal alcohol spectrum disorders in Northern Cape, South Africa: a multicentre before–after study. *Alcohol and Alcoholism*, 47(1):67-74. [Online]. Available: https://academic.oup.com/alcalc/article/47/1/67/216076. [Accessed 21 June 2020].

*Children's Hospital of Philadelphia: Camptodactyly*. [Online]. 2022. Available: https://www.chop.edu/conditions-diseases/camptodactyly. [Accessed 7 August 2022].

Chudley, A.E. 2011.Genetic factors contributing to FASD. In: Riley, E.P., Clarren, S., Weinberg, J. & Jonsson, E. *Fetal alcohol spectrum disorder, management and policy perspectives of FASD.* Weinheim: Wiley- VCH Verlag, GmbH & Co., KgaA, 1-10.

Church, M. W. & Abel, E. L. 1998. Fetal alcohol syndrome: hearing, speech, language, and vestibular disorders. *Obstetrics and Gynecology Clinics of North America,* 25(1):85–97.

Church, M.W. & Gherkin, K.P. 1988. Hearing disorders in children with fetal alcohol syndrome: findings from case reports. *Pediatrics*, 82(2):147-154.

Cloete, L. 2005. Occupations of women who live and/or work in a rural farming community and who are at risk for having children with foetal alcohol syndrome (FAS). Unpublished master's thesis, University of Cape Town, Cape Town. [Online]. Available: http://hdl.handle.net/11427/2969. [Accessed 29 February 2020].

Coriale. G., Battagliese, G., Pisciotta, F., Attilia, M.L., Porrari, R., De Rosa, F., Vitali, M., Carito, V., Messina, M.P., Greco, A., Fiore, M. & Ciccanti, M. 2019. Behavioral responses in people affected by alcohol use disorder and psychiatric comorbidity: correlations with addiction severity. *Annali dell'Istituto Superiore di sanità*, 55(2):131-142.

Costa, L.G, Aschner, M., Vitalone, A., Syversen, T. & Soldin, O.P. 2004. Developmental neuropathology of environmental agents. *Annual review of pharmacology and toxicology*, 44:87-110.

Stellenbosch University https://scholar.sun.ac.za

Cousins, W. & Wells, K. 2005. “One more for my baby”: foetal alcohol syndrome and its implications for social workers. *Child in Care Practice,* 11(3):375-383.

Crawford-Williams, F., Steen, M., Esterman, A., Fielder, A. & Mikocka-Walus, A. 2015. “My midwife said that having a glass of red wine was actually better for the baby”: a focus group study of women and their partner’s knowledge and experience relating to alcohol-consumption in pregnancy. *BMC Pregnancy and Childbirth*, 15:79.

Creswell, J.W. 2013. *Qualitative inquiry and research methods: Choosing among five approaches*. (3rd edition). Thousand Oaks, CA: Sage publications.

Creswell, J.W. 2014. Research design: Qualitative, quantitative, and mixed method approaches. (4th edition). Thousand Oaks, CA: Sage publications.

Creswell, J. W. & Poth, C.N. 2018. *Qualitative inquiry and research design: choosing among five approaches* (4th edition). United States of America: Sage publications.

Crocker, N., Vaurio, L., Riley, E.P. & Mattson, S.N. 2009. Comparison of adaptive behavior in children with heavy prenatal alcohol exposure or attention deficit / hyperactivity disorder. *Alcoholism: Clinical and Experimental Research,* 33(11): 2015–2023. [Online]. Available: https://pubmed.ncbi.nlm.nih.gov/19719794/. [Accessed 15 November 2020].

Daniel, J. 2012. Sampling essentials: practical guidelines for making sampling choices. [Online]. Available: https://dx.doi.org/10.4135/9781452272047. [Accessed 3 April 2020].

Davhana-Maselesele, M., Myburgh, C.P.H. & Poggenpoel, M. 2009. Lived experiences of women victims of domestic violence in rural areas of Vhembe district: Limpopo Province, South Africa. *Gender and Behaviour*, 7(2):2517-2540.

Davidson, L. & Strauss, J.S.1995. Beyond the biopsychosocial model: integrating disorder, health and recovery. *Psychiatry,* 58:44-55.

Dawson, D.A., Grant, B.F. & Ruan, W.J. 2005. The association between stress and drinking: modifying effects of gender and vulnerability. *Alcohol and Alcoholism*, 40(5):453-460.

Stellenbosch University https://scholar.sun.ac.za

De Jager, N. 2021. FASD prevention services. E-mail to M.M. de Vries [Online], 29 June. Available E-mail: mmdevries@sun.ac.za.

De Jong, M., George, A. & Jacobs, T. 2021. A scoping review of the determinants of foetal alcohol spectrum disorder in South Africa: an intersectional perspective. *Health Policy and Planning,* 36(9):1459-1469.

Delport, C.S.L. & Fouché, C.B. 2011. The qualitative research report. In: De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L. (eds). *Research at grass roots for the social sciences and human service professions* (4th ed). Pretoria, SA: Van Schaik Publishers.

Delport, C.S.L., Fouché, C.B. & Schurink, W. 2011. Theory and literature in qualitative research. In: De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L. (eds). *Research at grass roots for the social sciences and human service professions* (4th ed). Pretoria, SA: Van Schaik Publishers.

Department of Health. 2016. *Guidelines for maternity care in South Africa: A manual for clinics, community health centres and district hospitals*. (4th ed). Republic of South Africa.

Department of Social Development. 2006. *Integrated service delivery model towards improved social services.* Republic of South Africa.

De Vries, M.M. 2012. The prevention of fetal alcohol spectrum disorders: an ecological approach. Unpublished master's thesis, Stellenbosch: Stellenbosch University.

De Vries, M. and Green, S. 2013. The prevention of fetal alcohol spectrum disorders: the need for a coordinated service by roleplayers in the wine producing areas in the Breede River Valley. *Social Work/Maatskaplike Werk*, 49(3):369-386.

De Vries, M.M., Joubert, B., Cloete, M., Roux, S., Baca, B.A., Hasken, J.M., Barnard, R., Buckley, D., Kalberg, W.O., Snell, C.L., Marais, A.S., Seedat, S. & May. P.A. 2015. Indicated prevention of fetal alcohol spectrum disorders in South Africa: effectiveness of case management. *International Journal of Environmental Research and Public Health,* 13(76):1-14.

Donald, D., Lazarus, S. & Lolwana, P. 2002. *Educational psychology in social context* (2nd ed). Cape Town: Oxford University Press.

Stellenbosch University https://scholar.sun.ac.za

Dörrie, N., Föcker, M., Freunscht, I. & Hebebrand, J. 2014. Fetal alcohol spectrum disorders. *European Child and Adolescent Psychiatry*, 23:863-875.

Dozet, D., Burd, L. & Popova, S. 2021. Screening for alcohol use in pregnancy: a review of current practices and perspective. *International Journal of Mental Health and Addiction.* [Online]. Available: https://doi.org/10.1007/s11469-021-00655-3. [Accessed 5 July 2022].

Eagan, M., Combs-Orme, T. & Neely-Barnes, S.L. 2011. Integrating neuroscience knowledge into social work education: a case- based approach. *Journal of Social Work Education*, 47(2):269-282.

*Early Years Services: Early years services programs*. 2017. [Online]. Available: http://earlyyearsservices.co.za/programs.htm. [Accessed 17 June 2021].

Eaton, L.A., Kalichman, S.C., Sikkema, K.J., Skinner, D., Watt, M.H., Pieterse, D. & Pipiman, E. 2012. Pregnancy, alcohol intake and intimate partner violence among men and women attending drinking establishments in a Cape Town, South Africa, township. *Journal of Community Health,* 37(1):208-216.

Engel, G.L. 1977. The need for a new medical model: A challenge for biomedicine. *Science, 196*(4286), 129–136.

Engel, G.L. 1980. The clinical application of the biopsychosocial model. *The American journal of psychiatry*, 137(5), 353-544.

Engel, G.L. 1996. From biomedical to biopsychosocial: a personal odyssey. *Family systems and health*, 14(4):434-449.

Engel, G.L. 1997. From biomedical to biopsychosocial: being scientific in the human domain. *Psychosomatics,* 38(6):521-528.

Englund, M.M., Egeland, B., Olivia, E.M. & Collins, W.A. 2008. Childhood and adolescent predictors of heavy drinking and alcohol use disorders in early adulthood: a longitudinal developmental analysis. *Addiction*, 103(Suppl.1):23–35.

Erasmus, L.A. 2021. Personal interview. 9 July, Cape Town.

Stellenbosch University https://scholar.sun.ac.za

*European FASD Alliance: Linking European professionals concerned with alcohol and pregnancy.* [Online]. [n.d.]. Available: European Fetal Alcohol Spectrum Disorders Alliance (eufasd.org). [Accessed 5 January 2021].

Ezekwe, E.C., Nwankwo, I.U. & Osayi, K.K. 2019. Prevalence, patterns and factors influencing alcohol consumption among mothers of reproductive age in some selected societies: Lessons for intervention agencies. *International Journal of Health and Social Inquiry,* 5(1):149-176. [Online]. Available: https://journals.aphriapub.com/index.php/IJHSI/article/view/1068/1028. [Accessed 5 April 2021].

Falletisch, L.A. 2008. Understanding the legacy of dependency and powerlessness experienced by farm workers on wine farms in the Western Cape. Unpublished master's thesis, Stellenbosch: Stellenbosch University.

Farooq, M.B. & De Villiers, C. 2017. Telephonic qualitative research interviews, when to consider them and how to do them. *Meditari Accountancy Research*, 25(2), 291 - 316.

*FASD HUB Australia: Prevention strategies*. [Online]. 2021.Available: https://www.fasdhub.org.au/fasd-information/prevention-strategies/. [Accessed 4 January 2021].

*FASfacts: Fetal Alcohol Syndrome (FAS) Programme* [Online]. [n.d.]. Available: https://fasfacts.org.za/programme/ [2022, August 12].

*FASfacts: Sailing towards a FAS free society*. [Online]. [n.d.] Available: https://www.givengain.com/cause/5214/campaigns/14458/. [Accessed 9 January 2021].

Fast, D.K. & Conry, J. 2009. Fetal alcohol spectrum disorders and the criminal justice system. *Developmental Disabilities Research Reviews*, 15(3):250-257.

Feldman, H.S., Jones, K.L., Lindsay, S., Slymen, D., Klonoff-Cohen, H., Kao, K., Roa, S. & Chambers, C. 2012. Prenatal alcohol exposure patterns and alcohol-related birth defects and growth deficiencies: a prospective study. *Alcoholism: Clinical and Experimental Research*, 36(4):670-676.

*Fetal Alcohol Spectrum Disorder: The FASD Task Team.* [Online]. [n.d.]. Available: https://www.fasdsa.org/team.html. [Accessed 9 January 2021].

Stellenbosch University https://scholar.sun.ac.za

Fletcher, O.V., May, P.A., Seedat, S., Sikkema, K.J. & Watt, M.H. 2018. Attitudes toward alcohol use during pregnancy among women recruited from alcohol-serving venues in Cape Town, South Africa: a mixed-methods study. *Social Science & Medicine*, 215:98-106.

Floyd, R.L., Sobell, M., Velasques, M.M., Ingersoll, K., Nettleman, M., Sobell, L., Mullen, P.D., Ceperich, S., Von Sternberg, K., Bolton, B., Skarpness, B. & Nagaraja, J. 2007. Preventing alcohol-exposed pregnancies: a randomized controlled trial. *American Journal of Preventive Medicine*, 32(1):1-10.

Fouché, C.B. 2021. Introduction to the research process. In: Fouché, C.B., Strydom, H. & Roestenburg, W.J.H. (eds). *Research at grass roots for the social sciences and human service professions* (5th ed). Pretoria, SA: Van Schaik Publishers.

Fouché, C.B. & Chubb, L.A. 2021. Research dissemination and impact. In: Fouché, C.B., Strydom, H. & Roestenburg, W.J.H. (eds). *Research at grass roots for the social sciences and human service professions* (5th ed). Pretoria, SA: Van Schaik Publishers.

Fouché, C.B. & De Vos, A.S. 2011. Formal formulations. In: De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L (eds). *Research at grass roots for the social sciences and human service professions* (4th ed). Pretoria, SA: Van Schaik Publishers.

Fouché, C.B. & Geyer, L.S. 2021. Developing the research proposal. In: Fouché, C.B., Strydom, H. & Roestenburg, W.J.H. (eds). *Research at grass roots for the social sciences and human service professions* (5th ed). Pretoria, SA: Van Schaik Publishers.

Fouché, C.B. & Schurink, W. 2011.Qualitative research designs. In: De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L (eds). *Research at grass roots for the social sciences and human service professions* (4th ed). Pretoria, SA: Van Schaik Publishers.

Francis, D. & Webster, E. 2019. Poverty and inequality in South Africa: critical reflections. *Development Southern Africa*, 36(6):788-802.

Fransman, T. & Yu, D. 2019. Multidimensional poverty in South Africa in 2001–16. *Development Southern Africa*, 36(1):50–79.

Stellenbosch University https://scholar.sun.ac.za

Fryer, S.L., McGee, C.L., Matt, G.E., Riley, E.P. & Mattson, S.N. 2007. Evaluation of psychopathological conditions in children with heavy prenatal alcohol exposure. *Pediatrics*, 119(3). [Online]. Available: http://pediatrics.aappublications.org/content/119/3/e733. [Accessed 25 October 2020].

Garland, E.L., Boettiger, C.A. & Howard, M.O. 2011. Targeting cognitive-affective risk mechanisms in stress-precipitated alcohol dependence: an integrated biopsychosocial model of automaticity, allostasis and addiction. *Medical Hypotheses*, 76:745-754.

Germain, C.B. 1979. Introduction: ecology and social work. In: Germain, C.B. (ed). *Social work practice: An ecological perspective*. New York: The Free Press, 1-22.

