Sepedi cultural views on Autism Spectrum Disorder

by

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Submitted in partial fulfilment of the requirements for the degree

MAGISTER EDUCATIONIS

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PRETORIA

April 2020

DECLARATION OF ORIGINALITY

I, Adriana van der Merwe (student number 26008883), declare that the dissertation **“Sepedi cultural views on Autism Spectrum Disorder”** which I hereby submit for the degree Masters Educationis in Educational Psychology at the University of Pretoria, is my own work and has not previously been submitted by me for a degree at this or any other tertiary institution.” [1]

....
Adriana van der Merwe

14 April 2020

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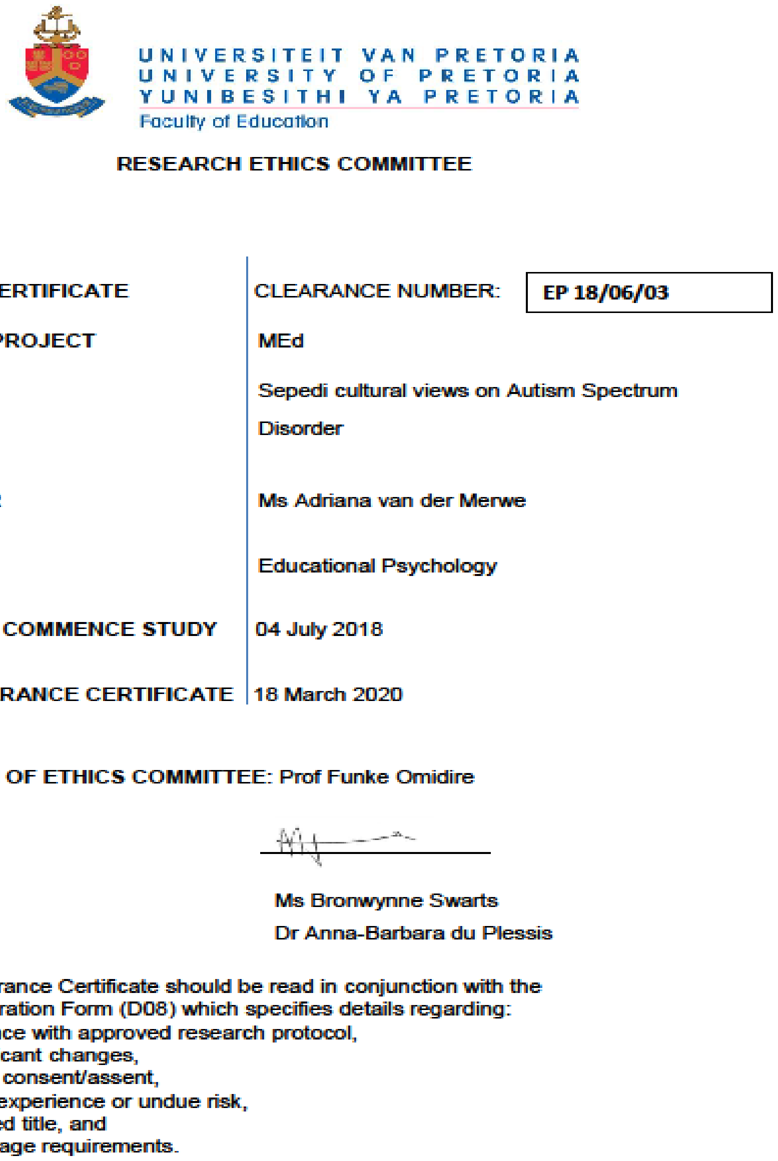
[1] The guidelines as stipulated by the American Psychological Association (6th edition) manual was applied consistently throughout this dissertation.

ETHICAL CLEARANCE CERTIFICATE

The author, whose name appears on the title page of this mini-dissertation, has obtained, for the research described in this work, the applicable research ethics approval. The author declares that she has observed the ethical standards required in terms of the University of Pretoria's *Code of ethics for researchers and the Policy guidelines for responsible research*.



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- Informed consent/assent,
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- Data storage requirements.

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ABSTRACT

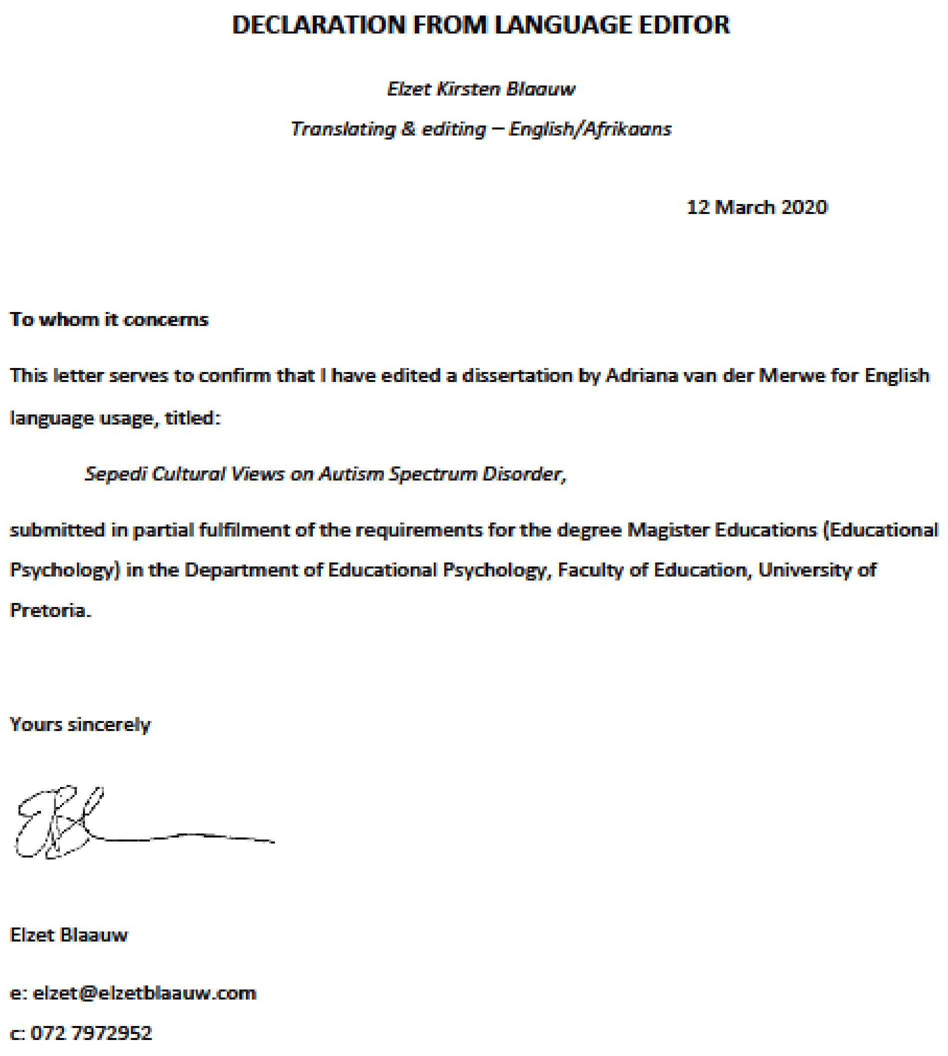
Cultural views are known to play a critical role in the identification, diagnosis and intervention of developmental disorders, such as Autism Spectrum Disorder (ASD). Indigenous views regarding the nature and causes of ASD have often been overlooked. Based on the paucity of research on indigenous perspectives on ASD in South Africa, as well as the alarming rise in the incidence of ASD, the purpose of the study is to investigate the views held by members of the Sepedi group in South Africa regarding ASD. Research relating to ASD has mostly been conducted in other countries or according to Western or conventional scientifically proven positions. The study attempts to answer the following primary research question: "***What are Sepedi cultural views regarding the nature, cause/s as well as intervention of Autism Spectrum Disorder?"***

The theoretical framework that was utilised during the study was that of Indigenous Knowledge Systems (IKS). Furthermore, the study was approached from a phenomenological paradigm. A qualitative approach as well as case study design were followed, and purposive sampling was used. The first method of data collection was a focus group and subsequently, semi-structured interviews were conducted. The data were analysed using inductive thematic analysis to pinpoint recurring themes. These five themes are (1) Indigenous African Views, (2) Participants' views of causes, (3) Circumstances surrounding diagnosis, (4) Personally coping with ASD, and (5) Intervention with a child with ASD. Results obtained from the study could be utilised within a diagnostic, intervention and educational approach that is uniquely South African.

Key Terms:

Autism Spectrum Disorder, culture, Sepedi, Indigenous knowledge systems.

DECLARATION FROM LANGUAGE EDITOR



DECLARATION FROM LANGUAGE EDITOR

Elzet Kirsten Blaauw

Translating & editing – English/Afrikaans

12 March 2020

To whom it concerns

This letter serves to confirm that I have edited a dissertation by Adriana van der Merwe for English language usage, titled:

Sepedi Cultural Views on Autism Spectrum Disorder,

submitted in partial fulfilment of the requirements for the degree Magister Educations (Educational Psychology) in the Department of Educational Psychology, Faculty of Education, University of Pretoria.

Yours sincerely

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LIST OF ACRONYMS AND ABBREVIATIONS

SA	South Africa
ASD	Autism Spectrum Disorder
Atlas.Ti	Software for Qualitative and Mixed Methods Data Analysis
FG1	Focus Group Participant One
FG2	Focus Group Participant Two
HPCSA	Health Professions Council of South Africa
I1	Semi-structured Interview Participant One
I2	Semi-structured Interview Participant Two
IKS	Indigenous Knowledge Systems
MC1	Member Checking Focus Group Participant One
MC 2	Member Checking Focus Group Participant One and Semi-Structured Interview Participant One
MC 3	Member Checking Semi-Structured Interview Participant Two

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CHAPTER 1

INTRODUCTION AND RATIONALE OF THE STUDY

1.1 INTRODUCTION

When diagnosing developmental disorders, the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5), compiled after strenuous research by the American Psychiatric Association (APA) (APA, 2013), and the International Classification of Diseases and Disorders (ICD-10) are consulted as authoritative tools worldwide and in SA (Koudstaal, 2016). The DSM-5 and ICD-10 are international classification tools used by medical and health professionals as well as medical aids in the process of diagnosis and intervention. However, the relevance and applicability of these tools to mental health concerns in the diversity of South African populations are uncertain (Koudstaal, 2016).

Autism spectrum disorder (ASD) is one developmental disorder in the DSM-5 and the ICD-10 that warrants further scrutiny. According to De Vries (2016), diagnostic instruments for ASD are not informed by any data which have been standardised and validated for African populations, meaning that diagnoses may be made with instruments and sets of criteria which have not been researched or normed for African and South African populations.

Investigating ASD in African countries such as SA remains relevant for two main reasons. Firstly, there is a notable lack of research on ASD in the African continent (Bakare & Munir, 2011; De Vries, 2016). Indigenous views regarding the nature and causes of ASD have mostly been overlooked in favour of research on other areas, such as epilepsy and physical disability. Research relating to ASD has mostly been conducted in non-African countries or according to Western or conventional, scientifically proven positions (Stephens, 2012). (Refer to Chapter Two for a discussion of available research on ASD in Africa.) Secondly, the incidence of ASD has increased dramatically worldwide (Shelton, Hertz-Picciotto, & Pessah, 2012; Stephens, 2012). Stephens (2012, p.3) states that “Autism Spectrum Disorder (ASD) occurs at a rate of 1 in 100 children worldwide, making it one of the most common neurodevelopmental disorders.” A South African study (Wilford, 2013) found the same

ASD prevalence in SA as that suggested by Stephens (2012). Other studies estimate the incidence of ASD to be as high as one in 68 (Koudstaal, 2016).The worldwide incidence of ASD could therefore most likely also apply in SA.

For these reasons, studies aimed at contributing to the current knowledge base regarding some indigenous South African views about this prevalent disorder may serve as a useful point of departure for future studies. They may also assist in developing a uniquely South African approach to diagnosis, intervention and education with regards to ASD.

1.2 PURPOSE OF THE STUDY

Based on the paucity of research on indigenous perspectives on ASD in SA and the alarming rise in the incidence of ASD, the purpose of this study is to investigate the cultural views of ASD held by members of the Sepedi group in SA. The researcher's decision to select the Sepedi group was prompted by her childhood years growing up in the Limpopo Province of SA where many people belonging to the Sepedi group reside.

A Sepedi proverb says, "Matsogo a a hlatswana" (R. Mokobe, personal communication, January 5, 2018). Paraphrased, it means that if one helps others, those individuals will help you. This proverb reflects a major purpose of the study, which is that in researching Sepedi cultural views on ASD (if one helps others), the findings might contribute to the enlargement of the currently limited body of research regarding indigenous, South African views of ASD (those individuals will help you).

Health care practitioners, including educational psychologists, in SA should have knowledge regarding indigenous views of ASD, including those held by specific populations such as the Sepedi. Such knowledge is vital so that they can understand ASD as it presents in SA and so that they can provide appropriate support to the ever-increasing prevalence of ASD burdening healthcare and education systems. Results and findings obtained from this study might be used for a diagnostic, intervention and educational approach that is uniquely South African.

This study also investigates whether the South African Sepedi population might have similar views of the cause, nature and intervention of ASD than those held by other populations groups in Africa. Views on disability in general found during the research might also elucidate indigenous South African views regarding differences other than ASD.

1.3 RESEARCH QUESTIONS

1.3.1 Primary research question

To fulfil the primary purpose of the study, the primary research question is:

> What are Sepedi cultural views regarding the nature and cause/s of as well as intervention for autism spectrum disorder?

1.3.2 Secondary research question

SA is a multicultural country, and boundaries among different cultures are sometimes vague. The following secondary research question needs to be asked to elucidate, understand and contextualise the primary research question:

> What are the views of some other groups in Africa regarding the nature and cause/s of as well as intervention for autism spectrum disorder?

1.4 WORKING ASSUMPTIONS

Working assumptions for this study are stated upfront because they may influence the research process as well as the interpretation of data, results and findings (Krefting, 1991).

It is assumed that specific groups, in this case, people from a mainly Sepedi culture in SA, have unique views regarding the nature and causes of and intervention for ASD. It is also assumed that these views are rooted mainly in cultural beliefs, which might have been passed on from generation to generation. In many instances, these views are assumed to be an explanation for behaviour that is thought to be culturally atypical. Whether these views are culturally or factually motivated, they are assumed to play an integral part in the lives of those diagnosed with ASD in these communities as well as in the lives of their primary caregivers. It is further assumed that these ideas have a profound influence on the way ASD is identified and diagnosed in the community, how those diagnosed are supported in the community, how interventions are approached, as well as how characteristics of ASD are managed. Furthermore, it is assumed that the researcher may have preconceived ideas which will be noted and bracketed when she becomes aware of them by using a reflective journal during the research process (Chan, Fung, & Chien, 2013).

1.5 CONCEPT CLARIFICATION

1.5.1 Autism spectrum disorder (ASD)

ASD is generally regarded as a neurodevelopmental disorder (APA, 2013; Klauck, 2006). According to the DSM 5 (APA, 2013, p. 50), ASD manifests as "Persistent deficits in social communication and social interaction across multiple contexts as well as restricted, repetitive patterns of behaviour, interests, or activities…". The ICD-10 (World Health Organisation, 1992, p.198) describes ASD as "A pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behaviour."

Several researchers have attempted to define autism; however, there are many disputes among experts concerning an exact working definition of autism (Kenny et al., 2016). In line with the epistemological view of this study, definitions are regarded as too limited, and an understanding or description of ASD is favoured over a definition. According to Klauck (2006) and the APA (2013), autism encompasses inadequacies in neurological development which is known to thwart satisfactory verbal and social progress. Shelton, Hertz-Picciotto and Pessah (2012) emphasise that autism is a disorder which is mainly distinguished from other disorders based on atypical conduct displayed by an individual.

Henceforth, for this study, the term *autism* refers to a developmental disorder of neurological origin which manifests as inappropriate and inadequate behaviour in the social and verbal domains of functioning.

1.5.2 Culture

Culture plays a role in how ASD is understood and supported. Ennis-Cole, Durodoye and Harris (2013, p.279) describe culture as “the values, beliefs, language, rituals, traditions, and other behaviours that are passed from one generation to another within any social group.” Ravindran and Myers (2012) propose that culture consist of common objectives, views and mindsets in a community which are generally constant but susceptible to change over time.

Taking into consideration existing literature and the context of the study, this study regards *culture* as joint customs, ideas and convictions adopted and followed by a specific group of people which might affect their behavioural patterns and societal viewpoints. Culture also determines what is deemed as typical or normative behaviour. This might be influenced by the ideas and convictions adopted by individuals who identify with a specific culture.

1.5.3 Sepedi

Although *Sepedi* is a difficult concept to describe, with references being surprisingly scarce, clarity regarding this concept is essential since the sample group for the proposed study will consist of people from a (mainly) Sepedi culture.

According to South African History Online[2] (2016), Sepedi is the language spoken by the BaPedi people who mainly reside in provinces such as Mpumalanga, Limpopo, Gauteng as well as the North-West province. Joffe (2016) states that the Northern Sotho language endeavours to include a collection of about 30 interrelated dialects which are all commonly understood by its speakers and are all related to Sepedi.

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[2] Online sources were consulted as scholarly articles containing a definition for Sepedi are outdated. An information specialist at the University was also consulted in this regard.

1.6 THEORETICAL FRAMEWORK

Studying certain views of a specific group in SA requires a specific approach to theory. The theoretical framework used during this study is that of indigenous knowledge systems (IKS). The basic principle of the selected framework is that knowledge is the product of culture, socio-geographical environment, relationships and interaction, as well as the worldview of a specific group (Refer to Figure 1.2 in Chapter Two). IKS acknowledges that customs and social interaction in cultural systems have a profound effect on the knowledge base of specific groups (Agrawal, 1995; Maila & Loubser, 2003; Mapara, 2009; Owusu-Ansah & Mji, 2013). The theoretical framework for this study is explained in more detail in Chapter Two. A brief understanding of IKS as theoretical framework is, however, required at this stage as the theoretical framework can influence the paradigmatic perspectives and research methodology of the study.

1.7 PARADIGMATIC PERSPECTIVES

1.7.1 Epistemology of the study

This research study used a phenomenological paradigm as origin of knowledge, in other words knowledge is regarded as being derived from the lived experiences of an individual or a group of individuals. Table 1.1 summarises some of the descriptions of phenomenology. Phenomenology is discussed in more detail in Chapter Three.

Table 1.1: Summary of the phenomenological paradigm

Phenomenology is based on:	Phenomenology is facilitated and created by:	Phenomenology explains:
• individual awareness (Davidsen, 2013); • established realities (past, present and future) (Davidsen, 2013); • own understanding (Lopez & Willis, 2004);	• human experience (Groenewald, 2004; Hein & Austin, 2001; Kumar, 2012).	• social frame of reference according to a specific group or population (Flood, 2010), that is culture and corresponding beliefs.

- own environment (Lopez & Willis, 2004), also shaped by culture; and - caring, healing and completeness (Connelley, 2010; Kumar, 2012).		

1.7.2 Methodological approach

This study used a qualitative methodological approach. Qualitative research aims to clarify and/or supplement existing knowledge pertaining to human behaviours or occurrences by making use of explorative and descriptive methods (Lichtman, 2017; Nieuwenhuis, 2007b; Wertz et al., 2011). Additionally, qualitative research takes into account traditions and presupposed cultural knowledge (Wertz et al., 2011), which makes the selection of a qualitative approach compatible with a phenomenological approach to the origin of knowledge.

A qualitative approach was chosen to collect the data for this study because the purpose of this study is not to obtain or compare statistical data (Lichtman, 2017; Nieuwenhuis, 2007b) nor to generalise, but to clarify and describe Sepedi cultural views on ASD. A qualitative approach is also appropriate to yield data on how participants understand the world based on their experiences and the social and cultural influences on their understanding (Nieuwenhuis, 2007b).

1.8 RESEARCH METHODOLOGY

Figure 1.1 represents the research methodology and corresponding research design and research process of this study. More detail regarding research methodology and reasons for selecting specific methods are found in Chapter Three.