Germain, C.B. 1991. *Human behaviour in the social environment.* New York: Columbia University Press.

Germain, C.B. & Gitterman, A. 1996. *The life model of social work practice* (3rd ed). New York: Columbia University Press.

Geyer, L. S. 2021. Interviews as data collection method. In: Fouché, C.B., Strydom, H. & Roestenburg, W.J.H. (eds). *Research at grass roots for the social sciences and human service professions* (5th ed). Pretoria, SA: Van Schaik Publishers.

Gibbs, A., Jewkes, R., Willan, S. & Washington, L. 2018. Associations between poverty, mental health and substance use, gender, power, and intimate partner violence amongst young (18-30) women and men in urban informal settlements in South Africa: A cross-sectional study and structural equation model. [Electronic], 13(10): e0204956. [Online]. Available: Associations between poverty, mental health and substance use, gender power, and intimate partner violence amongst young (18-30) women and men in urban informal settlements in South Africa: A cross-sectional study and structural equation model | PLOS ONE. [Accessed 14 May 2022].

Stellenbosch University https://scholar.sun.ac.za

Gossage, J.P., Snell, C.L., Parry, C.D.H., Marais. A.S., Barnard, R., De Vries, M., Blankenship, J., Seedat, S., Hasken, J. & May, P.A. 2014. Alcohol use, working conditions, job benefits, and the legacy of the “dop” system among farm workers in the Western Cape Province, South Africa: hope despite high levels of risky drinking. *International Journal of Environmental Research and Public Health,* 11:7406-7424.

Greeff, H. 2011. Information collection: interviewing. In: De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L (eds). *Research at grass roots for the social sciences and human service professions* (4th ed). Pretoria, SA: Van Schaik Publishers.

Hall, K. & Mokomane, Z. 2018. The shape of children’s families and households: A demographic overview. *South African Child Gauge*. [Online]. Available: http://www.ci.uct.ac.za/sites/default/files/image_tool/images/367/Child_Gauge/South_African_Child_Gauge_2018/Chapters/the_shape_of_childrens_families_and_households.pdf. [Accessed 25 April 2022].

Hankin, J.R. 2002. Fetal alcohol syndrome prevention research. *Alcohol Research and Health*, 26(1):58+. [Online]. Available: https://link.gale.com/apps/doc/A90681221/AONE?u=27uos&sid=AONE&xid=c7687e22. [Accessed 19 November 2020].

Hanson, J.D., Nelson, M.E., Jensen, J.L., Willman, A., Jacobs-Knight, J. & Ingersoll, K. 2017. Impact of the CHOICES intervention in preventing alcohol-exposed pregnancies in American Indian women. *Alcoholism: Clinical and Experimental Research*, 41(4):828-835. [Online]. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5378586/. [Accessed 19 December 2020].

*Hantam Community Education Trust: FASD awareness programme*. [Online]. 2022. Available: http://hantam-trust.org.za/fasd-awareness-programme/. [Accessed 13 June 2021].

Stellenbosch University https://scholar.sun.ac.za

Hasken, J.M., Marais, A.S., De Vries, M., Joubert, B., Cloete, M., Botha, I., Symington, S., Kalberg, W.O., Buckley, D., Robinson., L.K., Manning, M.A., Parry, C.D.H., Seedat, S., Hoyme, H.E. & May, P.A. 2021. Gestational age and birth growth parameters as early predictors of fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research*, 00:1-15.

Hellemans, K.G.C., Sliwowska, J.H., Verma, P. & Weinberg, J. 2010. Prenatal alcohol exposure: fetal programming and later life vulnerability to stress, depression and anxiety disorders. *Neuroscience and Biobehavioral Reviews*, 34:791–807.

Hertzog, C., Kramer, A.F., Wilson, R.F. & Lindenberger, U. 2009. Enrichment effects on adult cognitive development: can the functional capacity of older adults be preserved and enhanced? *Psychological Science in the Public Interest*, 9(1):1–65.

Highland, K.B., Herschl, L.C., Klanecky, A. & McChargue, D.E. 2013. Biopsychosocial pathways to alcohol-related problems. *The American Journal on addictions,* 22:366-372.

*Home of Hope: Our projects*. [Online]. [n.d.]. Available: https://www.homeofhope.co.za/index.php/our-projects. [Accessed 17 June 2021].

Hoyme, H.E., May, P.A., Kalberg, W.O., Kodituwakku, P., Gossage, J.P., Trujillo, P.A., Buckley, D.G., Miller, J.H., Aragon, A.S., Khaole, N., Viljoen, D., Jones, K.L. & Robinson, L.K. 2005. A practical clinical approach to diagnosis of fetal alcohol spectrum disorder: clarification of the 1996 Institute of Medicine criteria. *Pediatrics,* 115(1):39-47.

Hoyme, H.E., Kalberg, W.O., Elliot, A.J., Blankenship, J., Buckley, D., Marais, A.S., Manning, M.A., Robinson, L.K., Adam, M.P., Abdul-Rahman, O., Jewett, T., Coles, C.D., Chambers, D., Jones, K.L., Adnams, C.M., Shah, P.E., Riley, E.P., Charness, M.E., Warren, K.R. & May, P.A. 2016. Updated clinical guidelines for diagnosing fetal alcohol spectrum disorders. *Pediatrics,* 138(2):138-156.

Stellenbosch University https://scholar.sun.ac.za

Hoyme, H. E. & Shah, P.E. 2021. Fetal alcohol spectrum disorders. In: Carey, J.C., Battaglia, A., Viskochil, D. & Cassidy, S.B. (eds.) C*assidy and Allinson's Management of Genetic Syndromes* (4th ed.), New Jersey: John Wiley & Sons Inc.

*Instrument: AUDIT-C questionnaire.* [Online]. [n.d.]. Available: https://cde.drugabuse.gov/instrument/f229c68a-67ce-9a58-e040-bb89ad432be4. [Accessed 7 August 2022].

Jensen, J.M. 2020. Improving behavioural health in young people: it is time for social work to adopt prevention. *Research on social work practice*, 30(7):707-711.

Jones, K.L., Hoyme, H.E., Robinson, L.K., Del Campo, M., Manning, M.A., Prewitt, L.M. & Chambers, C.D. 2010. Fetal alcohol spectrum disorders: extending the range of structural defects. *American Journal of medical genetics,* Part A 152A:2731–2735.

Joyner, K. & Mash, B. 2014. Quality of care for intimate partner violence in South African primary care: a qualitative study. *Violence And Victims*, 29(4):652-669. [Online]. Available: Https://Www.Proquest.Com/Docview/1549953702?Parentsessionid=W9t9ird0r6o77%2fb2ukpdb%2fcuk0kszuf4ysag8lbmxkq%3d&Pq-Origsite=Primo&Accountid=14049. [Accessed 15 August 2022].

Kalberg, W.O. & Buckley D. 2006. Educational planning for children with fetal alcohol syndrome. *Annali dell'Istituto Superiore di sanità,* 42(1):58-66.

Kalberg, W.O., Marais, A.S., De Vries, M.M., Seedat, S., Parry, C.D.H. & May, P.A. 2017. Neuropsychological aspects of prevention and intervention for FASD in South Africa. *Journal of Pediatric Neuropsychology,* 3:68-78.

Kalberg, W.O., May, P.A., Blankenship, J., Buckley, D., Gossage, J.P & Adnams. C.M., 2013. A practical testing battery to measure neurobehavioral ability among children with FASD. *International Journal of Alcohol and Drug Research*, 2(3):51-60.

Stellenbosch University https://scholar.sun.ac.za

Kalberg, W.O., May, P.A., Buckley, D., Hasken, J.M., Marais, A.S., De Vries, M.M., Bezuidenhout, H., Manning. M.A., Robinson, L.K., Adam, M.P., Hoyme, D.B., Parry, C.D., Seedat. S., Elliot, A.J. & Hoyme, H.E. 2019. Early-life predictors of fetal alcohol spectrum disorders. *Pediatrics,* 144(6). [Online]. Available: http://pediatrics.aappublications.org/content/early/2019/11/15/peds.2018-2141. [Accessed 21 May 2020].

Kambeitz, C., Klug, M.G. Greenmyer, J., Popova, S. & Burd, L. 2019. Association of adverse childhood experiences and neurodevelopmental disorders in people with fetal alcohol spectrum disorders (FASD) and non-FASD controls. *BMC Pediatrics*, 19(1). [Online]. Available:https://bmcpediatr.biomedcentral.com/articles/10.1186/s12887-019-1878-8#citeas. [Accessed 25 May 2020].

Karat, A.S., McCreesh, N., Baisley, K., Govender, I., Kallon, I.I., Kielman, K., MacGregor, H., Vassal, A., Yates, T.A. & Grant, A.D. 2021. Waiting times, patient flow, and occupancy density in South African primary health care clinics: implications for infection prevention and control. *MedRxiv.* [Online]. Available: https://doi.org/10.1101/2021.07.21.21260806. [Accessed 6 July 20232].

Kelly, S.J., Day, N. & Streissguth, A.P. 2000. Effects of prenatal alcohol exposure on social behaviour in humans and other species. *Neurotoxicol Teratol*, 22:143–149.

Kleine, M. 2019. Accounts and attributions following marital infidelity. *Western Journal of Communication*, 85(2) 211-229. [Online]. Available: https://www-tandfonline-com.ez.sun.ac.za/doi/full/10.1080/10570314.2019.1702714. [Accessed 17 June 2022].

Knudsen, E.I. 2004. Sensitive periods in the development of the brain and behaviour. *Journal of Cognitive Neuroscience*,16(8):1412–1425.

Kodituwakku, P.W. 2009. Neurocognitive profile in children with fetal alcohol spectrum disorders. *Developmental Disabilities Research Reviews,* 15:218–224.

Kodituwakku, P.W., Kalberg, W.O. & May, P.A. 2001. The effects of prenatal alcohol exposure on executive functioning. *Alcohol Health and Research World,* 25(3):192-198.

Stellenbosch University https://scholar.sun.ac.za

Kodituwakku, P.W. & Kodituwakku, E.L. 2011. From research to practice: an integrative framework for the development of interventions for children with fetal alcohol spectrum disorders. *Neuropsychological Review*, 21:204-223.

Kritzinger, A. 2005. Global markets, employment restructuring and female labourers on Western Cape fruit farms. *Acta Academica*, 37(1):99-126.

Kumar, R. 2019. *Research methodology: a step-by-step guide for beginners*. (5th ed). London: Sage publications.

Lafferty, L.P., Becker, M., Dresner, N., Meltzer-Brody, S., Gopalan, P., Glance, J., St. Victor, G., Mittal, L., Marshalek, P., Lander, L. & Worley, L.L.M. 2016. Guidelines for the management of pregnant women with substance use disorders. *Psychosomatics*, 57:115-130.

Landgren, V., Svensson, L., Gyllencreutz, E., Aring, E., Grönlund, M.A. & Landgren, M. 2019. Fetal alcohol spectrum disorders from childhood to adulthood: a Swedish population- based naturalistic cohort study of adoptees from Eastern Europe. *BMJ Open*, 9:e032407. [Online]. Available: https://bmjopen.bmj.com. [Accessed 25 August 2020].

La Raya, A. 2020. Super bowl swigs: Applying social practise theory to alcohol consumption. *The DRAM, 16(2).* [Online]. Available: https://www.basisonline.org/2020/02/social-practice-theory-alcohol-consumption.html. [Accessed 15 February 2020].

Leech, N. & Onwuegbuzie, A. 2007. An array of qualitative data analysis tools: a call for data analysis triangulation. *School Psychology Quarterly*, 22(4):557-584.

Lemola, S., Stadlmayer, W. & Grob. A. 2009. Infant irritability: the impact of fetal alcohol exposure, maternal depressive symptoms, and low emotional support from the husband. *Infant mental health journal*, 30(1):57–81.

Le Roux, G.B. 2020. Contributing and protective factors affecting the well-being of wine farm workers: perceptions of professionals. Unpublished master’s thesis, Stellenbosch: Stellenbosch University.

Lester, J.N., Cho, Y. & Lochmiller, C.R. 2020. Learning to do qualitative data analysis: A starting point. *Human Resource Development Review,* 19(1):94-106.

Stellenbosch University https://scholar.sun.ac.za

Lindau, S.T., Laumann, E.O., Levinson, W. & Waite, L.J. 2003. Synthesis of scientific disciplines in pursuit of health: The interactive biopsychosocial model. *Perspectives in Biology and Medicine*, 46(3 Suppl): S74-S86. [Online]. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1201376/. [Accessed 1 February 2021].

Lindinger, N.M., Malcolm-Smith, S., Dodge, N.C., Molteno, C.D., Thomas, K.G.D., Meintjes, E.M., Jacobson, J.L. & Jacobson, S.W. 2016. Theory of mind in children with fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research*, 40(2):367-376.

Longmore, M.A., Sevareid, E.E., Manning, W.D., Giordano, P.C., Clemens, W. & Taylor, H. 2022. Adolescents' frequency of alcohol use and problems from alcohol abuse: Integrating dating partners with parent and peer influences. *Journal of Youth and Adolescence,* 51:320–334 (2022). [Online]. Available: https://doi-org.ez.sun.ac.za/10.1007/s10964-021-01486-0. [Accessed: 14 August 2022].

Loudermilk, E., Loudermilk, K., Obenauer, J. & Quinn, M.A. 2018. Impact of adverse childhood experiences (ACEs) on adult alcohol consumption behaviors. *Child abuse & neglect,* 86:368-374.

Lubbe, M., Van Walbeek, C. & Vellios, N. 2017. The prevalence of fetal alcohol syndrome and its impact on a child's classroom performance: a case study of a rural South African school. *International journal of environmental research and public health*, 14(8):896. [Online]. Available: https://www.mdpi.com/1660-4601/14/8/896. [Accessed 30 September 2020].