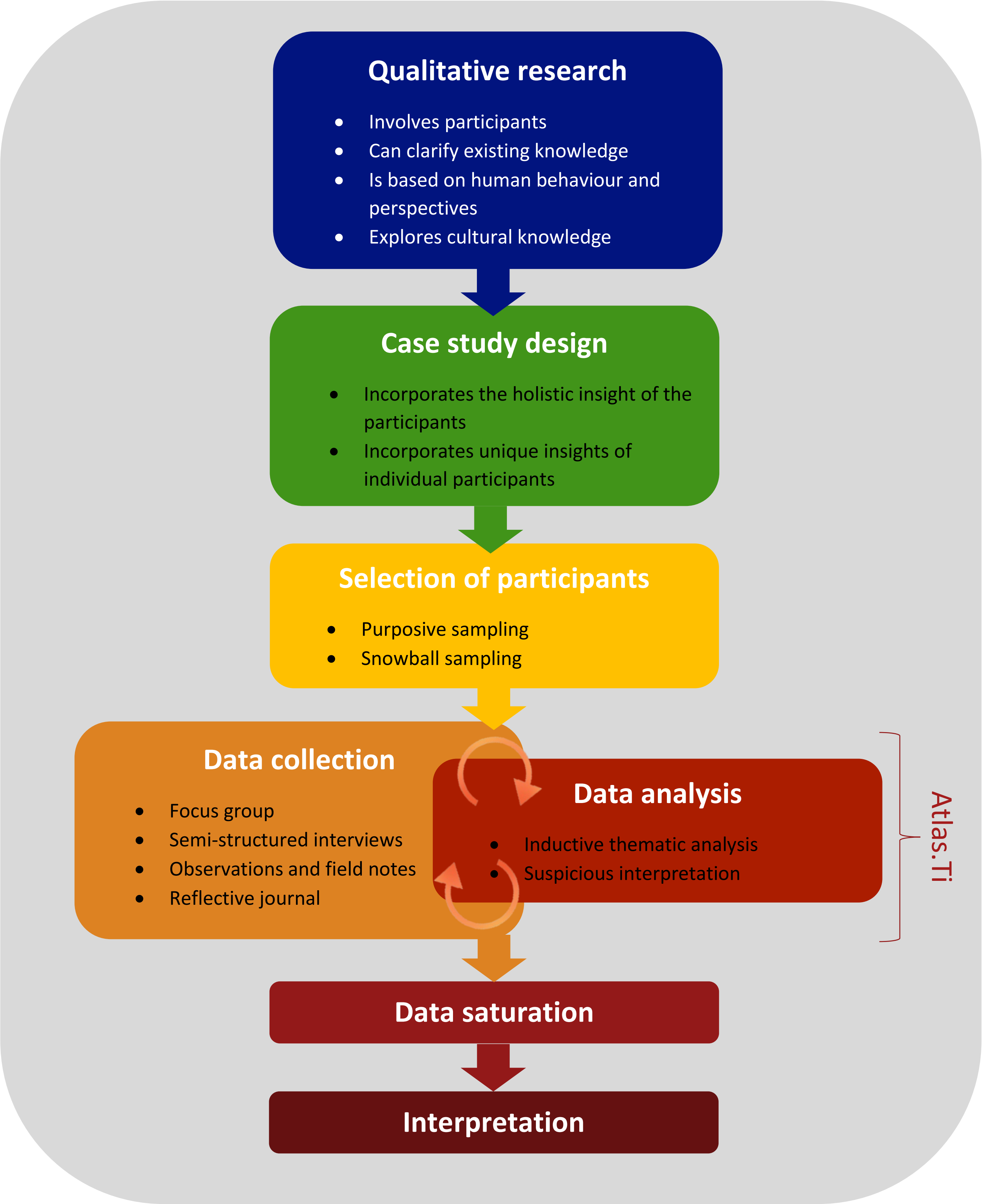

Figure1.1: Research methodology, research design and research process

1.8.1 Research design

A case study design enables the researcher to gain holistic insight into the viewpoints of participants regarding complicated, realistic, social and behavioural issues (Andrade, 2009; Fouché, 2007; Nieuwenhuis, 2007c; Zainal, 2007; Tellis, 1997). Data collected via a case study design often shed light on phenomena which have limited available scholarly data (Andrade, 2009). Therefore, this design is especially applicable to this study, as there is little research on ASD in the African continent generally, and in the Sepedi culture specifically (Bakare & Munir, 2011; Bayat, 2015).

1.8.2 Selection of the research site and participants

A private school in Pretoria for learners with ASD was chosen as the research site from which participants for this study were selected. All parents who viewed themselves as part of the Sepedi culture were invited to participate in the study through a focus group.

From those parents who participated in the focus group, the researcher made use of purposive sampling to select two participants to participate in individual semi-structured interviews to further explore Sepedi cultural views on ASD. Purposive sampling entails the selection of specific participants who possess specific characteristics and who can probably contribute valuable information to the study (Delport & Strydom, 2005).

The researcher could also make use of snowball sampling, as necessary, by requesting participants in the focus group to refer the researcher to other individuals who might be able to contribute to the study (Atkinson & Flint, 2011). (Refer to Chapter Three for a more detailed discussion with regards to the selection of the research site and participants.)

1.8.3 Data collection and documentation strategies

(1) Focus group

The first method of data collection was a focus group. According to Greeff (2005), focus groups are used to collect data through group conversations aimed at eliciting meaningful dialogue concerning a specific topic.

The number of parents in the private school who viewed themselves as part of the Sepedi culture determined whether one or more focus groups would have been held. Focus group participants contributed to the study by providing their views on ASD.

(2) Semi-structured interviews

Based on their contributions to the focus group/s, two participants were purposefully selected to participate in individual semi-structured interviews. Semi-structured interviews can provide the researcher with flexibility and in-depth information about views, understandings or explanations regarding the topic being investigated (Greeff, 2005). The researcher prepares fixed open ended questions to ask participants and probes their answers to elicit more detailed information which the researcher might not have anticipated and is not included in the set questions (Nieuwenhuis, 2007c).

In this study, the researcher conducted one individual, semi-structured interview with each of the two selected participants as well as with any other participants identified during snowball sampling, as explained above. Follow-up individual interviews for member checking of data analysis and interpretation (refer to section 3.5.2) were also conducted. All interviews were audio-recorded and transcribed (Marvasti, 2014).

(3) Observation, field notes and a reflective journal

According to Nieuwenhuis (2007c, p.83), observation is “the systematic process of recording the behavioural patterns of participants, objects and occurrences without necessarily questioning or communicating with them”. During observation, the researcher pays attention to participants’ behavioural patterns and body language to gain insight into the social subtleties that might influence aforementioned aspects, without interfering with natural occurrences in the context of the study (Nieuwenhuis, 2007c). One of the advantages of observation is that insight can be gained about the interpersonal nature of the research (Tellis, 1997).

Therefore, observation notes, one of the most important approaches to collect data in case study research (Yin, 2013), were incorporated in field notes (Andrade, 2009; Nieuwenhuis, 2007c) to document important information obtained through observation that might have been lost if the researcher did not keep meticulous records. Field notes also contained reflections of the researcher concerning the research process, personal insight and/or biases, and further questions or uncertainties to explore. Field notes prove particularly useful during the analysis and interpretation of data (Andrade, 2009).

Data were collected until data saturation occurred, meaning that no new themes and topics presented themselves during the interviews (Saumure & Given, 2008).

1.8.4 Data analysis and interpretation

It is important to note that data collection and analysis are interwoven (De Vos, 2005; Nieuwenhuis, 2007a). For this reason, the researcher made use of a dual method to analyse data. Firstly, data were analysed briefly for themes to probe while being collected at the research location. Secondly, data were also analysed when the researcher had departed from the location and before the next site visit. Data analysis in the field was conducted as a part of taking field notes (De Vos, 2005). Meticulous notes of themes related to both similarities and differences with regards to the views of the participants and existing research were analysed to elicit potential reasons for those similarities and differences.

Inductive thematic analysis was done to pinpoint recurring themes (Vaismoradi, Turunen, & Bondas, 2013), assisting the researcher to understand how participants made sense of their experiences about Sepedi cultural views of ASD (Marvasti, 2014; Nieuwenhuis, 2007a; Weninger, 2012). These themes were identified by utilising ATLAS.Ti analysis software.

1.9 QUALITY CRITERIA

Two important strategies to ensure quality data collection, analysis and interpretation are to gather rich, descriptive data and to do thorough member checking (Cho & Trent, 2006; Krefting, 1991). Other quality criteria, such as transferability, dependability, credibility and confirmability, are discussed in Chapter Three.

1.10 ETHICAL CONSIDERATIONS

According to Annexure 12 of Form 223 of the Health Professions Act (1974) and Brinkmann and Kvale (2017), it is important that participants sign a confidential and an informed and voluntary consent form before research commences. Such a form should contain information regarding the nature of the research, state that all information will be treated strictly confidential and include the option to withdraw from the research at any stage without detrimental consequences. When some participants do not understand English as comprehensively as their home language, the researcher must provide them with information in their home language, for example, by using a qualified translator (Health Professions Act, 1974).

According to the Health Professions Act (1974), the researcher must also keep all information gathered from the participants strictly confidential and store it in a secure location, for example, a locked cabinet which only the researcher has access to for hard copy information and password-protected for computer documents. The identities of the participants must also be protected by using pseudonyms (Allen, 2016; Health Professions Act, 1974). The researcher must endeavour to act in the best interest of participants, do no harm and respect participants (Allen, 2016; Health Professions Act, 1974), especially when their viewpoints differ from that of the researcher.

The researcher for this study complied with the above-mentioned regulations. Details are elaborated on in Chapter Three.

1.11 OUTLINE OF CHAPTERS

Chapter One introduced the topic of the research, provided the rationale for and purpose of the study, and provided a brief background of how the topic would be investigated. As such, the research questions driving the research, the implicit assumptions with which the research would be done, the theoretical framework underpinning the understanding and clarification of concepts used were explained. The epistemology and methodological approach were briefly explained with the planned research methodology, underlying quality criteria and ethical considerations.

As **Chapter One** merely introduced the research topic and research methodology, references were made to more comprehensive discussions of certain matters elsewhere in the dissertation.

Chapter Two discusses the theoretical framework guiding the understanding of the research topic, together with a literature review of available research regarding Sepedi and other indigenous African views of ASD. Gaps in the literature are also identified and discussed.

Chapter Three explains the paradigmatic perspectives and research methodology introduced in Chapter One in more detail, including the reasons for selecting those approaches, advantages and limitations of the choices, as well as ways in which the limitations may be dealt with. The chapter concludes with quality criteria and ethical considerations.

Chapter Four presents the data collected and the data analysis by discussing the emerging themes and associated subthemes. Extracts of transcriptions provide evidence for the results and findings.

Chapter Five answers the primary and secondary research questions by incorporating the findings of the study with the literature review and applying the theoretical framework. The limitations and contributions of the study as well as suggestions for future research are highlighted.

1.12 SUMMARY

Chapter One contextualised the research questions. Chapter Two will discuss some of the available literature to answer the research questions in the understanding of IKS as theoretical framework. Chapter Two will also expose some of the gaps in the current knowledge of Sepedi cultural views on ASD, thus confirming the necessity of the current research study.

CHAPTER 2

LITERATURE REVIEW AND THEORETICALFRAMEWORK

2.1 INTRODUCTION

Research suggests that cultural views play a role in the identification, diagnosis and intervention of developmental disorders (Bakare & Munir, 2011; Bernier, Mao, & Yen, 2010; Gona et al., 2015; Qi, Zaroff, & Bernardo, 2016; Ravindran & Myers, 2012; Stephens, 2012). Cultural views of differences are of crucial importance for the welfare of people with differences, as it has been established that people displaying characteristics of disability or other disorders are sometimes shunned, punished and, in some cases, put to death in the African continent owing to supernatural or ancestral beliefs attributed to the origins of these disorders (Bakare & Munir, 2011; Bayat, 2015; Gona et al., 2015; Munsaka & Charnley, 2013; Tilahun et al., 2017). Exclusionary practices such as those mentioned above may also be found in communities in SA which hold non-Western views of ASD.

To acknowledge non-Western views of ASD, Chapter Two posits using IKS as a theoretical lens through which to view literature and the results and findings of the research. Chapter Two explains IKS and discusses current available academic literature of the views of both Western and non-Western societies regarding aspects such as ASD causation, symptomology, diagnosis and intervention.

2.2 THEORETICAL FRAMEWORK

2.2.1 Understanding IKS

Figure 1.2 graphically portrays the essence of IKS.