Lunde, E. R., Washburn, S.E. Golding, M.C., Bake, S., Miranda, S.C. & Ramadoss, J. 2016. Alcohol-induced developmental origins of adult-onset diseases. *Alcohol: Clinical and Experimental Research*, 40(7):1403-1414.

Lutke, J. 1997. Spider web walking: hope for children with FAS through understanding. *In*: Streissguth, A. & Kanter, J. (eds). *The challenge of fetal alcohol syndrome. Overcoming secondary disabilities*. Seattle and London: University of Washington Press, 181-188.

Stellenbosch University https://scholar.sun.ac.za

Machisa, M.T., Christofides, N. & Jewkes, R. 2016. Structural pathways between child abuse, poor mental health outcomes and male-perpetrated intimate partner violence (IPV). PLoS One, 11(3):e0150986.

Manning, M.A. & Hoyme, H.E. 2007. Fetal alcohol spectrum disorders: a practical clinical approach to diagnosis. *Neuroscience and Biobehavioral Reviews*, 31:230–238.

Marais, S., Jordaan, E., Olivier, L. & Viljoen, D. 2012. Fetal alcohol spectrum disorders. In A. van Niekerk, E. Suffia & M. Seedat (eds), *Crime, violence and injury in SA, 21st century solutions for child safety*, 214-228. [Online]. Available: http://www.mrc.ac.za/crime/Chapter15.pdf. [Accessed 21 March 2020].

Maree, K. 2020. *First Steps in Research*. (3rd ed). Pretoria: Van Schaik Publishers.

Masis, K.B. & May, P.A. 1991. A comprehensive local program for the prevention of fetal alcohol syndrome. *Public Health Reports*, 106(5):484-489. [Online]. Available: https://www.jstor.org/stable/4596987. [Accessed 2 March 2020].

Martino, S., Ondersma, S.J., Forray, A., Olmstead, T.A., Gilstad-Hayden, K., Howell, H.B., Kershaw, T. & Yonkers, K.A. 2018. A randomized controlled trial of screening and brief interventions for substance use in reproductive health. *American Journal of Obstetrics and Gynecology*, 218:322e1-12.

Massachusetts Department of Public Health Bureau of Substance Abuse Services. 2009. *Provider Guide: Adolescent Screening, Brief Intervention, and Referral to Treatment Using the CRAFFT Screening Tool*. Boston, MA. [Online]. Available: https://www.masspartnership.com/pdf/CRAFFTScreeningTool.pdf. [Accessed 7 August 2022].

Matabese, S., Macleod, C.I. & Tsetse, N. 2021. The shame of drinking alcohol while pregnant: The production of avoidance and ill-health. *Journal of Women and Social Work,* 36(4):626-646. [Online]. Available: https://journals-sagepub-com.ez.sun.ac.za/doi/10.1177/0886109920985139. [Accessed 19 June 2022].

Matsika, A.B. 2021. Intimate partner violence (IPV) in Zimbabwe: views of service providers on contributing factors and implications for social work intervention. Unpublished PhD thesis. Stellenbosch: Stellenbosch University.

Stellenbosch University https://scholar.sun.ac.za

Mattson, S.N., Crocker, N. & Nguyen. T.T. 2011. Fetal alcohol spectrum disorder: neuropsychological and behavioural features. *Neuropsychology Review*, 21(2):81-101.

Mattson, S.N., Schoenfeld, A.M. & Riley, E.P. 2001. Teratogenic effects of alcohol on brain and behavior. *Alcohol Research & Health*, 25(3):185-191.

May, P.A. 1995. A multiple level, comprehensive approach to the prevention of fetal alcohol syndrome (FAS) and other alcohol-related birth defects (ARBD). *The International Journal of the Addictions*, 30(12):1549-1602.

May, P.A. 2021. PhD proposal, E-mail to M.M. de Vries [Online], 16 March, Available E-mail: mmdevries@sun.ac.za.

May, P.A. 2020. Personal interview. 5 June. (Zoom)

May, P.A., Beate, A., Russo, J., Elliot, A.J., Blankenship, J., Kalberg, W.O., Buckley, D., Brooks, M., Hasken., J., Abdul-Rahman, O., Adam, M.P., Robinson, L.K., Manning, M. & Hoyme, H.E. 2014. Prevalence and characteristics of fetal alcohol spectrum disorders. *Pediatrics*, 134(5):854-866.

May, P.A., Blankenship, J., Marais, A.S., Gossage, J.P., Kalberg, W.O., Barnard, R., De Vries, M., Robinson, L.K., Adnams, C.M., Buckley, D., Manning, M., Jones, K.L., Parry, C., Hoyme, E. and Seedat, S. 2013. Approaching the prevalence of the full spectrum of fetal alcohol spectrum disorders in a population-based study. *Alcoholism: Clinical and Experimental Research,* 37(5):818-830.

May, P.A.; Blankenship, J., Marais, A.S., Gossage, J.P., Kalberg, W.O., Joubert, B., Cloete, M., Barnard, R., De Vries, M., Hasken, J., Robinson, L.K., Adnams, C.M., Buckley, D., Manning, M., Parry, C.D.H., Hoyme, H.E., Tabachnick, B. & Seedat, S. 2013. Maternal alcohol consumption producing fetal alcohol spectrum disorders (FASD): quantity, frequency, and timing of drinking. *Drug and Alcohol Dependence,* 33: 502– 512.

May, P.A., Brooke, L., Gossage, J.P., Croxford, J., Adnams, C., Jones, K.L., Robinson, L. & Viljoen, D. 2000. Epidemiology of fetal alcohol syndrome in a South African community in the Western Cape Province. *American Journal of Public Health*, 90(12):1905-1912.

Stellenbosch University https://scholar.sun.ac.za

May, P.A., Chambers, C.D., Kalberg, W.O., Zellner, J., Feldman, H., Buckley, D., Kopald, D., Hasken, J., Xu, R., Honerkamp-Smith, G., Taras, H., Manning, M.A., Robinson, L.K., Adam, M.P., Abdul-Rahman, O., Vaux, K., Jewett, T., Elliot, A.J., Kable, J.A., Akshoornoff, N., Falk, D., Arroyo, J.A., Hereld, D., Riley, E.P., Charness, M.E., Coles, C.D., Warren, K.R., Jones, K.L. & Hoyme, E. 2018. The prevalence of fetal alcohol spectrum disorders in 4 US communities. *JAMA*, 319(5):474-482.

May, P.A., De Vries, M.M., Marais, A.S., Kalberg, W.O., Adnams, C.M., Hasken, J.M., Tabachnick, B., Robinson, L.K., Manning, M.A., Jones, K.L., Hoyme, D., Seedat, S., Parry, C.D.H. & Hoyme, E. 2016. The continuum of fetal alcohol spectrum disorders in four rural communities in South Africa: prevalence and characteristics. *Drug and Alcohol Dependence,* 159:207-18.

May, P.A., De Vries, M.M., Marais, A.S., Kalberg, W.O., Buckley, D., Adnams, C.A., Hasken, J.M., Tabachnick, B., Robinson, L.K., Manning, M.A., Bezuidenhout, H., Adam, M.P., Jones, K.L., Seedat, S., Parry, C.D.H. & Hoyme, H.E. 2017. Replication of high fetal alcohol spectrum disorder prevalence rates, child characteristics, and maternal risk factors in a second sample of rural communities in South Africa. *International Journal of Environmental Research and Public Health,* 14:522.

May, P.A., De Vries, M.M., Marais, S.S., Kalberg, W.O., Buckley, D., Hasken, J.M., Rahman, O.A., Robinson, L.K., Manning, M.A., Seedat, S., Parry, C.D.H. & Hoyme, H.E. 2022. The Prevalence of Fetal Alcohol Spectrum Disorders in Rural Communities in South Africa: A Third Regional Sample of Child Characteristics and Maternal Risk Factors. *Alcoholism: Clinical and Experimental Research*, in press.

May, P.A., Gossage, J.P., Kalberg, W.O., Robinson, L.K. Buckley, D., Manning, M. & Hoyme, H.E. 2009. Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Developmental Disabilities Research Reviews*, 15:176-192.

Stellenbosch University https://scholar.sun.ac.za

May, P.A., Gossage, J.P., Marais, A.S., Adnams, C.M., Hoyme, H.E., Jones, K.I., Robinson, L.K., Khaole, N.C.O., Snell, C., Kalberg, W.O., Hendricks, L., Brooke, L., Stellvato, C. & Viljoen, D. 2007. The epidemiology of fetal alcohol syndrome and partial FAS in a community in South Africa. *Drug and Alcohol Dependence,* 88:259-271.

May, P.A., Gossage, J.P., Marais, A.S., Hendricks, L.S., Snell, C.L., Tabachnick, B.G., Stellavato, C., Buckley, D.G., Brooke, L.E. & Viljoen, D.L. 2008. Maternal risk factors for fetal alcohol syndrome and partial fetal alcohol syndrome in South Africa: a third study. *Alcoholism: Experimental and Clinical Research*, 32(5):738-753.

May, P.A., Gossage, J.P., Smith, M., Tabachnick, B.G., Robinson, L.K., Manning, M., Cecanti, M., Jones, K.L., Khaole, N., Buckley, D., Kalberg, W.O., Trujillo, P.M. & Hoyme, H.E. 2010. Population differences in dysmorphic features among children with fetal alcohol spectrum disorders. *Journal of developmental & behavioural pediatrics*, 31(4):304-316.

May, P.A., Hamrick, K.J., Corbin, K.D., Hasken, J.M., Marais, A.S., Blankenship, J, Hoyme, H.E. and Gossage, J.P. 2016. Maternal nutritional status as a contributing factor for the risk of fetal alcohol spectrum disorders. *Reproductive Toxicology*, 50:101-108.

May, P.A., Hamrick, K.J., Corbin, K.D., Hasken, J.M., Marais, A.S., Brooke, L.E., Blankenship, J., Hoyme, H.E. and Gossage, J.P. 2014. Dietary intake, nutrition and fetal alcohol spectrum disorders in the Western Cape Province of South Africa. *Reproductive Toxicology*, 46:31-39.

May, P.A., Hasken, J.M., Baete, A., Russo, J., Elliot, A.J., Kalberg, W.O., Buckley, D., Brooks, M., Ortega, M.A., Hedrick, D.M., Tabachnick, B., Abdul-Rahman, O., Adam, M.P., Jewett, T., Robinson, L.K., Manning, M.A. & Hoyme, H.E. 2020. Fetal alcohol spectrum disorders in a midwestern city: child characteristics, maternal risk traits, and prevalence. *Alcoholism: Clinical and experimental research*, 44(4):919-938.

Stellenbosch University https://scholar.sun.ac.za

May, P.A., Hasken, J.M., Blankenship, J., Marais, A.S., Joubert, B., Cloete, M., De Vries, M.M., Barnard, R., Botha, I., Roux, S., Doms, C., Gossage, J.P., Kalberg, W.O., Buckley, D., Robinson, L.K., Adnams, C.M., Manning, M.A., Parry, C.D.H., Hoyme, E., Tabachnick, B. & Seedat, S. 2016. Breastfeeding and maternal alcohol use: prevalence and effect on child outcomes and fetal alcohol spectrum disorders. *Reproductive Toxicology,* 63:13-21.

May, P.A., Hasken, J.M., De Vries, M.M., Marais, A.S., Stegall, J.M., Marsden, D., Parry, C.D.H., Seedat, S. & Tabachnick, B. 2018. A utilitarian comparison of two alcohol use biomarkers with self-reported drinking history collected in antenatal clinics. *Reproductive Toxicology*, 77:25-32.

May, P.A. & Hymbaugh, K.J. 1989. A macro-level fetal alcohol syndrome prevention program for Native Americans and Alaska Natives: Description and evaluation. *Journal of Studies on Alcohol*, 50(6):505-518.

May, P.A., Marais, A.S., De Vries, M.M., Buckley, D., Kalberg, W.O., Hasken, J.M., Stegall, J.M., Hedrick, D.M., Robinson, L.K., Manning, M.A., Tabachnick, B.G., Seedat, S., Parry, C.D.H. & Hoyme, H.E. 2021. The prevalence, child characteristics, and maternal risk factors for the continuum of fetal alcohol spectrum disorders: a sixth population-based study in the same South African community. *Drug and Alcohol Dependence*, 218:10848.

May, P.A., Marais, A.S., De Vries, M.M., Kalberg, W.O., Buckley, D., Hasken, J.M., Adnams, C.M., Barnard, R., Joubert, B., Cloete, M., Tabachnick, B., Robinson, L.K., Manning, M.A., Jones, K.L., Bezuidenhout, H., Seedat, S., Parry, C.D.H. & Hoyme, H.E. 2016. The continuum of fetal alcohol spectrum disorders in a community in South Africa: prevalence and characteristics in a fifth sample. *Drug and Alcohol Dependence,* 168:274-286.

May, P.A., Marais, A.S., Gossage, J.P., Barnard, R., Joubert, B., Cloete, C., Hendricks, N., Roux, S., Blom, A., Steenekamp, J., Alexander, T., Andreas, R., Human, S., Snell, C., Seedat, S., Parry, Kalberg, W.O., Buckley, D. & Blankenship, J. 2013. Case management reduces drinking during pregnancy among high-risk women. *International Journal of Alcohol and Drug Research*, 2(3):61-70.

Stellenbosch University https://scholar.sun.ac.za

May, P.A. & Moran, J.R. 1995. Prevention of alcohol misuse: a review of health promotion efforts among American Indians. *American Journal of Health Promotion*, 9(4):288-299.

May, P.A., Tabachnick, B.G., Gossage, J.P., Kalberg, W.O., Marais, A.S., Robinson, L.K., Manning, M., Blankenship, J., Buckley, D., Hoyme, H.E. & Adnams, C.M. 2013. Maternal factors predicting cognitive and behavioral characteristics of children with fetal alcohol spectrum disorders. *Journal of Developmental and Behavioral Pediatrics,* 34(5):314-325

May, P.A., Tabachnick, B., Hasken, J.M., Marais, A.S., De Vries, M.M., Barnard, R., Joubert, B., Cloete, M., Botha, I., Kalberg, W.O., Buckley, D., Burroughs, Z., Bezuidenhout, H., Robinson, L.K., Manning, M.A., Adnams, C.M., Seedat, S., Parry, C.D.H. & Hoyme, H.E. 2017. Who is most affected by prenatal alcohol exposure: boys or girls? *Drug and Alcohol Dependence,* 177:258-267.

McBride, N. & Johnson, S. 2016. Fathers' role in alcohol-exposed pregnancies: Systematic review of human studies. *American Journal of Preventive Medicine*, 51(2):240–248.

Mchunu, G., Peltzer, K., Tutshana, B. & Seutlwadi, L. 2012. Adolescent pregnancy and associated factors in South African youth. *African Health Sciences*, 12(4):426-434.

McLafferty, L.P., Becker, M., Dresner, N., Meltzer-Brody, S., Gopalan, P., Glance, J., St. Victor, G., Mittal, L., Marshalek, P., Lander, L. & Worley, L.L.M. 2016. Guidelines for the management of women with substance use disorders. *Psychosomatics*, 57:115-130.

McLean, S. & McDougall, S. 2014. Fetal alcohol spectrum disorders: current issues in awareness, prevention and intervention. *Australian Institute of Family Studies, CFCA paper,* 29:1-19. [Online]. Available: https://www.indigenousjustice.gov.au/resources/fetal-alcohol-spectrum-disorders-current-issues-in-awareness-prevention-and-intervention/. [Accessed 2 January 2021].

Stellenbosch University https://scholar.sun.ac.za

McQuire, C., Daniel, R., Hurt, L., Kemp, A. & Paranjothy, S. 2020. The causal web of foetal alcohol spectrum disorders: a review and causal diagram. *European Child and Adolescent Psychiatry,* 29: 575–594 [Online]. Available: The causal web of foetal alcohol spectrum disorders: a review and causal diagram | SpringerLink. [Accessed 13 October 2020].

Mega, J.S. & Cummings, J.L. 1994. Frontal-subcortical circuits and neuropsychiatric disorders. *The journal of neuropsychiatry and clinical neurosciences*, 6(4):358-370. [Online]. Available: https://pubmed.ncbi.nlm.nih.gov/7841807/. [Accessed 28 October 2020].

Miles, M.B. & Huberman, A.M. 1994. *Qualitative data analysis: an expanded sourcebook.* Newbury Park, California: Sage publications.

Miller, W.R. & Rollnick, S. 2009. Ten things that motivational interviewing is not. *Behavioural and cognitive psychotherapy*, 37:129-140.

Molteno, C.D., Jacobson, J.L., Carter, R.C., Dodge, N.C. & Jacobsen, S.W. 2014. Infant emotional withdrawal: a precursor of affective and cognitive disturbance in fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research*, 38(2):479-488.

Muggli, E., O'Leary, C., Donath, S., Orsini, F., Forster, D., Anderson, P.J., Lewis, A., Nagle, C., Craig, J.M., Elliot, E. & Halliday, J. 2016. "Did you ever drink more?" A detailed description of pregnant women's drinking patterns. *BMC Public Health*, 16:683.

Nascimento, L. da S. & Steinbruch, F.K. 2019. "The interviews were transcribed", but how? Reflections on management research. *RAUSP Management Journal*, 54(4):413–429.

*National Institute on Alcohol Abuse and Alcoholism: Alcohol Use Disorders Identification Test (AUDIT).* [Online]. 2000. Available: https://pubs.niaaa.nih.gov/publications/audit.htm. [Accessed 13 August 2022].

Neuman, W.L. 2014. *Social research methods: qualitative and quantitative approaches* (7th ed). Essex: Pearson.

Stellenbosch University https://scholar.sun.ac.za

Nguyen, T.T., Coppins, J. & Riley, E.P. 2011. Prenatal alcohol exposure, FAS and FASD: an introduction. In: Riley, E.P., Clarren, S., Weinberg, J. & Jonsson, E. *Fetal alcohol spectrum disorder, management and policy perspectives of FASD.* Weinheim: Wiley- VCH Verlag, GmbH & Co., KgaA, 1-10.

Ntuli, B., Sebola, E. & Madiba, S. 2020. Responding to maternal loss: a phenomenological study of older orphans in youth-headed households in impoverished areas of South Africa. *Heatlhcare,* 8(3):259-273.

O'Connor, M. & Paley, B. 2009. Psychiatric conditions associated with prenatal alcohol exposure. *Developmental Disabilities Research Reviews*, 15:225–234.

Odendaal, H., Brink, L.T., Carstens, E., De Jager, M., Potter, M., Du Plessis, C. & Groenewald, C.A. 2020. Smoking and drinking habits of women in subsequent pregnancies after specific advice about the dangers of these exposures during pregnancy. *South African Medical Journal*, 110(11):1100-1104.

Odendaal, H., Kruger, M. & Botha, M.H. 2020. Dangers of smoking cigarettes and drinking alcohol during pregnancy. *South African Medical Journal*, 110(11):1066-1067. [Online]. Available: https://doi.org/10.7196/SAMJ.2020.v110i11.14738. [Accessed 17 November 2020].

Oliver, D.G., Serovic, J.M. & Mason, T.L. 2005. Constraints and opportunities with interview transcription: towards reflection in qualitative research. *Social Forces*, 84(2):1273–1289.

Olivier, L. 2017. Fetal alcohol spectrum disorders in South Africa: A 20-year journey. Unpublished PhD thesis. Maastricht: Maastricht University. [Online] Available: https://doi.org/10.26481/dis.20171212lo. [Accessed 21 March 2020].

Olivier, L., Curfs, L.M.G. & Viljoen, D.L. 2016. Fetal alcohol spectrum disorders: prevalence rates in South Africa. *South African Medical Journal*, 106(6) Supplement 1: S103-S106. [Online]. Available: http://doi.org/10.7196/samj.2016.v106i6.11009. [Accessed 20 June 2020]

Stellenbosch University https://scholar.sun.ac.za

Olivier, L., Urban, M., Chersich, M., Temmerman, M. & Viljoen, D. 2013. Burden of fetal alcohol syndrome in a rural west coast area of South Africa. *South African Medical Journal,* 103(6):402-405. [Online] Available: http://doi.org/10.7196/samj.6249. [Accessed 21 March 2020].

Ondersma, S.J., Beatty, J.R., Svikis, D.S., Strickler, R.C., Tsilos, G.K., Chang, G., Divine, D.W., Taylor, A.R. & Sokol, R.J. 2015. Computer-delivered screening and brief intervention for alcohol use in pregnancy: a pilot randomized trial. *Alcoholism: Clinical and Experimental Research*, 39(7):1219-1226.

O'Neill, E. 2011. Effects of prenatal alcohol exposure on cardiac development. *Embryo Project Encyclopedia*. [Online] Available: http://embryo.asu.edu/handle/10776/2097. [Accessed 15 September 2020].

Osterman, R.L. 2011. Decreasing women's alcohol use during pregnancy. *Alcohol Treatment Quarterly,* 29(4), 436-452.

Ott, K.M., Quinn, L. & Thompson, S.L. 2004. A social ecological analysis of fetal alcohol spectrum disorders prevention programming. *Journal of Fetal Alcohol Syndrome*, 2(e11):1-5.

Paley, B. & O'Connor, M. 2011. Behavioral interventions for children and adolescents with fetal alcohol spectrum disorders. *Alcohol Research and Health*, 34(1):64-75.

Pallito, C.C., Garcia-Moreno, C., Jansen, H.A.F.M., Heise, L., Ellsberg, M. & Watts, C. 2013. Intimate partner violence, abortion, and unintended pregnancy: Results from the WHO multi-country study on women's health and domestic violence. *International Journal of Gynecology and Obstetrics,* 120:3-9.

Palmer, C. 1985. Fetal alcohol effects - incidence and understanding in the Cape. *South African Medical Journal*, 68(11):779-780.

Parkington, H.C., Coleman, H.A., Wintour, E.M. & Tare, M. 2010. Prenatal alcohol exposure: implications for cardiovascular function in the fetus and beyond. *Clinical and Experimental Pharmacology and Physiology*, 37: e91–e98.

Parry, C.D.H. & Gossage, J.P. 2011. Report community surveys in Wellington and BRAM (Bonnievale, Robertson, Ashton and Montagu): 2008-2010. [Powerpoint Presentation]. 23 February. Nelson's Creek Wine Estate, Paarl.

Stellenbosch University https://scholar.sun.ac.za

Parry, C.D.H., Gossage, J.P., Marais, A.S., Barnard, R., De Vries, M., Blankenship, J., Seedat, S. & May, P.A. 2012. Comparison of baseline drinking practices, knowledge and attitudes of adults residing in communities taking part in the FAS prevention study in South Africa. *African Journal of Drug & Alcohol Studies,* 11(2).

*Pebbles Project: Community programmes*. [Online]. 2021. Available: https://www.pebblesproject.org/community-programmes/. [Accessed 17 June 2021].

Pelech, W., Badry, D. & Daoust, G. 2013. It takes a team: improving placement stability in children and youth with fetal alcohol spectrum disorder in care in Canada. *Children and Youth Services Review*, 35:120-127.

Pilgrim, D. 2015. The biopsychosocial model in health research: its strengths and limitations for critical realists. *Journal of Critical Realism*, 14(2):164-180.

Pilowsky, D.J., Keyes, K.M. & Hasin, D.S. 2009. Adverse childhood events and lifetime alcohol dependence. *American Journal of Public Health*, 99(2):258-263.

Poole, N., Schmidt, R.A., Green, C. & Hemsing, N. 2016. Prevention of fetal alcohol spectrum disorder: current Canadian efforts and analysis of gaps. *Substance Abuse: Research and Treatment*, 10(S1):1-11.

Popova, S., Dozet, D. & Burd, L. 2020. Fetal alcohol spectrum disorder: can we change the future? *Alcoholism, Clinical and Experimental Research*, 44(4):815-819.

Popova, S., Lange, S., Probst, C., Gmel, G. & Rehm, J. 2018. Global prevalence of alcohol use and binge drinking during pregnancy, and fetal alcohol spectrum disorder. *Biochemistry and Cell Biology*, 96(2):236-240.

Popova, S., Lange, S., Shield, K., Mihik, A., Chudley, A.E., Mukherjee, R.A.S., Bekmuradov, D. & Rehm, D. 2016. Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis. *Lancet*, 387:278-287.

Popova, S., Stade, B., Bekmuradov, D., Lange, S. & Rehm, J. 2011. What do we know about the economic impact of fetal alcohol spectrum disorder? A systematic literature review. *Alcohol and* Alcoholism, 46(4):490-497.

Stellenbosch University https://scholar.sun.ac.za

*Project for a European integrated communication campaign to increase awareness of and prevent fetal alcohol spectrum disorders*. [Online]. 2013. Available: https://www.eufasd.org/pdf/campaign.pdf. [Accessed 5 January 2021].

Rehner, T., Brazeal, M. & Doty, S.T. 2017. Embedding a social work–led behavioral health program in a primary care system: A 2012-2018 case study. *Journal of Public Health Management and Practice*, 23(6 Supp):S40-S46. [Online]. Available: https://doi.org/10.1097/PHH.0000000000000657. [Accessed 18 June 2022].

Rendall-Mkosi, K., Morojele, N., London, L., Moodley, S., Singh, C. & Girdler-Brown, B. 2012. A randomized controlled trial of motivational interviewing to prevent risk for an alcohol-exposed pregnancy in the Western Cape, South Africa. *Addiction*, 108:725-732.

Retief, R. & Green, S. 2015. Some challenges in policing domestic violence. *Social Work/Maatskaplike Werk*, 50(1):135-147.

Riley, E.P., Infante, M.A. & Warren, K.R. 2011. Fetal alcohol spectrum disorders: an overview. *Neuropsychology Review*, 21(2):73-80.

Riley, E.P., Mattson, S.N., Li, T.K., Jacobson, S.N., Coles, C.D., Kodituwakku, P.W., Adnams, C.M. & Korkman, M.I. 2003. Neurobehavioural consequences of prenatal alcohol exposure: an international perspective. *Alcoholism: Clinical and experimental research*, 27(2):362-373.

Rodger, E. & Gowsell, R. 2014. *Understanding mental health: fetal alcohol spectrum disorder*. Canada: Crabtree Publishing Company.

Roebuck, T.M., Mattson, S.N. & Riley, E.P. 1999. Behavioral and psychosocial profiles of alcohol-exposed children. *Alcoholism: Clinical and Experimental Research*, 23:1070–1076.

Roozen, S., Olivier, L., Niemczyk, J., Von Gontard, A., Peters, G.J.Y., Kok, G., Viljoen, D. & Curfs, L. 2017. Nocturnal incontinence in children with fetal alcohol spectrum disorders (FASD) in a South African cohort. *Journal of pediatric urology,* 13:496.e1-196.e7.

Stellenbosch University https://scholar.sun.ac.za

Roozen, S., Peters, G.Y., Kok, G., Townend, D, Nijhuis, J & Curfs, L. 2016. Worldwide prevalence of fetal alcohol spectrum disorders: a systematic literature review including meta-analysis. *Alcoholism: Clinical and Experimental Research,* 40(1):18-32.

Rosenthal, J., Christianson, A. & Cordero, J. 2005. Fetal alcohol syndrome prevention in South Africa and other low resource countries. *American journal of public health (Editorials)*, 95(7):1099-1101.

Roulston, K. & Choi, M. 2018. Qualitative interviews. In: Flick, U. (ed). *The SAGE handbook of qualitative data collection*. London: Sage publications.

Rubin, A. & Babbie, E. 2001. *Research methods for social work* (4th ed). Belmont, California: Sage publications.