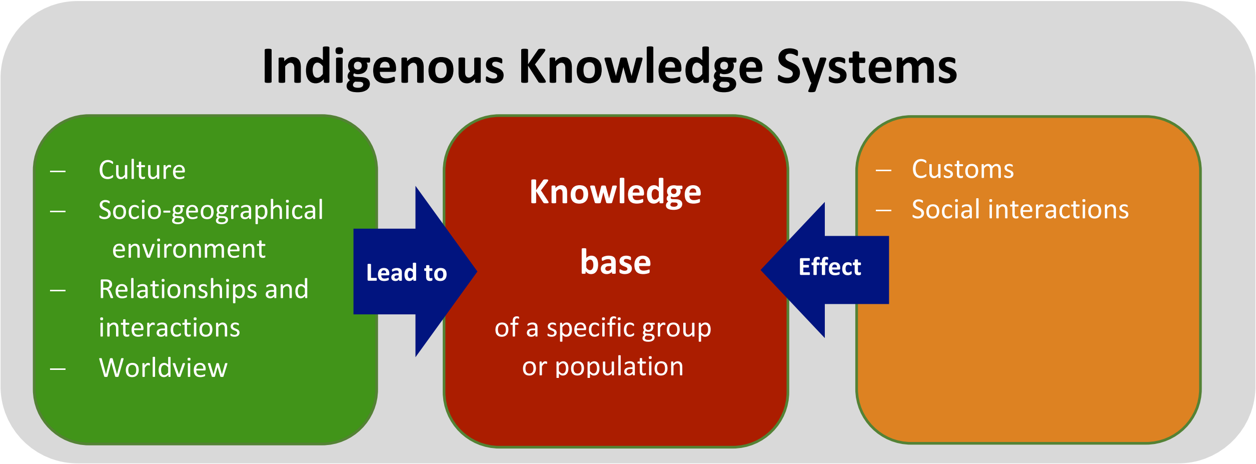

Figure 1.2: Theoretical framework: IKS

According to Masoga (2005), IKS can be regarded as the understanding of life stemming from within the human spirit. This understanding of life can be structured and arranged into accumulated wisdom. This wisdom aims to enhance the value of the lived experience and to establish a suitable environment for humans and other living beings (Masoga, 2005). A person who experiences a specific phenomenon first hand is regarded as the ideal point of departure to comprehend that which is under examination (Mutema, 2003). Breidlid (2008, p.141) poses that IKS includes "world-views, cultural values and practices and knowledge systems derived from these worldviews and practices and related to metaphysical, ecological, economic and scientific fields".

Masoga's understanding of IKS integrates the five processes constituting IKS, namely "social, institutional, technological, biodiversity/biotechnology and liberatory processes" (Masoga, 2005, p.20). Firstly, the components forming part of social processes (Masoga, 2005) include philosophy, spirituality, belief systems, language, religion, cosmology, politics and history. Communal beliefs, religions and practices are important aspects of IKS because religious beliefs are regarded as encompassing all facets of understanding one's existence (Loubser, 2005). Such religious truths can never be fully understood or experienced by any individual in a completely impartial manner (Loubser, 2005). Spoken customs, oral traditions, narrations and morals are also essential elements of IKS (Vogel, 2009) that can be regarded as social processes. Communal beliefs, religions and practices as well as the oral nature of indigenous knowledge might influence the perceptions of parents who care for children with ASD, and consequently the way intervention is done.

Secondly, the institutional processes of traditional leadership, traditional healing, *legotla* (meetings), family structures, national community, and societal and educational structures (Masoga, 2005) might influence the lives and therefore the views of the participants in this study. Thirdly, technological processes, such as cleansing and healing, rituals and conflict resolution, and, fourthly, biodiversity processes, in this case, humans, (Masoga, 2005) are also relevant. Lastly, the influence of liberatory processes such as politics, history, sociology, social anthropology, culture, customs, traditions, strategies, intelligence and tactics (Masoga, 2005) are also regarded as part of IKS.

All these processes are relevant to this study because this field of study contains components of all of them. Chapter Four (refer to section 4.5) will integrate the findings with the IKS as theoretical grounding for this study and give examples of how these processes and components can be identified.

IKS differs from Western scientific approaches because of variations in the focus and traits of the two approaches (Agrawal, 1995). Different means of inquiry are also used to determine the meaning of reality (Agrawal, 1995). Western approaches usually depend on laws entrenched in scientific techniques such as observation, prediction and hypothesising to better understand a phenomenon, whereas IKS is more embedded in social, physical and spiritual knowledge which contributes to knowledge of the natural environment (Mekoa, 2018). Indigenous knowledge is malleable, flexible and inventive (Breidlid, 2008). Therefore, IKS can be described as dynamic, because it takes the recurrent and fluctuating nature of viewpoints and customs and the role that the environment and other aspects play in these variations into account (Edwards, 2011; Masoga, 2005).

Meaning-making in IKS is based on embedded wisdom that is obtained from an indigenous understanding of the environment in which individuals find themselves (Loubser, 2005; Masoga, 2005). Knowledge and understanding of the world originate from experiences that occur over time. This knowledge and understanding become embedded in societal and spiritual systems in the form of folklore and traditions of traditional communities (Loubser, 2005). IKS takes into account the importance of the beliefs of others and how these diverse beliefs have the potential to offer valuable insight regarding behavioural patterns as well as ways of thinking in indigenous communities based on a personal point of view (Vogel, 2009).

According to Mutema's view of IKS (2003), research participants are not regarded as inactive role players. They are dynamic individuals who make sense of their beliefs. To recognise the viewpoints of participants in an IKS framework, researchers must espouse the language and classifications as they are used by participants when they identify and recount their experiences. Researchers thus observe and listen to participants to make the information obtained as accurate and realistic as possible (Mutema, 2003). That which is communicated to the researcher forms part of the participants' unique contextual understanding and preconceptions, an essential part of knowledge obtained from an IKS-based approach. The researcher, who is not part of that indigenous community, should receive this knowledge in a compassionate, thoughtful and resourceful manner to analyse and represent participants' viewpoints accurately (Mutema, 2003).

2.2.2 Aim of IKS

The aim of IKS is to advance the body of knowledge tied to the indigenous understanding of phenomena by suggesting that researchers be motivated by inquisitiveness, understanding and the pursuit to discover explanations to one-sided inquiries (Masoga, 2005). It entails considering African origins and culture and regarding culture as varied manifestations and experiences (Masoga, 2005). In this study, the researcher will attempt to examine the view of Sepedi parents with children who have been diagnosed with ASD in a South African context to discover answers to questions which have not yet been sufficiently answered by Western studies and approaches.

2.2.3 Applicability of IKS to the research

Psychology and the relevant comprehension, utilisation and abstraction of it are meaningfully challenged in an African context (Edwards, 2011). This is the case because of psychology’s Western origins. The researcher is of the opinion that these same challenges are found in the context of research, especially research regarding ASD.

According to Loubser (2005), all humans have indigenous and cultural cores. Indigenous cultural knowledge customs are regarded as holistic, and are positioned in an ethnic component, meaning that knowledge is derived from past systems held by specific cultural groups in different regions (Masoga, 2005). Furthermore, numerous individuals who have a traditional upbringing, in other words, raised according to the customs of a specific cultural group, risk losing their cultural origins when living in another (e.g. Western) context, and they yearn to maintain their cultural origins in the course of creating a new identity (Loubser, 2005). Therefore, the researcher deemed it essential to make use of a theoretical framework which acknowledges the challenges of retaining cultural origins and assists in actualising and enriching the purpose of the research at hand, namely, to uncover Sepedi cultural views regarding ASD.

The researcher deems IKS an appropriate fit for investigating Sepedi cultural views of ASD, as it allows contradictions with the dominant views often advocated by Western approaches to psychology (Breidlid, 2008; Masoga, 2005). Research from a Western perspective often disregards the interdependent nature of indigenous occurrences. IKS takes cultural and geographic aspects into account. It includes knowledge obtained over an extended period which is associated with a specific place, for example, the homestead (Breidlid, 2008; Mekoa, 2018). An IKS approach counters the restricted nature of many scientific disciplines (Breidlid, 2008).

Because the research will be conducted in a South African context, Western approaches alone may not provide a true representation of the phenomenon under study, as African reasoning manifests in a particular manner which sometimes stands in opposition to European convictions (Loubser, 2005). For this reason, indigenous communities should benefit from IKS research (Loubser, 2005). (Refer to Chapter Four and Chapter Five.)

In a South African context, oral expression is the main discourse of indigenous knowledge and culture. For this reason, indigenous South African knowledge is integrated into spoken conventions and ceremonies (Loubser, 2005). The lack of a text-based element in South African indigenous culture illustrates that oral communities stand in contrast to other civilisations which rely on documented sources of knowledge. It highlights the belief held by many African communities that group views or understandings are regarded as more important than the views of individuals (Loubser, 2005; Mekoa, 2018).

2.2.4 Conclusions and summary of IKS

IKS endorses life experiences, originates from these experiences and examines life thoroughly (Masoga, 2005). Therefore, according to IKS, the comprehension of indigenous knowledge should be facilitated by taking into account the multifaceted interaction of physical, societal and belief systems in the world of specific groups (Loubser, 2005): in this study, the experiences, understanding and the world of Sepedi parents of children who have been diagnosed with ASD.

Based on the discussion above, the researcher chose IKS as theoretical point of departure for this study. Table 2.1 provides a summary of the differences and similarities between Western scientific approaches and IKS.

Table 2.1: The differences and similarities between Western scientific approaches and IKS

Categories	Western scientific approaches	IKS
Foundation	Laws determined by scientific techniques.	Worldviews based on social, physical and spiritual understanding.
Nature	Scope of knowledge limited to understanding; or linked to scientific inquiry.	Understanding of phenomenon considers interaction of physical and societal belief systems.

Categories	Western scientific approaches	IKS
		Occurs over an extended period and is linked to specific locations
Learning	Individualistic	Collective
Transference of knowledge	Text-based	Oral
Similarities	Both approaches apply theories of knowledge to make sense of the world (Mekoa, 2018).	

In order to understand the various ways in which ASD can be conceptualised, western and some non-western perspectives on the causes, characteristics and intervention of ASD will be discussed.

2.3 VIEWS REGARDING CAUSES OF ASD

2.3.1 Western parental views[3] of the causes of ASD

ASD still poses many mysteries (Dale, Jahoda, & Knott, 2006). According to the DSM 5 (APA, 2013: 56), “A variety of nonspecific risk factors, such as advanced parental age, low birth weight, or fetal exposure to valproate, may contribute to the risk of autism spectrum disorder”. Based on research, current Western views of the possible causes of ASD are diverse and include biological causes (including genomes and neurological impairment), the role of the environment, toxins and parental influences (Jensen et al., 2016; Qi, Zaroff & Bernardo, 2016). Research shows that there are growing incidences of ASD that can be explained by bacteria with which individuals come into contact in their immediate environment (Grabrucker, 2013; Qi et al., 2016; Shelton, Hertz-Picciotto, & Pessah, 2012; Von Ehrenstein, Aralis, Cockburn, & Ritz, 2014;). Some research suggests that contact with airborne toxins, such as insecticides

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[3] For the purpose of this study, Western views are regarded as views emanating mainly from Europe, North America and English Australia.

and manufacturing discharges, generate essential characteristics of ASD, especially when a woman is exposed to these substances during certain trimesters of her pregnancy (Qi et al., 2016; Shelton et al., 2012; Von Ehrenstein et al., 2014). Contrary to out-dated beliefs that parental style causes ASD (Grabrucker, 2013), factors such as parents who decide to have children later in life as well as mothers with diabetes increase the likelihood that their children will have ASD (Grabrucker, 2013).