Rubin, H.J. & Rubin, I.S. 1995. *Qualitative interviewing: The art of hearing data.* Thousand Oaks, California: Sage publications.

*SANCA Western Cape: Fetal alcohol spectrum disorder awareness programme & capacity building.* [Online]. [n.d.]. Available: http://sancawc.co.za/fasd-programme-may-2014/. [Accessed 17 June 2021].

Sarmah, S. & Marrs, J.A. 2017. Embryonic ethanol exposure affects early- and late-added cardiac precursors and produces long-lasting heart chamber defects in zebrafish. *Toxics,* 5(35). [Online]. Available: http://dx.doi.org/10.3390/toxics5040035. [Accessed 3 July 2020].

Schurink, W., Fouché, C.B. & De Vos, A.S. 2011. Qualitative data analysis and interpretation. In: De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L (eds). *Research at grass roots for the social sciences and human service professions* (4th ed). Pretoria, SA: Van Schaik Publishers.

Schurink, W.J., Roestenburg, W.J.H. & Fouché, C.B. 2021. The place of literature and theory in research. In: Fouché, C.B., Strydom, H. & Roestenburg, W.J.H. (eds). *Research at grass roots. For the social sciences and human service professions* (5th ed). Pretoria, SA: Van Schaik Publishers.

Stellenbosch University https://scholar.sun.ac.za

Schurink, W.J., Schurink, E.M. & Fouché, C.B. 2021. Thematic inquiry in qualitative research. In: Fouché, C.B., Strydom, H. & Roestenburg, W.J.H. (eds). *Research at grass roots. For the social sciences and human service professions* (5th ed). Pretoria, SA: Van Schaik Publishers.

Schwandt, T.A. & Gates. E.F. 2018. Case study methodology. In: Denzin, N.K. & Lincoln, Y.S. (eds). *The Sage handbook of qualitative research method: A guidebook and resource* (5th ed). Thousand Oaks, CA: Sage publications, 341-358.

Sefotho, M.M. 2021. Research and professional practise. In: Fouché, C.B., Strydom, H. & Roestenburg, W.J.H. (eds). *Research at grass roots. For the social sciences and human service professions* (5th ed). Pretoria, SA: Van Schaik Publishers.

Sek, A., Cybulski, M., Olejnik, B. & Krajevska-Kulak, E. 2017. Biopsychosocial effects of foetal alcohol syndrome among children from the Interventional Care Facility in Otwock. *Pediatria i Medycyna Rodzinna*, 13(2):212–223.

Shogren, M.D., Harsell, C. & Heitkamp, T. 2017. Screening women for at-risk alcohol use:iIntroduction to screening, brief intervention and referral to treatment (SBIRT) in women’s health. *Journal of Midwifery and Women’s Health*, 62:746-754.

Slabbert, I. 2016. Domestic Violence and Poverty: Some Women’s Experiences. *Research on Social Work Practice*, 27(2):223-230.

Slabbert, I. 2019. “Ek het uiteindelik op straat beland; dis ŉ harde lewe”: Uitdagings van kwesbare vroue wat alkohol of dwelms misbruik. Tydskrif vir Geesteswetenskappe, 59(4):671-684.

Slabbert, I. 2010. The experience of low-income female survivors of domestic violence. Unpublished PhD thesis, Stellenbosch, Stellenbosch University.

Slabbert, I & Green, S. 2013. Types of domestic violence experienced by women in abusive relationships. Social Work/Maatskaplike Werk, 49(2):234-247.

Stellenbosch University https://scholar.sun.ac.za

Slabbert, I., Green, M.C., Womersley, J., Olateju, O.I., Soboka, M. & Lemieux, A.M. 2020. Women and substance use disorders in low- and middle-income countries: A call for advancing research equity in prevention and treatment. *Substance abuse*, 41(1):6-10.

Snell, C.L. 2019. Motivational enhancement therapy. [PowerPoint presentation]. June 4-7. Stellenbosch University, Robertson.

Soares, J.C. & Mann, J.J. 1997. The anatomy of mood disorders - review of structural neuroimaging studies. *Biological Psychiatry*, 41:86–106.

Sonke Gender Justice, Human Sciences Research Council. 2018. State of South Africa's fathers 2018. [Online]. Available: State of South Africa's Fathers 2018 – Sonke Gender Justice. [Accessed 25 April 2022].

*South African Council for Social Service Professions*: *Policy guidelines for course of conduct, code of ethics and the rules for social workers*. [Online]. [n.d.]. Available: https://socialdev.mandela.ac.za/socialdev/media/Store/documents/SACSSP-Code-of-Ethics.pdf. [Accessed 25 June 2022].

Spedding, M.F., Sorsdahl, K., Parry, C.D.H., Mathews, C., Stein, D.J. & Petersen Williams, P. 2020. Psychological distress during pregnancy. Cross-sectional prevalence and associated risk factors in a South African sample. *The Journal of Nervous and Mental Disease*, 208(10):755-763.

*State of the nation address by President Cyril Ramaphosa.* [Online]. 2022. Available: https://www.stateofthenation.gov.za/assets/downloads/SONA-2022-SPEECH.pdf. [Accessed 5 June 2022].

Stevens, S., Anstice, N., Cooper, A., Goodman, L., Rodgers, J. & Woulders, T.A. 2020. Multiple tools are needed for the detection of prenatal alcohol exposure: findings from a community antenatal setting. *Alcoholism: Clinical and experimental research*, 44(4):1001-1011.

Stratton, K. 1996. Prevention of fetal alcohol syndrome. In: Stratton, K., Howe, C. & Battaglia, F. (eds). *Fetal alcohol syndrome diagnosis, epidemiology, prevention and treatment.* Washington D.C.: National Academy Press.

Stellenbosch University https://scholar.sun.ac.za

Strine, T.W., Dube, S.R., Edwards, V.J., Prehn, A.W., Rasmussen, S., Wagenfeld, M., Dhingra, S. & Croft, J.B. 2012. Associations between adverse childhood experiences, psychological distress, and adult alcohol problems. *American Journal of Health Behavior*, 36(3):408-423.

Strydom, H. 2012. Sampling in the quantitative paradigm. In: De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L (eds). *Research at grass roots for the social sciences and human service professions* (4th ed). Pretoria, SA: Van Schaik Publishers.

Strydom, H. 2021. Sampling techniques and pilot studies in qualitative research. In: Fouché, C.B., Strydom, H. & Roestenburg, W.J.H. (eds). *Research at grass roots. For the social sciences and human service professions* (5th ed). Pretoria, SA: Van Schaik Publishers.

Strydom, H. & Delport, C.S.L. 2011. Sampling and pilot study in qualitative research. In: De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L (eds). *Research at grass roots for the social sciences and human service professions* (4th ed). Pretoria, SA: Van Schaik Publishers.

Strydom, H. & Roestenburg, W.J.H. 2021. Ethical conduct with research in human participants. In: Fouché, C.B., Strydom, H. & Roestenburg, W.J.H. (eds). *Research at grass roots. For the social sciences and human service professions* (5th ed). Pretoria, SA: Van Schaik Publishers.

Suttie, M., Wozniak, J.R., Pamell, S.E., Wetherill, L., Mattson, S.N., Sowell, E.R., Kan, E., Riley, E.P., Jones, K.L., Coles, C., Foroud, T., Hammond, P. & the CIFASD. 2018. Combined face–brain morphology and associated neurocognitive correlates in fetal alcohol spectrum disorders. *Alcoholism: Clinical & experimental research*, 42(9):1769-1782.

Symons, M., Pedruzzi, R.A., Bruce, K. & Milne, E. 2018. A systematic review of prevention interventions to reduce prenatal alcohol exposure and fetal alcohol spectrum disorder in indigenous communities. *BMC Public Health*, 18:1227-1245. [Online]. Available: https://doi.org/10.1186/s12889-018-6139-5. [Accessed 18 November 2020].

Stellenbosch University https://scholar.sun.ac.za

Taylor, G.J. 2002. Mind-body-environment: George Engels's psychoanalytic approach to psychosomatic medicine. *Australian and New Zealand Journal of Psychiatry*, 36:449-457.

Tekin, S. & Cummings, J.L. 2002. Frontal-subcortical neuronal circuits and clinical neuropsychiatry: an update. *Journal of psychosomatic research*, 53(2):647-654. [Online]. Available: https://pubmed.ncbi.nlm.nih.gov/12169339/. [Accessed 28 October 2020].

Tough, S.C & Jack, M. 2011. Frequency of FASD in Canada and what it means for prevention efforts. In: Riley, E.P., Clarren, S., Weinberg, J. & Jonsson, E. (eds). *Fetal alcohol spectrum disorder, management and policy perspectives of FASD.* Weinheim: Wiley- VCH Verlag, GmbH & Co., KgaA, 27-43.

Urban, K.A., Bodnar, T., Butts, K., Sliwowska, J.H., Comeau, W. & Weinberg, J. 2011. Direct and indirect mechanisms of alcohol teratogenesis: implications for understanding alterations in brain and behavior in FASD. In: Riley, E.P., Clarren, S., Weinberg, J. & Jonsson, E. (eds). *Fetal alcohol spectrum disorder, management and policy perspectives of FASD.* Weinheim: Wiley- VCH Verlag, GmbH & Co., KgaA,1-10.

Urban, M.F., Olivier, L., Louw, J.G., Lombard, C., Viljoen, D.L., Scorgie, F. & Chersich, M.F. 2016. Changes in drinking patterns during and after pregnancy among mothers of children with fetal alcohol syndrome: a study in three districts of South Africa. *Drug and Alcohol Dependence*, 168:13–21.

Urban, M.F., Olivier, L., Viljoen, D., Lombard, C., Louw, J.G., Drotsky, L.M., Temmerman, M. & Chersich, F. 2015. Prevalence of fetal alcohol syndrome in a South African city with a predominantly black population. *Alcoholism: Clinical & experimental research,* 39(6):1016-1026.

Urban, M., Chersich, M.F., Fourie, L.A., Chetty, C., Olivier, L. & Viljoen, D. 2008. Fetal alcohol syndrome among grade 1 schoolchildren in Northern Cape Province: Prevalence and risk factors. *South African Medical Journal*, 98(11):877-882.

Van Schalkwyk, I. 2021. Strengthening female-headed households: exploring the challenges and strengths of mothers with substance-problems living in a high-risk community, *Journal of Family Studies*, 27:2, 280-302.

Stellenbosch University https://scholar.sun.ac.za

Van Schalkwyk, I. & Naidoo, A.V. 2021a. A wellness program for mothers living in the context of a South African high-risk community. *Journal of Evidence-Based Social Work.* [Online]. Available: https://doi.org/10.1080/26408066.2021.1994077. [Accessed 25 April 2022].

Van Schalkwyk, I. & Naidoo, A.V. 2021b. Moeders van ’n hoërisikogemeenskap se fotostemverkenning aangaande gemeenskapsbronne en behoefte aan verandering. *LitNet Akademies*, 18(2):377-408.

Vernig, P.M. 2011. Family roles in homes with alcohol-dependent parents: an evidence-based review. *Substance Use & Misuse*, 46:535–542.

Vetten, L. 2005. Addressing domestic violence in South Africa: Reflections on strategy and practice. Unpublished paper delivered at the Expert Group meeting organized by the UN division for the advancement of women. 17 – 20 May 2005, Vienna, Austria.

Viljoen, D.L., Gossage, J.P., Brooke, L., Adnams, C.M., Jones, K.L., Robinson, L.K., Hoyme, H.E., Snell, C., Khaole, N.C.O., Kodituwakku, P., Asante, K.O., Findlay, R., Quinton, B., Marais, A.S., Kalberg, W.O. & May, P.A. 2005. Fetal alcohol syndrome epidemiology in a South African community: a second study of a very high prevalence area. *Journal of studies on alcohol,* 66(5):593-604.

Visser, M. & Ferrer, S. 2015. *Farm workers’ living and working conditions in South Africa: key trends, emergent issues, and underlying and structural problems*. Pretoria: The International Labour Organization. [Online]. Available: http://www.idll.uct.ac.za/sites/default/files/image_tool/images/3/ILO_Farm%20Workers%27%20Living%20and%20Working%20Conditions%20in%20SA_14%20July%202015.pdf. [Accessed 12 August 2022].

Wang, X., Cuson Carlson, V.C., Studholme, C., Newman, N., Ford, M.M., Grant, K.A. & Kroenke, C.D. 2020. In utero MRI identifies consequences of early-gestation alcohol drinking on fetal brain development in rhesus macaques. *PNAS*, 117(18): 10035-10044. [Online]. Available: https://www.pnas.org/content/117/18/10035. [Accessed 29 September 2020].

Wangberg, S.C. 2015. Norwegian midwives’ use of screening for and brief interventions of alcohol use in pregnancy. *Sexual and Reproductive Healthcare*, 6:186-190.

Stellenbosch University https://scholar.sun.ac.za

Ware, A.L., Crocker, N., O'Brien, J.W., Deweese, B.N., Roesch, S.C., Coles, C.D., Kable, J.A., May, P.A., Kalberg, W.O., Sowell, E.R., Jones, K.L., Riley, E.P., Mattson, S.N. & the CIFASD. 2012. Executive function predicts adaptive behavior in children with histories of heavy prenatal alcohol exposure and attention-deficit/ hyperactivity disorder. *Alcoholism: Clinical and experimental research*, 36(8):1431-1441.

Warren, K.R., Calhoun, F.J., May, P.A., Viljoen, D.L., Li, T.K., Tanaka, H., Marinicheva, G.S., Robinson, L.K. & Mundle, G. 2001. Fetal alcohol syndrome: an international perspective. *Alcoholism: Clinical and experimental research*, 25(5):202S-206S.

Washio, Y., Frederick, HJ., Archibald, A., Bertram, N. & Crowe, J.A. 2017. Community-initiated pilot program "my baby's breath" to reduce prenatal alcohol use. *Delaware medical journal*, 89(2):47-51.

*WebMD: What's the CAGE assessment*? [Online]. 2021. Available: https://www.webmd.com/mental-health/addiction/whats-the-cage-assessment. [Accessed 8 August 2022].

*Western Cape Government*: *Fetal alcohol syndrome awareness programme*. [Online]. 2020. Available: https://www.westerncape.gov.za/general-publication/foetal-alcohol-syndrome-awareness-programme. [Accessed 17 June 2021].

*Western Cape Government: First 1 000 days. Grow, love, play.* [Online]. 2022. Available: https://www.westerncape.gov.za/first-1000-days/. [Accessed 25 July 2021].

Weyrauch, D., Schwartz, M., Hart, B., Klug, M.G. & Burd, L. 2017. Comorbid mental disorders in fetal alcohol spectrum disorders: a systematic review. *Journal of Developmental and Behavioural Pediatrics*, 38(4):283-291.

Wickramasekera, I., Davies, T.E. & Davies, S.M. 1996. Applied psychophysiology: a bridge between the biomedical model and the biopsychosocial model in family medicine. *Professional Psychology: Research and Practise*, 27(3):221-233.

Stellenbosch University https://scholar.sun.ac.za

Wilcoxon, J.S. & Redei, E.E. 2004. Prenatal programming of adult thyroid function by alcohol and thyroid hormones. *American Journal of Physiology, Endocrinology and Metabolism*, 287(2):318-326.

Wilson, F. & Ramphele, M. 1994. *Uprooting poverty: The South African challenge*. (Fourth Impression). David Philip, Cape Town and Johannesburg.

World Health Organization. 2007. *The international classification of diseases and related health problems* (10th revision). Geneva, Switzerland.

World Health Organization. 2021. *Global alcohol action plan 2022 - 2030 to strengthen the implementation of the global strategy to reduce the harmful use of alcohol* (First draft). Geneva, Switzerland.

World Health Organization. 2011. *Global status report on alcohol and health*. Geneva, Switzerland.

World Health Organization. 2014. *Guidelines for the identification and management of substance use disorders in pregnancy*. Geneva, Switzerland.

Wozniak, J.R., Riley, E.P. & Charness, M.E. 2019. Clinical presentation, diagnosis, and management of fetal alcohol spectrum disorder. *The Lancet Neurology*, 18:760-770.

Yang,J., Qiu, H., Qu, P., Zhang, R., Zeng, L. & Yan, H. 2015. Prenatal alcohol exposure and congenital heart defects: a meta-analysis. PLoS ONE, 10(6):e0130681. [Online}. Available: https://europepmc.org/backend/ptpmcrender.fcgi?accid=PMC4482023&blobtype=pdf. [Accessed 15 September 2020].

Yin, R. 1981. The case study crisis: some answers. *Administrative science quarterly*, 26:58-65.

Yin, R.K. 2009. *Case study research: design and methods* (4th ed). Los Angeles and London, Sage publications.

Zust, B.L., Opdahl, B.F., Moses, K.S., Schubert, C.N & Timmerman, J. 2021. 10-Year Study of Christian Church Support for Domestic Violence Victims: 2005-2015 *Journal of Interpersonal Violence*, 36(7-8):2959–2985.

Stellenbosch University https://scholar.sun.ac.za

# ANNEXURE A:
# CONSENT TO PARTICIPATE IN RESEARCH STUDY

**STELLENBOSCH UNIVERSITY**

**TITLE OF THE RESEARCH PROJECT:**

***Stories of mothers exposed to biopsychosocial FASD services in the Langeberg Municipal area***

Dear Participant

You are invited to participate in a research study conducted by M. de Vries, a doctoral student from the Department of Social Work, Stellenbosch University.

If you require further explanation of any aspect of the study after the consent form was read to you and discussed with you, please ask any questions you may have. It is crucial that you are fully satisfied that you clearly understand what this research study entails and how you could be involved.

This study has been approved by the Research Ethics Committee (REC): Social, Behavioural and Education research and the Department of Social Work Ethical Screening Committee (DESC) at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the South African Council of Social Service Professions (SACSSP) for social workers, and the South African Guidelines for Good Clinical Practice.

1. **Participation and withdrawal**

Your participation is **entirely voluntary,** which means that you are free to decline participation. If you say no, this will not affect you negatively in any way whatsoever.

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You have the right to participate or to leave it at any point with no impact on any services to which you are otherwise entitled. If you feel uncomfortable at any time during the interview, you may stop the interview. You may decide to withdraw from the study anytime between today and the end of the study. If you decide to withdraw, all information collected from you will be destroyed.

You may also refuse to answer any questions you do not want to answer and still remain in the study. The researcher may withdraw you from the study in the event of three or more missed appointments.

2. **Why do we need to conduct this research study?**

The goal of this research is to gain a better understanding of the lives, realities and needs of pregnant women at risk of having a child with FASD by telling the stories of women who were exposed to services for the prevention of FASD during one of their pregnancies.

3. **Why have you been invited to participate in the study?**

You are invited to participate in this study because:

- You participated in the Case Management study of the Fetal Alcohol Syndrome Research Study of Stellenbosch University;
- You gave permission to be contacted again for future studies following on the Case Management study you participated in.

4. **What will your responsibilities be?**

If you agree to participate in this study, the information collected and stored in your case file during your participation in the Case Management study, will be accessed to provide background information about your pregnancy, general circumstances, and experiences during the time you were in case management.

You will also be asked to conduct not more than three to four semi-structured interviews with the researcher. In these interviews, you will be asked questions about your background, your health, your relationships with your family, partner and friends, as well as your experience of case management and the influence it had on your

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lifestyle and drinking behaviour during pregnancy. The duration of the interviews will be approximately one hour each.

This study is not the same as psychotherapy, counselling, mental health treatment, substance abuse treatment, or medical care. If you decide you need any of these other services, every effort will be made to refer you to the right agency with your permission. If, after this interview, you feel that you need further debriefing than that supplied by the researcher, you will be referred to a private practitioner, Mrs. Cate Doms.

5. **Will you benefit from participating in this research?**

There may or may not be a benefit to you by participating in this study. However, it is expected that the information gained from this study will help social workers to better understand the needs and realities of pregnant women in order to contribute to the prevention of Fetal Alcohol Syndrome. In so doing, it aims to deliver the services needed to inform pregnant women about the dangers of drinking during pregnancy and support them in abstaining from alcohol.

6. **Are there risks involved for you if you participate in this study?**

Any uncertainties you have about any part of the study, or the interview schedule can be discussed and clarified prior to or during the interview. You will not experience any physical discomfort. **However, you might experience some emotional discomfort when asked questions pertaining your life and experiences during your lifetime.**

7. **How will your confidentiality be protected?**

Your name will not be used or linked in any way to research results, nor will your name be used when results of the study are published. Confidentiality will further be ensured by numbering research questionnaires rather than using names, coding the information obtained during the interviews and storing all the information in a locked safe in the researcher's home, on a password protected computer and on OneDrive, Stellenbosch University. Your permission is asked to audio-record interviews to assist data capturing and the subsequent data transcriptions. Only the researcher will have access to these audio-recordings. The recordings will not be used for educational purposes.

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8. **Will you be paid to take part in this study and are there any costs involved for you?**

No, you will not be paid to take part in the study. There will not be any costs involved for you if you do take part. You will be provided with a gift voucher to the value of R100 after completion of the interviews to thank you for your time and participation in the study.

9. **Is there anything else that you should know or do?**

If you have any questions about this study, you may contact Dr. I. Slabbert (Supervisor) at Stellenbosch University's Department of Social Work via the email address: islabbert@sun.ac.za, or the telephone number: 021-808 2070.

If you have any questions regarding your rights as a research subject, you may contact Ms Maléne Fouché at the Division for Research Development by sending her an email at: mfouche@sun.ac.za or phoning her at: 021 808 4622.

**Declaration by participant**

By signing below, I ................................................................ agree to take part in a research study titled "Stories of mothers exposed to biopsychosocial FASD services in the Langeberg Municipal area" as conducted by M. de Vries.

As the research participant, I declare that:

- This consent form was explained to me in Afrikaans, a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

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- All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.

Signed at (*place*) ......................…........……………….. on (*date*) …………...……….. 20……..

...........................................................................

**Signature of participant**

| **Declaration by the investigator** |
|---|

As the investigator, I hereby declare that:

- The information contained in this document has been thoroughly explained to the participant,
- The participant has been encouraged and has been given ample time to ask any questions. In addition, I would like to select the following option:

| | |
|---|---|
| | The conversation with the participant was conducted in Afrikaans, a language in which the participant is fluent. |
| | The conversation with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this Consent Form is available to the participant in a language in which the participant is fluent. |

Signed at (*place*) ......................…........……………….. on (*date*) …………...……….. 20___

...........................................................................

**Signature of investigator**

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# ANNEXURE B:
# TOESTEMMING OM AAN N NAVORSINGSTUDIE DEEL TE NEEM

## UNIVERSITEIT STELLENBOSCH

**TITEL VAN DIE NAVORSINGSPROJEK**

***Stories van moeders wat blootgestel was aan biopsigososiale FASA dienste in die Langeberg Munisipale area.***

Beste Studiedeelnemer

Jy word genooi om deel te neem aan ŉ navorsingstudie wat uitgevoer word deur M. de Vries, ŉ doktorale student aan die Departement Maatskaplike Werk, Stellenbosch Universiteit.

Indien jy enige verdere inligting of verduideliking van enige aspek van die studie nodig het nadat die ingeligte toestemmingsvorm vir jou gelees en met jou bespreek is, vra asseblief enige vrae wat jy mag hê. Dit is baie belangrik dat jy heeltemal tevrede is dat jy alles wat hierdie studie behels en hoe jy moontlik daarby betrokke kan wees, verstaan.

Die studie is goedgekeur deur die *Navorsingsetiekkomitee: Sosiale, Gedrags- en Opvoedkunde Navorsing (NEK: SGO)* en die Etiese Komitee van die Departement Maatskaplike Werk by die Universiteit Stellenbosch, en sal uitgevoer word volgens die etiese riglyne en beginsels van die Suid Afrikaanse Raad vir Maatskaplike Werk Beroepe (SACSSP) vir maatskaplike werkers en die Suid-Afrikaanse riglyne vir “Good Clinical Practise”.

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## 1. Deelname en onttrekking

Jou betrokkenheid by hierdie studie **is ten volle vrywillig** en dit staan jou vry om te kies om nie deel te neem nie. Indien jy nie wil deelneem nie, sal dit jou op geen manier hoegenaamd benadeel nie. Indien jy enige tyd tydens die onderhoud ongemaklik voel, mag jy die onderhoud stop. Dit staan jou ook vry om op enige tydstip uit die studie te onttrek, sonder dat dit enige invloed sal hê op dienste waarop jy geregtig sou wees. Jy kan besluit om enige tyd tussen vandag en die einde van die studie te onttrek. Indien jy nie verder wil deelneem nie, sal alle inligting wat van jou ingesamel is, vernietig word.

Jy mag ook weier om enige vraag te beantwoord wat jy nie wil antwoord nie en steeds deel van die studie bly. Die navorser mag jou ook onttrek uit die studie in die geval dat jy drie of meer afsprake mis.

## 2. Waarom is dit nodig om hierdie navorsing te doen?

Die doel van hierdie navorsing is om die lewensomstandighede, realiteite en behoeftes van swanger vrouens wat die risiko loop om ‘n kind met FASA te hê, beter te verstaan deur die stories van vroue te vertel wat aan dienste tydens een van hul swangerskappe blootgestel is.

## 3. Hoekom is jy genooi om aan hierdie studie deel te neem?

Jy word uitgenooi om aan hierdie studie deel te neem omdat:

- Jy deelgeneem het aan die Gevallebestuurstudie van die Fetale Alkoholsindroom Navorsingstudie van die Universiteit Stellenbosch;
- Jy toestemming gegee het dat jy weer gekontak kan word vir toekomstige studies wat mag volg op die Gevallebestuurstudie waaraan jy deelgeneem het.

## 4. Wat sal jou verantwoordelikhede wees?

Indien jy instem om aan die studie deel te neem, sal toegang tot die inligting wat tydens jou deelname aan die Gevallebestuurstudie ingesamel is en in jou gevallelêer gestoor word, verkry word om agtergrondsinligting oor jou swangerskap, algemene

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omstandighede en ervarings tydens die tydperk wat jy in gevallebestuur was, te verskaf.

Jy sal ook gevra word om ‘n maksimum van drie tot vier semi-gestruktureerde onderhoude met die navorser te voer. In hierdie onderhoude sal jy vrae gevra word oor jou agtergrond, jou gesondheid, jou verhoudings met jou familie, lewensmaat en vriende, en laastens jou ervaring van gevallebestuur en die invloed wat dit gehad het op jou leefstyl en alkoholgebruik tydens jou swangerskap. Die onderhoude sal min of meer een uur elk duur.

Die studie is nie dieselfde as psigoterapie, berading, behandeling vir geestesgesondheidsprobleme, behandeling vir middelafhanklikheid of mediese sorg nie. Indien jy besluit dat jy enige van hierdie of ander dienste nodig het, sal alle moontlike pogings aangewend word om jou na die regte organisasie te verwys mits jy daartoe instem. Indien jy na hierdie onderhoud voel dat jy meer ontlonting nodig het as dit wat die navorser aan jou gebied het, sal jy na ‘n private berader, Mev. Cate Doms, verwys word.

**5. Sal dit vir jou enige voordele inhou om aan hierdie navorsing deel te neem?**

Deelname aan die studie mag vir jou persoonlik voordelig wees of nie. Ons hoop egter dat die inligting wat deur hierdie studie ingesamel word, maatskaplike werkers sal help om die behoeftes en omstandighede van swanger vroue beter te verstaan. Tot hierdie doel poog die studie om te verseker dat beter dienste gelewer kan word om swanger vroue in te lig oor Fetale Alkohol Sindroom, en om swanger vroue te ondersteun om nie alkohol te gebruik tydens swangerskap nie.