Although many parents are unable to pinpoint the exact cause of ASD, common beliefs among parents include genetic susceptibility, environmental influences, vaccination, antenatal and labour risk factors, eating habits and ailments during childhood. In some cases, parents attribute blame to themselves as a source of ASD (Al Anbar, 2010; Dale et al., 2006; Dardennes, Prado-Netto, Kaye, & Contejean, 2010; Harrington, Patrick, Edwards, & Brand, 2006; Mercer, Creighton, Holden, & Lewis, 2006; Selkirk, McCarthy Veach, Lian, Schimmenti, & LeRoy, 2009).

Although Western research suggests several causes of ASD, Dale et al. (2006) found that caregivers who attributed ASD to a particular cause were more likely to be influenced by their beliefs as opposed to caregivers who did not attribute ASD to a particular cause. For example, Dale et al. (2006) found that mothers who thought that vaccines caused ASD planned not to get younger siblings vaccinated due to this belief. Beliefs regarding the stability of the disorder and who is best suited to help their children are influenced by the attributions of causality held by caregivers (Dale et al., 2006).

According to Mercer et al. (2006), genetic susceptibility facilitates blame and guilt in some parents and among families. Some parents are of the opinion that they are the cause of their children’s disorder and report incidences of family blaming owing to the existence of genetic susceptibility. Genetic susceptibility as a cause influences families’ dynamics and family planning decisions: those perceived as possessing a genetic disposition sometimes opt not to have more children after their children’s diagnosis (Mercer et al., 2006). This occurrence is often referred to in literature as a stoppage rule (Selkirk et al., 2009).

Environmental triggers such as a change in family structure owing to the arrival of another sibling are also regarded as a cause for ASD among some parents (Selkirk et al., 2009).

Parents identified the following antenatal risk factors as causes of ASD: "advanced maternal age, smoking, influenza, prescription medications, maternal vaccination, uterine bleeding, toxaemia, street drugs, upper respiratory infection and genital herpes" (Mercer et al., 2006, p.45). Labour-related attributions include

> trauma or injury during birth, foetal distress or anoxia, premature labour or premature rupture of membrane, low birth weight/premature birth, induced labour, Hyperbilirubinemia, requirement for oxygen after birth, emergency caesarean section, blood group incompatibility, resuscitation/ventilation, respiratory distress syndrome, anaemia and infection after birth (Mercer et al., 2006, p.45).

According to Al Anbar et al. (2010), a few of the parents involved in their study stated that the cause of their children's ASD might have been accidental. Some other parents decided not to fixate on the cause but chose instead to focus on the future of their children (Dale et al., 2006). Some others still said that they were unaware of causes of ASD in their children (Selkirk et al., 2009). It is interesting to note the differences and similarities of caregiver perceptions regarding the causes of ASD as opposed to the causes of ASD suggested by research.

2.3.2 Non-Western[4] parental views of the causes of ASD

Parents in non-Western contexts identified an array of factors which they believe contributes to ASD in their children. These beliefs include genetic factors, environmental causes (pollution), pre- and perinatal factors, spiritual or religious factors, parental wrongdoings or inadequate parenting practices, stress, infections, malnutrition and dietary habits, vaccines, emotional challenges, head trauma and

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[4] For the purpose of this study, Non-Western views are regarded as views emanating mainly from African, Asian, South American and non-English Australian. In this study, Non-Western views regarding ASD are not regarded as being homogenous.

childhood ailments (Anthony, 2009; Franz, Chambers, Von Isenburg, & De Vries, 2017; Grinker et al., 2012; Guler, De Vries, Seris, Shabalala, & Franz, 2018; Law, 2000; Mathye & Eksteen, 2016; Millau, Rivard, & Mello, 2018; Papadopulous, 2016; Riccio, 2011). Some other parents showed limited awareness or a lack of understanding as to what caused their children's disorder (Law, 2000; Riccio, 2011).

More common pre- and perinatal causal factors expressed by parents included birth difficulties, medical complications and drug abuse during pregnancy (Franz et al., 2017; Milau et al., 2018). Less frequent parental beliefs of causes of ASD include maternal frame of mind or stress, diet during pregnancy, difficulty conceiving and in vitro fertilization (Grinker et al., 2012; Milau et al., 2018).

Many parents attribute ASD to spiritual causes such as witchcraft, curses and evil spirits (Franz et al., 2017; Guler et al., 2018; Millau et al., 2018; Papadopulous, 2016; Riccio, 2011). Guler et al. (2018) discussed the viewpoints of parents who expressed beliefs that ASD is the outcome of their children being cursed by disgruntled family members. Reports of spirits ensnaring a child's throat which limits the child's ability to speak were also noted, a concern which is often responded to by means of traditional methods such as making incisions through the child's skin to enable the child to speak again (Guler et al., 2018). According to Grinker et al. (2012) and Mathye and Eksteen (2016), some parents expressed the view that ASD is punishment invoked by the ancestors or God as a consequence of a family's misdemeanours or as a result of neglecting to follow tradition. Sage and Jegatheesan (2010) confirmed that developmental impairments are sometimes regarded as the products of disobedience to culturally acceptable conventions by families or by the forefathers of those affected by ASD. To appease the ancestors, parents may make use of purgative ceremonies which attribute the cause of the disorder to civilisation (Grinker et al., 2012). (Refer to Intervention in section 2.6.2.)

Ghana and the Ivory Coast are examples of two countries in Africa where some African families view ASD as a disability or curse set in motion by the parents of the child. This belief might result in abuse or the homicide of children displaying ASD characteristics (Bakare & Munir, 2011; Bayat, 2015; Gona et al., 2015; Munsaka & Charnley, 2013; Tilahun et al., 2017). The origin of ASD is often specifically attributed to the mother of the child as the main source of blame for the child's disorder (Anthony 2009; Mathye & Eksteen, 2016; Riccio, 2011), owing to the patriarchal societal structure of many non-Western communities (Anthony, 2009).

Parents who believed God had a hand in their children's ASD were of the opinion that ASD was God's decision. They see the child with ASD is a sign or a gift from God and that ASD is God's method of evaluating parents' parenting capabilities (Grinker et al., 2012; Mathye & Eksteen, 2016). In a study conducted by Law (2000), one of the parents stated that the cause of ASD could be attributed to parents internalising their burdens, which is then accumulated in their blood, transferred to their children and revealed as ASD. Another parent believed her child's disorder was the manifestation of an emotional response to disruption or quarrels which occurred in the family context (Milau et al., 2018).

Correlations were found between parents' gender and the causes they attribute for ASD, for example, fathers more frequently attributed a diagnosis of ASD to environmental causes, whereas mothers linked causes to factors associated with pregnancy (Milau et al., 2018). Also, some non-Western parents disagreed with the notion of witchcraft being involved in precipitating ASD, whereas others were adamant that it was indeed a causal factor (Guler et al., 2018). Despite the majority of views regarding ASD in the African continent being predominantly spiritual or ancestral in nature, parents in countries such as Kenya and SA were found to acknowledge the biomedical and more conventional scientific approaches to ASD as well (Gona et al., 2015).

According to research on Asian and Indian views regarding the origins of ASD, some Indian caregivers tend to attribute ASD to their parenting abilities. They believe that the atypical behaviour is not permanent, a perspective which is reinforced by some other Indian caregivers in the community who normalise these types of behaviours (Desai, Divan, Wertz, & Patel, 2012). Some Chinese caregivers, on the other hand, are not as concerned about behavioural manifestations, but rather the child's ability to adhere to expected everyday tasks and commitments (Qi et al., 2016).

2.4 VIEWS OF ASD DIAGNOSIS

2.4.1 Western parental views of ASD diagnosis

ASD is generally regarded as a neurodevelopmental disorder (APA, 2013; Klauck, 2006). According to the DSM 5 (APA, 2013, p.50), ASD manifests as “[p]ersistent deficits in social communication and social interaction across multiple contexts” as well as “restricted, repetitive patterns of behaviour, interests, or activities.”

According to several parents and studies on diagnostic procedures and timeframes, it is common for ASD diagnosis to be delayed (Dale et al., 2006; Harrington et al., 2006; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). Late diagnosis is observed more frequently among children who exhibit less obvious characteristics of ASD, which has a snowball effect on the swiftness with which parents identify characteristics which indicate that their children might potentially be diagnosed with ASD (Dale et al., 2006). A delayed diagnosis is also more common among parents who make use of public healthcare services rather than private practices (Keenan et al., 2010). Once a diagnosis is made, parents are often uncertain as to what such a diagnosis implies (Dale et al., 2006).

Some parents expressed their unhappiness regarding diagnostic delays (Keenan et al., 2010). Keenan et al. (2010) found that parents experienced the diagnostic process as upsetting because it was vague. Parents experienced difficulties comprehending what the process encompasses. They reported that they were of the opinion that professionals did not consult with them adequately, as they were the ones best acquainted with their children’s challenges (Keenan et al., 2010). Final diagnosis is also the root of many other concerns for parents. They stated that they did not receive any recommendations from professionals regarding how to proceed after the diagnosis was made and reported that some of the professionals conveyed the final diagnosis to them in an unethical manner, for example, via phone calls. Parents also stated that they believed some professionals omitted details from their final report regarding the exact diagnosis (Keenan et al., 2010).

In another study, parents voiced that they experienced increased stress levels during the diagnostic process (Keenan et al., 2010); they experienced acceptance of the diagnosis as a trying time, often characterised by feelings such as “shame, guilt and self-pity” (Dale et al., 2006, p.465). These feelings were mostly exacerbated by the aforementioned stress. Late diagnosis precipitated responses from parents such as doubt, bewilderment, antagonism and rancour towards the child (Keenan et al., 2010). Mothers expressed doubt regarding the prognosis for their children, but some had hope of the possibility of change (Dale et al., 2006). In studies conducted in mainly Westernized contexts, Broady, Stoyles and Morse (2017) and Jensen et al. (2016) found that those diagnosed with high functioning autism (HFA) and their families experienced an increased level of stigmatisation compared to other disorders.

Another factor which delays diagnosis is physicians who do not recognise difficulties, which delays parents consulting with specialised professionals which ultimately leads to (late) diagnoses. Delayed diagnoses delay the onset of intervention which might cause unintentional reinforcement of the children’s inappropriate behaviours (Harrington et al., 2006; Keenan et al., 2010). Many parents doubt that their primary physician has the necessary skills to identify ASD (Harrington et al., 2006). Parents were also of the opinion that the information dispensed to them by professionals regarding the disorder and its financial implications was insufficient (Keenan et al., 2010).

Disregarding the delay in diagnosis and the lack of information experienced, parents mostly expressed that they experienced emotional relief after a diagnosis was made (Anthony, 2009).

2.4.2 Non-Western parental views of ASD diagnosis

Because of the vital role of parents in the detection of ASD, cultural variance among parents regarding the stages of a child’s development can influence the timeframe of diagnosis and intervention (Milau et al., 2018; Tincani, Travers, & Boutot, 2009). Several studies found that delayed diagnosis is prevalent among non-Western populations (Anthony, 2009; Franz et al., 2017; Milau et al., 2018). One challenge to the speedy diagnosis of ASD in some non-Western contexts is HIV/AIDS. The symptoms of HIV/AIDS, which include developmental delays, mask the characteristics of ASD, thereby lengthening the time before ASD characteristics are identified (Grinker et al., 2012). Limited access to resources and services as well as parents who rely on overcrowded childcare facilities owing to poverty further complicate the diagnostic process (Daley, 2002; Grinker et al., 2012; Milau et al., 2018).

Medical diagnosis of ASD is also affected by professionals in non-Western contexts. According to Desai, Divan, Wertz, and Patel (2012), ASD is not a well-known disorder in the Indian community. Psychiatrists, psychologists and paediatricians in India hold different views regarding the usefulness of unique traits, and the influence of professional experience when making a diagnosis of ASD (Daley, 2002). According to Daley (2002), some of these professionals are of the opinion that ASD is more common in families who earn a higher income.

In other countries, such as South Korea, ASD is rarely diagnosed owing to the social stigma accompanied by such a diagnosis. Many South Koreans regard differences in those diagnosed with ASD to be severe rather than moderate (Grinker et al., 2012). As a result, many parents discard these ASD diagnoses and prefer to adopt their own viewpoints, treating the opinions of trained professionals with suspicion (Grinker et al., 2012). Parents prefer to see social rather than intellectual impediments as responsible for their children’s difficulties. According to Grinker et al. (2012), it allows parents to avoid the stigma associated with their children’s disorder and makes it seem as if the disorder is confined to a distinct domain rather than all-encompassing.

In a South African study, parents distinguish between a “Western” and a “traditional” diagnosis (Grinker et al., 2012, p.207). Some South African parents express divergent viewpoints regarding the advantages of these respective diagnoses. According to these parents, a more scientific or “Western” diagnosis reduced their anxiety regarding spiritual causation of ASD and offered a foundation according to which they could make sense of their children’s disorder. Furthermore, such a diagnosis confirmed to parents that the origin of the disorder comes from within the child as opposed to their social environment, which is often the premise of traditional approaches to treatment and healing (Grinker et al., 2012).

According to Anthony (2009), some parents interviewed in Ghana cited that they were completely unfamiliar with ASD. Obtaining a diagnosis was only achieved after an extensive amount of time consulting different professionals who repeatedly failed correct diagnosis.

2.5 VIEWS REGARDING ASD CHARACTERISTICS

2.5.1 Western parental Views regarding ASD characteristics

Contradictory findings were made when studying the identification of ASD symptoms or characteristics by parents in different Western populations. One such contradiction is found between French and American populations.

According to Dardenness et al. (2011), French parents most commonly observe ASD manifesting in their children in the form of ritualistic or sequence-type behaviour patterns. Additional initial characteristics identified

by parents include solitary play, a delay in language development and their children being highly attentive to detail (Dardenness et al., 2011). The minority of parents alluded to characteristics such as their children warding off physical contact like strokes and hugs and not responding to parents when addressed by their names (Dardenness et al., 2011).

Contradictory to the above, parents in the United States of America (USA) are more likely to notice and report characteristics pertaining to universal developmental delays as well as the regression of language abilities as opposed to social and communication discrepancies (Mandell & Novak, 2005). According to Mandell and Novak (2005), parents in the USA are more worried about the linguistic development of their children than their social development, of which they demonstrate little cognisance or no anxiety. For this reason, parents minimally report shortcomings in social barriers (Mandell & Novak, 2005).

After conducting a study among immigrant families in Canada, Milau et al. (2018) noted that initial symptom identification was influenced by the region of origin of immigrant families. For example, parents who emigrated from the Caribbean or Near

East regions rarely declared speech delays or the lack of speech. In contrast, some immigrant parents from regions such as Western Europe, Northwest Africa and Latin America reported speech-related challenges more often (Milau et al., 2018). Maghreb parents (from North Africa) specifically identified various characteristics across the continuum of ASD and reported these characteristics in high frequencies. In this study, characteristics most frequently cited by parents of Maghreb and African origin were related to nonverbal and speech challenges (Milau et al., 2018). Furthermore, a shortage of play-related behaviours, which was mostly reported by fathers, was only cited by Western European and Maghreb parents and rarely by parents from other regions included in the study. Initial characteristics such as language delays, nonverbal communication and stereotypical behaviours were mentioned by Latin American parents (Milau et al., 2018).

The parents included in one study seemed to understand the symptomology related to ASD that was affiliated with a scientific mode of enquiry, as the characteristics they identified and reported were scientifically aligned to Western findings. However, particular behaviours which are understood as ASD related were not necessarily viewed as inappropriate among other cultures (Milau et al., 2018). In another example, research conducted in Ireland elucidated that parents expressed more concern regarding behavioural manifestations of ASD such as shortfalls linked to social proficiency, play, communication and interaction (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010).

2.5.2 Non-Western parental views of ASD characteristics

According to Daley (2002), children displaying symptoms or characteristics of ASD are identified and labelled differently throughout the non-Western world. Stereotypical behaviours are also reported less by parents in Africa than by parents residing in Britain (Daley, 2002). In Senegal, children who exhibit characteristics of ASD such as inadequate speech and social indifference are called “marvellous children” (Daley, 2002, p.534). Laotians who reside in rural areas use a classification which they call “Samqng Uan” (Daley, 2002, p.353) to refer to children displaying developmental challenges, such as challenges with learning, relationship building and being flexible to change (Daley, 2002).

A study conducted by Anthony (2009) in Ghana revealed how parents referred to initial characteristics of ASD, such as their children's social interactions, as being characterised by the children seemingly not wanting to interact with others, avoiding eye contact or not knowing in what way to participate in social activities. Other parents described their children as being socially functional but in a manner that might be perceived as eccentric in comparison to other children (Anthony, 2009). Still other parents stated that they did not identify any telling signs of ASD. Many research participants and professionals in Ghana were unacquainted with the word 'autism' (Anthony, 2009).

Indian parents recognised characteristics of ASD approximately seven months later than their American counterparts, and initial awareness was related to their children's struggle to interact socially with others (Daley, 2002; Mandell & Novak, 2005). Parents in sub-Saharan Africa most commonly expressed that one of the first signs of ASD was the slow pace at which their children started to speak and that their communication abilities were limited to certain settings (Franz et al., 2017). The challenge of children not being able to apply social or communication skills across various contexts was also reported among South African populations (Guler et al., 2018).

In SA, a large number of children, including orphans with HIV/AIDS, are minded in nurseries filled to capacity under the supervision of numerous custodians, which makes it particularly challenging to identify characteristics of ASD as most of these custodians have limited interaction with the children (Daley, 2002).

South Indian parents cited that it never crossed their minds that their children's challenges were related to something other than a normal part of everyday life (Daley, 2002). Some South African and South Korean parents who were interviewed showed limited knowledge about ASD. Characteristics related to the disorder were often overlooked owing to cultural factors, such as expecting children to avoid eye contact as a form of respect and not realising that lack of eye contact or avoiding social interaction are possible characteristics of ASD (Daley, 2002; Grinker et al., 2012; Milau et al., 2018). In South Korea, parents do not view characteristics of ASD as problematic unless it influences their children and their children’s peers unfavourably in an academic context (Grinker et al., 2012).

2.6 VIEWS OF ASD INTERVENTION

2.6.1 Western parental views of ASD intervention

According to Al Anbar et al. (2010) and Mandell et al. (2005), choices of intervention for children diagnosed with ASD depend on the parents’ understanding of the disorder and the manner in which the intervention will alter the functioning of the family. Country of origin also influences intervention methods and preferences (Daley, 2002). Therapeutic interventions for ASD are usually of medicinal, occupational, speech and language as well as behavioural nature. The aim of most intervention approaches to ASD is to improve social and behavioural functioning in children with ASD (Ospina et al., 2008) and to empower parents/caregivers to support their children.

Medicinal interventions are utilised to address symptoms associated with ASD such as “irritability, aggression, self-injurious behaviors, anxiety, hyperactivity, impulsivity, inattention, and insomnia” (DeFilippis & Wagner, 2016, p.20). Occupational therapy intervention usually entails activities which focus on sensory and auditory integration with the aim of improving concentration abilities (Case-Smith & Arbesman, 2008). Speech and language intervention usually involve a range of strategies, such as augmentative and alternative communication strategies, which aim to enhance communication skills by increasing the frequency and range of verbal expression (Paul, 2008). Behavioural interventions include strategies which aim to lessen ASD symptoms such as “repetitions carried out in exactly the same way, verbal rituals recurring all day long, insistence on sameness, satisfaction unless someone made a persistent attempt to interfere with self-chosen activities and dread of change” (Sevin, Riesk and Matson, 2015, p.329).These behaviours can be addressed by making use of operant conditioning strategies such as Contemporary Applied Behavior Analysis (ABA) (Paul, 2008).

According to a study by Dale et al. (2006) conducted in the United Kingdom, intervention for ASD was more often considered by parents who had hope that change is possible for their children than those parents who had little hope and negative views regarding the outcome. Parents who nurtured hopeful attitudes also experienced less stress than their more pessimistic counterparts. A third of the participants in this study believed that their children's disorder could be defeated entirely, which makes them susceptible to those who advocate that there is a cure for ASD.

In France and the USA, many parents engaged in a combination of more than three intervention methods. Methods included potentially harmful unconventional interventions owing to the failure of more established interventions, limited access to recovery programmes, disagreement regarding the best intervention and providers of unconventional methods being more supportive compared to professionals who make use of conventional intervention methods (Daredennes et al., 2011). In France, some parents prefer intervention that is less invasive and more natural; many French parents are unhappy with conventional approaches and limited conventional intervention options (Daredennes et al., 2011; Harrington, Patrick, Edwards, & Brand, 2006). Because many French citizens receive funding for conventional approaches, non-conventional interventions were less frequently used because parents have to pay for these interventions (Daredennes et al., 2011).

In the same study (Daredennes et al., 2011), the majority of French parents combined learning therapy with pharmaceutical treatments or other interventions such as speech therapy, psychomotor therapy and psychoanalytic psychotherapies. Alternatively, pharmaceutical treatment was used as the only method of intervention. Parents who viewed early traumatic experiences as a contributing factor to ASD seldom made use of behaviour therapy. Parents who attributed illness during pregnancy as a causal factor most likely used prescribed medication to intervene. Vitamins, specific diets and detoxification were among the intervention strategies employed by parents who regarded food allergy and food intolerance as causal factors for ASD.

Another study conducted in France (Al Anbar et al., 2010) linked parents' views about the seriousness of ASD to their use of behaviour and social skills therapy as the intervention methods of choice; prescribed medication was primarily favoured by parents who believed that the course of ASD is cyclic or episodical. Parents who ascribed the cause of ASD to external rather than internal factors were more inclined to make use of metabolic interventions such as special diets and vitamin supplements, similar to parents who linked ASD to hereditary causes (Al Anbar et al., 2010).