**6. Is daar enige risiko’s daaraan verbonde as ek aan die studie deelneem?**

Indien jy enige onsekerheid het oor die studie of die vrae wat aan jou gevra gaan word, kan dit bespreek en aan jou verduidelik word voor of tydens die onderhoud. Jy sal geen fisiese ongemak ervaar nie. **Nogtans mag jy moontlik emosionele ongemak ervaar wanneer jy vrae oor jou lewe en ondervindings wat jy in jou lewe gehad het, gevra word.**

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### 7. Hoe sal jou privaatheid beskerm word?

Jou naam sal nie gebruik of op enige manier aan die navorsingsresultate verbind word nie. Jou naam sal ook nie gebruik word wanneer die resultate van die studie gepubliseer word nie. Vertroulikheid sal verder verseker word deur die vraelyste te nommer eerder as om name daarop te gebruik. Die inligting wat tydens die onderhoude verkry word sal ook kodeer word, en alle inligting sal in ‘n geslote kluis in die navorser se huis, op ‘n rekenaar met wagwoordbeheer en elektronies op OneDrive, Stellenbosch Universiteit, gestoor word. U toestemming word gevra om klankopnames van alle onderhoude te maak om te help met die invoer en transkripsie van die data na afloop van die onderhoude. Slegs die navorser sal toegang tot die klankopnames hê. Die klankopnames sal nie vir opleidingsdoeleindes gebruik word nie.

### 8. Sal jy betaal word om aan die studie deel te neem en is daar vir jou enige kostes aan deelname verbonde?

Nee, jy sal nie betaal word om aan die studie deel te neem nie. Daar sal ook nie vir jou enige onkostes wees as jy aan die studie deelneem nie. Jy sal ‘n geskenkbewys ter waarde van R100 na voltooiing van die onderhoude ontvang om jou te bedank vir jou tyd en deelname aan die studie.

### 9. Is daar enigiets anders wat jy behoort te weet of doen?

Indien jy enige vra omtrent hierdie studie het, kan jy Dr. I. Slabbert (Studieleier) van Universiteit Stellenbosch se Departement Maatskaplike Werk kontak by die telefoonnommer: 021-808 2070, of vir haar ’n epos stuur na: islabbert@sun.ac.za.

Indien jy enige vrae het omtrent jou regte as navorsingsdeelnemer, kan jy kontak maak met Me Malène Fouché van die Afdeling vir Navorsingsontwikkeling deur haar te kontak by die telefoonnommer: 021-808 4622, of vir haar te epos by: mfouche@sun.ac.za.

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## Verklaring deur studiedeelnemer

Deur hieronder te teken, stem ek, ……………………………………………… in om deel te neem aan 'n navorsingstudie getiteld "Stories van moeders wat blootgestel was aan biopsigososiale FASA dienste in die Langeberg Munisipale area" soos uitgevoer deur M. de Vries.

As studiedeelnemer verklaar ek dat:

- Die toestemmingsvorm in Afrikaans, 'n taal wat ek vlot praat en gemaklik mee is, aan my verduidelik is.
- Ek die geleentheid gehad het om vrae te vra en al my vrae bevredigend beantwoord is.
- Ek verstaan dat my deelname aan hierdie studie **vrywillig** is en dat ek nie onder enige druk geplaas is om deel te neem nie.
- Ek kan kies om my deelname aan die studie enige tyd te staak en dat ek nie op enige manier daardeur benadeel of veroordeel sal word nie.
- Alle kwessies rakende my privaatheid, die vertroulikheid en gebruik van die inligting wat ek verskaf, is aan my verduidelik.

Geteken te (plek) ……………………………………………… op (datum) ………………………………… 20…..

…………………………………………………………..

**Handtekening van studiedeelnemer**

## Verklaring deur die navorser

As navorser verklaar ek hiermee dat:

- Die inligting in hierdie dokument vervat, deeglik aan die studiedeelnemer verduidelik is;
- Die studiedeelnemer aangemoedig is en genoeg tyd gegun is om enige vrae te vra. Ter aanvulling, selekteer ek die volgende opsie:

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| | |
|---|---|
| | Die onderhoud met die studiedeelnemer is in Afrikaans gevoer, ‘n taal waarin die studiedeelnemer vlot kan kommunikeer. |
| | Die onderhoud met die studiedeelnemer is met behulp van ‘n tolk (wat ‘n vertroulikheidsklousule onderteken het) gevoer, en hierdie toestemmingsvorm is beskikbaar gestel aan die studiedeelnemer in ‘n taal waarin sy vlot kan kommunikeer. |

Geteken te (plek)……………………………………………… op (datum) ………………………………. 20…..

…………………………………………………………..

**Handtekening van studiedeelnemer**

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# ANNEXURE C:
# THEMES FOR SEMI-STRUCTURED INTERVIEWS WITH STUDY PARTICIPANTS

## 1. Biographical information

- Name, age, relationship status, number of pregnancies, live births, and live children

## 2. Biological aspects

- Health in general and during the index pregnancy
- Eating habits prior to and during the index pregnancy
- Nature of health services received during pregnancy such as use of supplements, antenatal care, nature of information received from health services during pregnancy regarding use of alcohol, tobacco products, drugs, dietary recommendations
- Need for more health services during pregnancy such as detox, psychology services, information about future family planning methods?
- Influence of case management process on sobriety or the lack thereof during pregnancy and whilst breastfeeding

## 3. Psychological aspects

- Was the pregnancy planned?
- Feelings regarding pregnancy
- Fears and hopes about pregnancy and pregnancy outcome
- Father of the baby's reaction to and support of the pregnancy
- Nature of the relationship with the father of the child – permanency, occurrence of inter-partner violence and unfaithfulness in relationship during pregnancy
- Family and friends' reaction to and support during pregnancy
- Emotional needs during pregnancy
- Influence of case manager and the case management process as a support system and the woman's ability to stop drinking alcohol during pregnancy
- Current feelings about her child's growth and development

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**4. Social aspects**

- Living circumstances during pregnancy
- Income, livelihood and ability to make provision for a new baby
- Influence of family and friends on choices made during pregnancy
- Influence it had/would have had on her position in her social circle if she stopped/ would have stopped drinking
- Support from organisations such as a church or other social group

**5. Cultural aspects**

- Description of the kind of household, its knowledge, attitude and beliefs about alcohol use she grew up with
- Drinking culture of the group of friends, family and immediate surroundings
- Drinking culture of the community
- Cultural beliefs about drinking habits during pregnancy and whilst breastfeeding

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# ANNEXURE D:
# TEMAS VIR SEMI-GESTRUKTUREERDE ONDERHOUDE MET STUDIEDEELNEMERS

## 1. Biografiese inligting

- Naam, ouderdom, verhoudingstatus, aantal swangerskappe, aantal lewende geboortes en lewende kinders

## 2. Biologiese aspekte

- Gesondheid oor die algemeen en gedurende die indeks swangerskap.
- Eetgewoontes voor en gedurende die indeks swangerskap.
- Aard van gesondheidsdienste ontvang gedurende swangerskap, byvoorbeeld gebruik van aanvullings, voorgeboortesorg, die aard van die inligting wat is gedurende die swangerskap van gesondheidsdienste ontvang is in verband met die gebrujk van alkohol, tabakprodukte, dwelmmiddels en aanbevelings oor dieet.
- Behoefte aan meer gesondheidsdienste byvoorbeeld detoksifikasie, sielkundige dienste, inligting oor toekomstige gebruik van gesinsbeplanningsmetodes gedurende die swangerskap.
- Die invloed van die gevallebestuursproses op soberheid of die gebrek daaraan gedurende die swangerskap en tydens die tydperk van borsvoeding.

## 3. Sielkundige aspekte

- Was die swangerskap beplan?
- Gevoelens oor die swangerskap.
- Vrese en hoop omtrent die swangerskap en die uitkoms daarvan
- Die vader van die baba se reaksie op en ondersteuning tydens die swangerskap
- Aard van die verhouding met die pa van die kind – permanensie, voorkoms van gesinsgeweld en ontrouheid in die verhouding tydens swangerskap.
- Emosionele behoeftes tydens swangerskap.

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- Invloed van die gevallebestuurder en die gevallebestuursproses as ‘n ondersteuningstelsel op die vrou se vermoë om alkoholgebruik te staak tydens die swangerskap.
- Huidige gevoelens oor die kind se groei en ontwikkeling.

**4. Sosiale aspekte**

- Lewensomstandighede gedurende die swangerskap
- Inkomste, bestaansmiddele en vermoë om voorsiening te maak vir ‘n nuwe baba
- Invloed van familie en vriende op die keuses wat sy gemaak het tydens swangerskap.
- Invloed wat dit op haar posisie in haar vriendekring gehad het/sou gehad het indien sy ophou drink het of sou ophou drink tydens haar swangerskap.
- Ondersteuning deur organisasies soos ’n kerk of ander sosiale groepe.

**5. Kulturele aspekte**

- Beskrywing van die tipe huishouding, die kennis, houding en menings oor alkohol in die huis waarin sy grootgeword het.
- Drinkkultuur van haar vriendekring, familie en onmiddellike omgewing.
- Drinkkultuur van die gemeenskap.
- Kulturele menings oor drinkgewoontes tydens swangerskap en tydens die periode van borsvoeding.

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# ANNEXURE E:
# DEBRIEFING LETTER

## Cate Doms Play Therapy Practice

Practice number: 0385034

Cell number 082 3725540

1 June 2020

To whom it may concern:

Doctoral study: Mrs. M.M. de Vries

Hereby I, Cate Doms, confirm that I will be available to offer debriefing services to participants in regards with the study carried out by Mrs. M.M. de Vries on "Stories of mothers exposed to FASD prevention and intervention services in the Langeberg Municiapal area."

My involvement in the proposed study was explained to me by Mrs. De Vries and I had the opportunity to ask and have all relevant questions answered sufficiently.

Kind regards

Cate Doms

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# ANNEXURE F:
# LETTER OF CONSENT TO APPROACH STUDY PARTICIPANTS

UNC
NUTRITION
RESEARCH INSTITUTE

THE UNIVERSITY
*of* NORTH CAROLINA
*at* CHAPEL HILL

500 LAUREATE WAY
KANNAPOLIS, NC 28081
www.uncnri.org

T 704.250.5000
F 704.250.5001

April 2, 2021

Ms. Marlene De Vries
Project Manager
Fetal Alcohol Syndrome Epidemiology Research
(FASER) Program
Robertson, South Africa

RE: Dissertation Research Request: Principal Investigator Approval with

Stipulations

Dear Ms. De Vries (Marlene):

Thank you for our various discussions and e-mails over the past couple of years inquiring about the plans for, and specific details and topical elements of your proposed dissertation research at Stellenbosch University. As I now understand it, the title of your proposed dissertation will be "Stories of Mothers Exposed to Biopsychosocial FASD Services in the Langeberg Municipal Area". Furthermore, I have read your dissertation proposal. Therefore, I have been well briefed by you that it will be a qualitative study employing the biopsychosocial perspective as your theoretical point of departure to collect, via targeted, one-on-one interviews, salient empirical information from mothers who were previously provided case management or similar services in past FASER studies. I also understand that the information will be collected from mothers with some exemplary case histories to anonymously tell the stories of their lives that examine the impact their exposure to prevention had on them and their lives.

Your specific request addressed here is for approval to approach past participants from the various research and prevention projects carried out by the FASER program in Robertson and the Bonnievale, Robertson, Ashton, and Montagu (BRAM) communities to ask them to participate in your Ph.D. dissertation Research underway via Stellenbosch University. Since I have studied carefully your proposal, and discussed participant access with several of our FASER

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project colleagues here in the United States, we all have agreed that your request is appropriate, that research is important, and therefore approved with the following procedural stipulations. As long as the required Ethics Committee at Stellenbosch University reviews and approves your approach to invite individuals to participate in your dissertation study and the procedures to protect human subject rights (particularly confidentiality) with both the new data and the previously collected FASER data, you have my full support and permission to continue this line of inquiry with previous FASER clients and the previously collected, confidential information they provided.

Over the past 13 years, you have been a completely forthright, upstanding, reliable, and compassionate professional in respecting and supporting our study participants. You have demonstrated concern for, and strict adherence to, the ethics and human protection protocols of our studies. I have every reason to believe that you will be equally professional and appropriate in pursuing this qualitative study. The study, when completed, should add a great deal to our knowledge of case management and other prevention and intervention procedures that we have been employing over the years in the Western Cape. It will fill in the gaps in our knowledge about the lives of women who had no or little support for drinking cessation and for improving their lives in general from their partners, families, and immediate social environment. It should shed light on these barriers to prevention and intervention, how they have coped, and how we may helped or hindered positive changes in their lives. I hope that you will be able to delve deeper into this aspect of their lives in these follow-up interviews with women in such circumstances.

This letter is your written permission to continue this study, that you may obtain and utilize the names of women to contact those who have participated in and completed in case management or Motivational Enhancement Therapy in the past. Furthermore, you may access and utilize the previous information and data in FASER files to supplement the interviews if the Ethics Committee so approves.

Best wishes for Ethics Committee approval and a productive study.

Sincerely,

Philip A. May,
Ph.D.
Professor
Department of Nutrition
Gillings School of Global Public Health

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# ANNEXURE G:
# ETHICAL CLEARANCE

**NOTICE OF APPROVAL**

REC: Social, Behavioural and Education Research (SBER) - Initial Application Form

27 July 2021

Project number: 22210

Project Title: Stories of mothers exposed to biopsychosocial FASD services in the Langeberg Municipal area

Dear Mrs MM De Vries

**Co-investigators:**

Your REC: Social, Behavioural and Education Research (SBER) - Initial Application Form submitted on 06/07/2021 20:57 was reviewed and approved by the REC: Social, Behavioural and Education Research (REC: SBE).