In Ireland, it is reported that some parents make use of as many as seven different therapies (Dillenburger et al., 2011). Many Irish parents have adopted applied behaviour analysis (ABA) as intervention. Parents who are trained to make use of ABA displayed increased levels of gratification and decreased levels of stress (Dillenburger et al., 2011).

2.6.2 Non-Western parental views of ASD intervention

In Israel, parents make use of medicine as well as spiritual and religious intervention methods (Daley, 2002). An ultra-orthodox Israeli community has embraced a practice called facilitated communication (FC) which purportedly enables an individual with verbal expressive challenges to communicate via physical support from a facilitator (Daley, 2002), which is not similar to conventional augmentative and alternative communication (AAC) methods. Children who are regarded as severely or profoundly incapacitated mentally and physically are believed to be an asset in the FC procedure, as mystic-religious perspective implies that these individuals are more capable of connecting to the pure soul, something from which normal people are essentially estranged. Therefore, it is believed that messages from unearthly sources can be communicated through children diagnosed with ASD (Daley, 2002).

Owing to limited intervention or support, Indian parents make use of pranic healing, vitamin therapy, astrologists, reflexology, acupressure, speech therapy, tutoring, behaviour therapy, yoga, homoeopathic treatment and/or Siddha, which are often classified as experimental interventions (Daley, 2002). Milau et al. (2018) confirm that Indian families who immigrate to the USA tend to combine these intervention strategies with conventional methods used in North America, such as language, behaviour and speech therapy.

Owing to high levels of help-seeking, South Asia has numerous structures of intervention, such as medical treatments, homoeopathic medicine, alternative medicine and Unani customs found in India (Daley, 2002). Parents are also known to expose their children to experimental intervention methods (Harshini & Preeti, 2017). Speech and language therapy is also common interventions among Asian populations (Milau et al., 2018). Some Taiwanese parents use spiritual rituals of a Buddhist nature or to change a child's name as supplementary to behaviour and educational interventions (Milau et al., 2018).

According to Papadopulous (2016), some Saudi Arabian parents employed interventions by consulting religious healers and attributed ASD to the "evil eye". In sub-Saharan Africa, parents were found to intervene when their children are diagnosed with ASD in the hope that the disorder would be cured (Franz et al., 2017).

In Kenya, some parents use a combination of Western and traditional intervention methods (Milau et al., 2018). Parents, especially fathers, expressed their concern regarding having additional children if one of their other children has been diagnosed with ASD (Riccio, 2011), which corresponds with views held by Western populations. Kenyan communities tend to support the abandonment of children with ASD. For this reason, many parents are reluctant to seek help for their children. They often resort to witchdoctors to free them of evil spirits or curses that were imposed on the families. In Kenya, the well-being of children who are not impaired is prioritised rather than spending money on children who are diagnosed with ASD, as they are regarded as not having the capacity to be contributing members of society (Riccio, 2011).

In SA, traditional views that a child with ASD is cursed is still prevalent; studies show that parents in isolated parts of the country cited beliefs that community members have the ability to heal people, especially children (Grinker et al., 2012; Guler, De Vries, Seris, Shabalala, & Franz, 2018). When asked if they still use the services of traditional healers, parents disclosed that they indeed consulted with these healers and that they might have denied it at the onset of the interview owing to the humiliation of holding such beliefs in a modern context (Grinker et al., 2012).

ASD intervention in SA is influenced by location-specific barriers such as a lack of resources and access to resources as well as financial constraints (Guler et al., 2018). The child's behavioural tendencies, which parents often find difficult to manage, also serve as a barrier to intervention. These barriers might have prompted parents to express their preference for intervention administered by therapists at their homes. In this study, parents also cited that those who provide therapy have to exhibit sensitivity and understanding towards cultural beliefs, practices and traditional medicine and take these into account when planning and executing intervention for their children.

2.7 Concluding thoughts on ASD in Non-Western contexts

Similarities with regards to views pertaining to causation of ASD by many parents from non-Western contexts believe that there are spiritual and/or religious components involved in the causation of ASD. However, other parents from non-western contexts viewed scientific and biomedical approaches as being more credible explanations for the cause of ASD. Regarding the diagnosis of ASD, parents from most non-western contexts expressed that ASD was diagnosed at a later age. However, in some instances a diagnosis was not made at all due to the stigma associated with a diagnosis of ASD. Non-western views pertaining to ASD characteristics were very similar as in most cases delayed development as well as challenges with social interaction were identified. The identification of these characteristics was also delayed due to parents mistaking them for characteristics that are associated with a specific culture. Intervention strategies for ASD amongst non-western parents differ from context to context and include medicinal, spiritual or traditional intervention strategies. The choice of intervention seems to be determined by the personal belief system as well as cultural views of parents whose children have been diagnosed with ASD.

2.8 SUMMARY

Chapter Two provided a discussion of IKS as the theoretical framework, showing its relevance to this study. An overview of literature pertaining to the research question was presented. Chapter Three contains an exposition of the paradigmatic lens as well as the research methodology and design through which the research was conducted. It includes aspects such as selection of participants, data collection and documentation, data analysis and interpretation, quality criteria as well as ethical considerations applicable to the research.

CHAPTER 3

RESEARCH METHODOLOGY AND DESIGN

3.1 INTRODUCTION

Chapter Three positions the research in terms of the chosen epistemology and research methodology which align with the nature of the specific research questions about gaining knowledge pertaining to Sepedi cultural views regarding ASD. Chapter Three also includes an exposition of the selected research design, selection of the research site and participants, methods of data collection, data documentation and data analysis as well as quality criteria. Ethical considerations conclude the chapter. Reasons for choices, criticism and advantages with practical implications for this study are provided throughout the chapter. Taking these practical implications into account contributes to the authenticity and trustworthiness of the results.

3.2 EPISTEMOLOGICAL PARADIGM: PHENOMENOLOGY

3.2.1 Understanding phenomenology

Chapter One introduced phenomenology as the study of individual awareness and how people project their perception of the world based on established realities. These realities are based on how past, present and future experiences, which are exclusive to them, influence their lives. These experiences are all fundamentally created via the social frame of reference from within their own environment (Davidsen, 2013; Flood, 2010; Lopez & Willis, 2004). Phenomenology facilitates further investigation of these human experiences (Hein & Austin, 2001). According to Connelley (2010) and Kumar (2012), phenomenology endeavours to explain and comprehend happenings such as caring, healing and completeness as undergone by individuals who have experienced such happenings (Groenewald, 2004). In this study, these happenings are the experiences related to having children with ASD.

Phenomenology entails uncovering significance as opposed to disputing a point of view or constructing nonconcrete theory. It proposes that wisdom can be encountered not by the empirical-analytical sciences, but by imparting shared meanings of culture, history and language which presents the opportunity for improved awareness of the reality of others (Flood, 2010). In this study, the shared meaning of Sepedi culture, history and language will be investigated to uncover Sepedi cultural views of ASD.

According to Davidsen (2012) and Groenewald (2004), the aim of phenomenology entails the encapsulation of how certain events are experienced and the meanings attached to these events by those who live them. These meanings are communicated by means of extensive descriptions, which are influenced by cultural, social and relational occurrences (Davidsen, 2012).

According to Flood (2010), phenomenology maintains that humanistic realities are comprehended via internal subjectivity and that the person is a central component of the environment. It proposes the examination of the phenomenon itself as an entity which should be regarded as detached from the researcher's former preconceptions, an aspect of which the researcher must remain fully cognisant throughout the study (Davidsen, 2012; Lopez & Willis, 2004). (See section 3.4.1 for ways in which the researcher tried to accomplish detachment from personal preconceptions.)

3.2.2 Criticisms of a phenomenological paradigm

Davidsen (2012) challenges the warning for researchers to detach themselves from preconceptions from within them by saying that researchers are incapable of fully detaching themselves from their assumptions. They have been influenced by their own contexts, historical events and biases, despite engaging in reflexive practices, which prevent them from remaining completely objective and detached from the phenomenon under examination. Hein and Austin (2001) make a similar remark. According to them, as the researcher becomes aware of assumptions, new ones are discovered. Therefore, researchers cannot fully separate themselves from assumptions as they are not aware of all their assumptions at the start of the study. Researchers can merely recognise and make explicit these assumptions (as done in section 1.4 which are inherent to their biology and history).

Plunkett, Leipert and Ray (2013) suggest that research conducted from a phenomenological lens may either produce a distortion of the true meaning or merely promote the mainstream understanding of certain people or groups. In other words, interviews conducted with participants might not facilitate the accurate representation of specific participant experiences and meaning-making. Therefore, researchers have to take care when formulating questions in order for these questions not to reflect the researchers' assumptions. Researchers must also deliberate the historical and social aspects of participants when interpreting data and presenting findings (Plunkett et al., 2013).

Owing to the subjective nature of participant views, their views might not necessarily reflect the experiences of the rest of the population from which participants were selected; their views might be limited to their specific group (Lopez & Willis, 2004). Therefore, it is essential that the researcher acknowledges it when reporting the findings.

3.2.3 Justification of a phenomenological paradigm

Despite the above criticism, phenomenology still has value. Phenomenology enables the researcher to arrive at an essential understanding of the occurrence or phenomenon being researched as well as an understanding of how the meaning-making of their lived experiences occurred for the participants (Davidsen, 2012; Flood, 2010; Groenewald, 2004). According to Plunkett et al. (2013), such an essential understanding is indispensable, as it extends and/or replaces commonplace knowledge and comprehension of current social concepts. A better understanding of generally accepted concepts by minority groups, which are often overlooked, may offer health professionals the opportunity to provide better care to those who experience the examined phenomenon (Plunkett et al., 2013). For this reason, phenomenology is of value to the study as it enables the researcher to gain more insight into the daily, lived experiences unique to the participants.

Phenomenology also has value because it considers humans as holistic beings. It merits their experiences by examining how they lived these experiences in a manner that does not merely reduce the experiences to their reactions but includes how they made sense of it in a way that yields rich information (Connelly, 2010). In other words, phenomenology may not only give answers to the question of *how* Sepedi parents view ASD, but it may also answer the question as to *why* they view ASD in specific ways.

Methodologically, a phenomenological paradigm steers the researcher away from employing a pre-determined set of criteria for interpretation of data shaped by the researchers' personal frame of reference (Groenewald, 2004). Groenewald (2004) cautions against intruding on a phenomenon with a specific method as it could lead to prejudice towards it.

Phenomenology has proven helpful in revealing new insights, and it has permeated nearly all disciplines of knowledge (Kumar, 2012; Wojnar & Swanson, 2007). It may be of value to the current study as the literature review revealed a scarcity of research on Sepedi cultural views of ASD. Using a phenomenological lens may assist in determining the essence of Sepedi cultural views of ASD.