Please note below expiration date of this approved submission:

**Ethics approval period:**

| Protocol approval date (Humanities) | Protocol expiration date (Humanities) |
|---|---|
| 27 July 2021 | 26 July 2022 |

**GENERAL REC COMMENTS PERTAINING TO THIS PROJECT:**

**INVESTIGATOR RESPONSIBILITIES**

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

**If the researcher deviates in any way from the proposal approved by the REC: SBE, the researcher must notify the REC of these changes.**

Please use your SU project number (22210) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

**CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD**

You are required to submit a progress report to the REC: SBE before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary).

Once you have completed your research, you are required to submit a final report to the REC: SBE for review.

**Included Documents:**

| Document Type | File Name | Date | Version |
|---|---|---|---|
| Proof of Ethics Clearance | Stellenbosch_Ethics Approval Letter_2019 | 09/05/2019 | One |
| Letter of support_counselling | Cate Doms letter AE[11088] | 19/08/2020 | one |
| Proof of Ethics Clearance | Annual ethics approval 26.08.2020 | 26/08/2020 | One |
| Proof of permission | Marlene De Vries dissertation letter[64577] | 02/04/2021 | One |
| Budget | Budget | 28/04/2021 | One |
| Data collection tool | Semi-structured questionnaire | 28/04/2021 | One |
| Investigator CV (PI) | Short CV MM de Vries -REC application | 05/05/2021 | One |
| Default | Covid-19 contact register | 08/05/2021 | One |

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| | | | |
|---|---|---|---|
| Privacy Impact Self-Assessment Report | IG-2350 - Privacy Impact Assessment Result_ Medium Risk | 09/05/2021 | One |
| Non-disclosure agreement | Non-disclosure agreement research assistant | 03/07/2021 | One |
| Research Protocol/Proposal | PhD proposal Marlene de Vries final approved 5.07.2021 | 05/07/2021 | 2 |
| Informed Consent Form | CONSENT FORMS final edited with REC changes | 05/07/2021 | 2 |
| Default | Covid-19 strategy version 2 | 06/07/2021 | 2 |
| Default | RESPONSE LETTER for REC | 06/07/2021 | One |

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Social, Behavioral and Education Research

*National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.*
*The Research Ethics Committee: Social, Behavioural and Education Research complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes* (2nd Ed.) 2015. *Annually a number of projects may be selected randomly for an external audit.*

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## Principal Investigator Responsibilities

### Protection of Human Research Participants

As soon as Research Ethics Committee approval is confirmed by the REC, the principal investigator (PI) is responsible for the following:

**Conducting the Research**: The PI is responsible for making sure that the research is conducted according to the REC-approved research protocol. The PI is jointly responsible for the conduct of co-investigators and any research staff involved with this research. The PI must ensure that the research is conducted according to the recognised standards of their research field/discipline and according to the principles and standards of ethical research and responsible research conduct.

**Participant Enrolment:** The PI may not recruit or enrol participants unless the protocol for recruitment is approved by the REC. Recruitment and data collection activities must cease after the expiration date of REC approval. All recruitment materials must be approved by the REC prior to their use.

**Informed Consent:** The PI is responsible for obtaining and documenting affirmative informed consent using **only** the REC-approved consent documents/process, and for ensuring that no participants are involved in research prior to obtaining their affirmative informed consent. The PI must give all participants copies of the signed informed consent documents, where required. The PI must keep the originals in a secured, REC-approved location for at least five (5) years after the research is complete.

**Continuing Review:** The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period.** Prior to the date on which the REC approval of the research expires, **it is the PI's responsibility to submit the progress report in a timely fashion to ensure a lapse in REC approval does not occur.** Once REC approval of your research lapses, all research activities must cease, and contact must be made with the REC immediately.

**Amendments and Changes:** Any planned changes to any aspect of the research (such as research design, procedures, participant population, informed consent document, instruments, surveys or recruiting material, etc.), must be submitted to the REC for review and approval before implementation. Amendments may not be initiated without first obtaining written REC approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

**Adverse or Unanticipated Events:** Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research-related injuries, occurring at this institution or at other performance sites must be reported to the REC within **five (5) days** of discovery of the incident. The PI must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants.

**Research Record Keeping:** The PI must keep the following research-related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence and approvals from the REC.

**Provision of Counselling or emergency support:** When a dedicated counsellor or a psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.

**Final reports:** When the research is completed (no further participant enrolment, interactions or interventions), the PI must submit a Final Report to the REC to close the study.

**On-Site Evaluations, Inspections, or Audits:** If the researcher is notified that the research will be reviewed or audited by the sponsor or any other external agency or any internal group, the PI must inform the REC immediately of the impending audit/evaluation.

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# ANNEXURE H:
# INDEPENDENT CODER

I, ........................................................................... hereby declare that I am willing to act as Independent Decoder for the research study of:

Maria Magdalena de Vries
Research for PhD in Social Work

Subject: Stories of mothers exposed to biopsychosocial FASD services in the Langeberg municipal area

To adhere to the confidentiality requirements of this study, I, as an independent decoder, I will not disclose any information gained from the research study

Signed: ............................................ on this .............................................. day of ............................................................ 2022.

| THEMES | SUB-THEMES | CATEGORIES |
|---|---|---|
| 1. Childhood | 1.1 Instability | a. Single mothers |
| | | b. Different caretakers |
| | 1.2 Childhood trauma | a. Death of a caretaker |
| | | b. Abuse and/or rejection |
| | | c. Poverty |
| | 1.3 High risk behaviour | a. Early onset of drinking |
| | | b. Influence of friends |
| | | c. Teenage pregnancies |
| 2. Intergenerational patterns | 2.1 Drinking patterns | a. Weekend binge drinking |
| | 2.2 The role of mothers or grandmothers | a. Influence on drinking behaviour |
| | | b. Support or a lack thereof |
| | | c. Support in caring for the children |
| 3. Level of education and work circumstances | 3.1 Early termination of schooling | a. Financial reasons or school fees |
| | | b. Parents' attitude towards schooling |
| | 3.2 Permanent jobs or incomes | a. Unemployment |
| | | b. Seasonal jobs |
| | | c. Farm work |

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| THEMES | SUB-THEMES | CATEGORIES |
|---|---|---|
| | 3.3 The circle of poverty | a. Children with learning or behavioural difficulties |
| | | b. Hope to break the cycle |
| 4. The role of partners | 4.1 Support or a lack thereof | a. Partners' reaction to pregnancy |
| | | b. Abandonment / Breaking off relationships |
| | | c. Affairs |
| | | d. Emotional support |
| | | e. Financial support |
| | | f. Alcohol and/or drug abuse by partners |
| | | g. Cultural differences |
| | 4.2 Domestic violence | a. Physical violence |
| | | b. Emotional violence |
| | | c. Financial violence |
| 5. Pregnancies and children | 5.1 Unplanned pregnancies | |
| | 5.2 Drinking in pregnancy | |
| | 5.3 Drinking whilst breastfeeding | |
| 6. Psychological factors | 6.1 Depression | a. Defaulting on treatment |
| | | b. Views of psychological services |
| | 6.2 Hopelessness | a. Nowhere to go |
| | | b. Circumstances stay the same |
| | | c. Nobody cares |
| 7. Availability of services and a need for more services | 7.1 Health services | a. Primary health care services |
| | | b. A need for communication |
| | 7.2 Mental health services | a. A need for interventions |
| | 7.3 Legal services | a. SAPD |
| | | b. Protection orders |
| | 7.4 Social services | a. Perceptions of social work services |
| | | b. A need for practical help |
| | | c. A need for counselling for children |
| | 7.5 Community support | a. Family support |
| | | b. Disposition of the community and its resources |

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I hereby agree that the above themes and sub-themes are clearly identified within the transcribed interviews of the empirical study.

…………………………………………………………..

**Signature of Independent Decoder**

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# ANNEXURE I:
# CONFIRMATION

**STELLENBOSCH UNIVERSITY**

**DEPARTMENT OF SOCIAL WORK**

I, .......................................................................... hereby declare that I was a study participant for the research study of:

Maria Magdalena de Vries

Research for PhD in Social Work

Subject: Stories of mothers exposed to biopsychosocial FASD services in the Langeberg municipal area

As study participant I agree to read the transcription of the interview conducted with me and to confirm that the data collected is reflected correctly.

Signed: ........................................... on this ............................................ day of ........................................................... 2022.

Hereby I agree that the transcribed interview is a true reflection of the empirical study.

…………………………………………………………..

**Signature of study participant**

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# ANNEXURE J:
# REFLECTIVE REPORT

According to Babbie (2014) one's own characteristics influence what you observe in a situation and how you interpret what you observe. The importance of reflection in research lies in the evaluation of the impact of your own values, background, culture, beliefs, and previous experiences on what you see, hear and experience. Such reflection increases the trustworthiness, transparency and integrity of the research process and its findings (Finlay, 2002).

This report reflects on the influence of my own background, beliefs, and personal experiences on this research.

As a social worker working for an NGO, I often encountered children with failure to thrive, children with behavioural problems and children playing truant. In many cases these children were in foster care due to neglect or parental alcohol abuse and showed behavioural and learning problems now well-known to be linked to FASD. At that time, however, very little was known about FASD and its effect on the individual. My interest in and curiosity about FASD, led me to apply for a position with the Fetal Alcohol Syndrome Epidemiological Research study funded by the NIAAA in 2008. This study, a collaboration between the Universities of Stellenbosch, North Carolina, and New Mexico, studied the prevalence of FASD in SA, as well as the efficacy of specific prevention and intervention efforts. Part of my responsibilities at that time was to conduct research interviews with mothers of grade 1 learners to collect background and drinking information. While I was conducting hundreds of these interviews, I became aware that these women had stories of very difficult lives and that they experienced the research interview as an opportunity to talk and to share their hardships with someone. It also made me aware that much more should be done to prevent FASD, that single primary prevention efforts are not enough, and that SA needs to do more to change our unenviable position as the country with the highest recorded prevalence of FASD in the world.

Being involved in FASD research since 2008 exposed me to a wide range of research in the field of FASD, which fuelled my interest in the topic. However, as a social worker,

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I always found the social and environmental factors associated with FASD intriguing. Because I got to know the maternal risk factors for having a child with FASD I became aware of the important role social workers should play in the prevention of FASD. This said, the intension of this research is not to place all the responsibility for FASD prevention and intervention efforts on social workers. The research rather aimed to emphasise that FASD prevention and interventions can only truly be successful once all the role players that should be involved take up their roles to contribute and work together towards change.

By telling the stories of high-risk drinking women the opportunity was created to let others hear what they say, what they think, how they experience life and support services in various sectors. Despite being an experienced social worker and being involved in research for a number of years, the most challenging part of this research for me was to stick to the role of researcher and not blur the lines between being a researcher and being a social worker. Seeing and hearing the accounts of domestic violence and the impact it had on these women and their children made it very difficult to be just the researcher in these situations. However, being a social worker and someone they knew was involved with the FASD research study, where they felt safe and supported, was an advantage for this study. My experience was that the women trusted me, and they felt encouraged by just talking about their lives. During their second interviews, three of the study participants said that they already felt much "lighter" because they could share their difficulties with someone. The flexibility of the interview guide made it possible to give the participants enough time to talk about the things that mattered most to them or represented their most pressing needs.

My personal view is that age, class, ethnicity and economic status differences between the researcher and the study participants did not make a difference to me or the study participants in this research. What mattered was that someone was willing to listen to them, without judging them or telling them what to do. Being able to discuss my own experiences and sometimes my need to do more with my supervisor was extremely helpful in order to remain objective throughout the data collection and interpretation processes.

The research findings as reported are unbiased reproductions of the stories the women told. Record was kept by means of field notes, recordings and transcriptions and the

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selection of the themes was verified by an independent decoder. Personal experiences, data and data analysis was discussed with the supervisor throughout the process to ensure that the findings of this study are a true reflection of the stories of high-risk drinking women in the Langeberg Municipal area.

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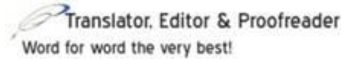
# ANNEXURE K:
# LANGUAGE EDITING

Cyril JM Clarke


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South Africa
Mobile: +27 (0)83 384 0766
E-mail: cyril@mweb.co.za

**To Whom It May Concern**

I, Cyril JM Clarke, the undersigned, a qualified editor, hereby declare that I have edited the following thesis:

Title

**Stories of mothers exposed to biopsychosocial FASD services in the Langeberg Municipal area**

written by

**Maria Magdalena de Vries**

to be

**submitted in fulfilment of the requirements for the PhD degree in Social Work**

in the Faculty of Arts and Social Sciences at the

**Stellenbosch University**.

I have made changes regarding the use of grammar and language. I have also made changes regarding the layout and references in the text and the reference list. Furthermore, I declare that all the suggestions I made have been implemented by the author of the thesis, because I received detailed written feedback from the author regarding my suggested changes.

Kind regards

CJM Clarke
5 September 2022

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# ANNEXURE L:
# TECHNICAL EDITING

## TECHNICAL EDITING

+27+82 757 8708
email address: cdp@sun.ac.za

Postal address: 2 Constantia Ave, Stellenbosch 7600, South Africa

## DECLARATION

I hereby declare that the dissertation by **Maria Magdalena de Vries** was technically edited by me.

Title of dissertation presented for the degree of Doctor of Philosophy (PhD) in Social Work in the Faculty of Arts and Social Sciences (Department of Social Work) at Stellenbosch University:

**STORIES OF MOTHERS EXPOSED TO BIOPSYCHOSOCIAL FASD SERVICES IN THE LANGEBERG MUNICIPAL AREA**

CD Park — 14 September 2022

........................................................................ ................................................
**CD PARK** **DATE**