3.3 METHODOLOGICAL PARADIGM: QUALITATIVE APPROACH

3.3.1 Introduction

This study uses a qualitative methodological approach. A qualitative approach aims to clarify and/or supplement existing knowledge pertaining to human behaviours or occurrences by making use of explorative and descriptive methods (Lichtman, 2017; Nieuwenhuis, 2007; Wertz et al., 2011). Additionally, it takes into account traditions and presupposed cultural knowledge (Wertz et al., 2011). New phenomena can also be investigated (De Vos, 2005). A qualitative research approach can further be explained by discussing criticism and justification of such an appraoch.

3.3.2 Criticisms of a qualitative approach

A disadvantage of a qualitative approach is that data are not generalisable to other settings. This challenge can be minimalised by explicitly stating the exact conditions of data collection and analysis (De Vos, 2005), which makes the application of the findings to similar contexts a possibility. According to Rahman (2017), data interpretation and analysis in a qualitative study is a time consuming and complicated process. The meaning behind data is often ambiguous, and analysis needs to adhere to specific requirements. Data analysis and the refinement of research questions are a challenging and constant process that occurs throughout a qualitative study (Rahman, 2017).

3.3.3 Justification of a qualitative approach

Because the purpose of this study is neither to obtain or compare statistical data (Lichtman, 2017; Nieuwenhuis, 2007) nor to generalise but to clarify and describe Sepedi cultural views of ASD in an indigenous context, the researcher deemed the qualitative approach as an appropriate means of collecting data. A qualitative approach yields data regarding how participants understand the world based on their experiences as well as the social and cultural influences on this understanding (Nieuwenhuis, 2007), which applies to this study.

According to Lichtman (2017), the researcher plays an essential role in all stages of the qualitative research process. This fact may be regarded as both an advantage and a challenge. The researcher can design and mould the study to generate the necessary data to answer essential research questions, especially since the qualitative approach is dynamic (Lichtman, 2017). However, if the researcher is uninformed or subjective, the risk of data not reflecting the aim of the study might increase. Therefore, the researcher must be well-informed of cultural practices, research methods and techniques, the theoretical underpinnings of the study and her own subjectivities and assumptions (Lichtman, 2017; Swartz & Rohleder, 2017). As already mentioned, member checking will be done in this study to minimise or eliminate possible biases of the researcher in the data analysis and interpretation (See section 3.5.2).

A qualitative approach also provides the researcher with the opportunity to comprehend practices which she did not experience personally (Lichtman, 2017). This aspect of qualitative research lends itself well to the proposed study since the researcher does not share the same culture nor the same challenges regarding raising children with ASD as the participants.

Another advantage of a qualitative approach is that data collection occurs under natural rather than superficial conditions (Nieuwenhuis, 2007). Natural conditions such as an informal environment with which participants are familiar (in this case, their children's school), can help set participants at ease during data collection and give them the opportunity to express their views authentically in an environment with which they are comfortable.

3.4 RESEARCH DESIGN

The research design is an essential part of research as it provides the researcher with a logical framework which guides the exploration and answering of research questions (DeForge, 2010). It is therefore important to select a research design which will enable the researcher to best answer the research questions.

3.4.1 Case study design

This study uses a case study design. According to Fouché (2005), a case study can be considered as an extensive inquiry into a system that is connected by time and/or place. "The case being studied might refer to a process, activity, event, programme or individual or multiple individuals" (Fouché, 2005, p. 272). The key motivation for this type of inquiry ought to be the prospect of obtaining new knowledge which produces an in-depth explanation of a case (Fouché, 2005).

A case study design enables the researcher to gain holistic insight into the viewpoints of participants regarding complicated, realistic, social and behavioural issues (Andrade, 2009; Fouché, 2007; Nieuwenhuis, 2007; Tellis, 1997; Zainal, 2007). For a case study to deliver quality and trustworthy data, the researcher needs to employ different methods to collect data (Nieuwenhuis, 2007; Yin, 2013). (Refer to section 3.5.)

Data collected via a case study design often shed light on phenomena which have limited available scholarly data (Andrade, 2009). This design is, therefore, especially applicable to this study, as there is little research regarding ASD on the African continent (Bakare & Munir, 2011; Bayat, 2015). Even though generalising is difficult with case studies, the purpose of this study is to understand and not to generalise, which makes a case study design appropriate. (Zainal, 2007).

A possible challenge of a case study design is the risk of collecting data that might prove to be insufficient or irrelevant to the proposed study (Yin, 2013). This criticism can be addressed by using multiple cases instead of single cases and by diversifying the variety of methods employed when collecting data (Yin, 2013). This study started with a focus group discussion, followed by two single case studies and adding another case study, or studies, only if the collected data could not answer the research questions. Lack of meticulousness is usually not a result of research design but of inadequate ways of working. In this study, verbatim transcriptions were used, with the option of double back translations where necessary (Gill, Stewart, Treasure, & Chadwick, 2008; Swartz & Rohleder, 2017).

Another criticism, as highlighted by Zainal (2007), is that case study designs are often accused of shortfalls in precision. Researchers are sometimes careless: they allow biased views to influence findings or they are unaware of their personal biases. Expressing assumptions at the start of the study, member checking transcriptions, data analysis and findings, and working with a supervisor are all steps to minimise biased results.

Because a small number of participants are involved in the research, findings derived from case studies also have limitations with regards to generalisation to other contexts (Zainal, 2007). However, the purpose of the current study is not to generalise findings, but to explore, and therefore a case study design is regarded as appropriate.

3.4.2 Selection of research site and participants

The research site was selected through convenience sampling. “Convenience sampling … involves selecting sample units that are readily accessible to the researcher” (Phua, 2004, p.197). The advantages of convenience sampling are that it is cost-effective, easily accessible and valuable when the target population of the study is difficult to reach (Phua, 2004). A potential challenge of convenience sampling is that findings have limited potential for generalisation (Phua, 2004). As the goal of this research is to increase understanding of a phenomenon not yet researched much and not generalising results, convenience sampling is appropriate.

The chosen site to select participants was a private school in Centurion for learners with individual support needs, including ASD. It was a feasible site as potential participants, parents of children diagnosed with ASD, would be accessible. The site was also close to the researcher and the university, thereby simplifying logistics. As most of the parents had employment in the city, they would probably be fluent in conversational English as their second language - important because the research will be conducted in English. An unobtrusive, relaxed, private, reachable venue free of distraction at the research site was used to collect data (Gill et al., 2008). Permission was obtained from the director of the school to conduct research at that specific school with a letter approved by the Ethics Committee of the Faculty of Education. (Refer to section 3.8 and Appendix A.)

The researcher made use of purposive sampling to select participants from whom to collect data. Purposive sampling entails the selection of specific participants who possess specific characteristics and who can probably contribute valuable information pertaining to the proposed study (Delport & Strydom, 2005). According to Delport and Strydom (2005), purposive sampling can provide solid data and detail regarding the phenomenon being studied. Criteria based on specific underlying justifications and the research question of the proposed study guided this selection (Nieuwenhuis, 2007).

For this study, inclusion criteria were parents who identify with a Sepedi culture whose children have been diagnosed with ASD. The reason is that these parents have experienced the process of diagnosis and intervention, which might shed light on their understanding and views regarding the nature and causes of and intervention for ASD. The participants must also have time available and be prepared to participate in the study (Andrade, 2009). Potential participants were invited through a letter approved by the Ethics Committee of the Faculty of Education (See section 3.8 and Appendix B.) that had to be signed by the participants in which it was stated that the study was based on Sepedi views. The principal, having intimate knowledge of every learner in the school, was asked to distribute the letters to those parents who identified with a Sepedi culture.

The researcher was also prepared to make use of snowball sampling to select participants if it was needed. In this method of sampling, current participants are requested to refer the researcher to other individuals who may make a valuable contribution to the study (Atkinson & Flint, 2011). For example, participants could refer the researcher to other parents of children with ASD, to elders in the community who might have been of assistance to explain viewpoints on ASD, or to family members, since there is evidence that ASD may be a genetic disorder (Jensen et al., 2016; Qi et al., 2016). However, it was not necessary to use snowball sampling because enough parents volunteered to participate and the small sample size was regarded as appropriate for the scope of a mini-dissertation.

A potential challenge related to the selection of participants is the fact that some participants might not be able to reflect or communicate in the language of the researcher (Andrade, 2009). Although it was assumed that parents enrolling their children with ASD at a private school can use conversational English as medium of conversation, the researcher still made the necessary arrangements to obtain a qualified translator should one have been required for data collection. Owing to cultural beliefs, it was also possible that male or female participants might not want to communicate freely with the researcher, who is female. If that proved to be the case, a male translator would have been used to translate interviews with male participants and a female translator for female participants, as verbal communication and meaning-making is sometimes reliant on or influenced by gender (Pfeiffer & Butz, 2005).

Once the site and participants have been selected, the collection of data can proceed.

3.5 RESEARCH METHODS AND DATA DOCUMENTATION

To enable the researcher to collect data that have the potential to answer the research questions for the current study, research methods and data documentation deemed most suited were selected.

3.5.1 Focus groups

As the researcher wanted to collect in-depth information from the perspective of participants from a Sepedi culture in a natural setting to enable her to understand better their experiences and beliefs regarding ASD, she made use of focus groups (Gibson & Riley, 2010; Gill, Stewart, Treasure & Chadwick, 2008). Focus groups are often used when not much is known about a phenomenon, and exploratory questions are asked (Liamputtong, 2011). Focus groups generally consist of six to eight participants (Gibson & Riley, 2010). Focus groups often start with certain pre-determined questions which are discussed in the group. The researcher and focus groups members can probe and reflect on answers through discussion (Liamputtong, 2011), making it especially beneficial in this study as the researcher is not part of the participants' culture.

One advantage of focus groups is that group interaction has the potential to make the experience more enjoyable to participants. Another benefit is that discussions led by participants may expose themes or important information which might have been overlooked by the researcher due to the scarcity of available research on the particular phenomenon (Gibson & Riley, 2010). As focus groups bring together individuals with specific characteristics, focus groups can also form a mini-community to which the researcher does not belong but which can provide emotional and social safety to prompt members to reveal experiences and support one another (Liamputtong, 2011).

In this study, focus groups consisted of parents who did not necessarily know one another or were merely acquaintances at the school. This situation was foreseen to potentially create an environment in which participants would feel free to have discussions with other participants without fear of negative outcomes from the discussion (Gill et al., 2008). Invitation letters were given to six parents of the Sepedi culture at three campuses of one school. After reminders and another round of invitation, three parents volunteered to participate in the focus groups. Therefore, only one focus group was formed, which two parents of the three who had volunteered, attended. The sample size was considered appropriate for the research scope of a mini dissertation. The focus group discussion was audio-recorded and transcribed. The questions asked in the focus group are in Appendix C, and the transcript thereof is in Appendix D.

3.5.2 Semi-structured interviews

Semi-structured interviews can provide the researcher with flexibility and in-depth information about views, understandings or explanations regarding the topic being investigated (Greeff, 2005). The researcher prepares fixed questions which are asked to participants and probes their answers to elicit more detailed information which might not have been anticipated and was therefore not included in the set questions (Nieuwenhuis, 2007).

Once the focus group of this study concluded, the original plan was for the researcher to identify two of the participants for further semi-structured interviews regarding Sepedi cultural views of ASD. The participants for the semi-structured interviews would have been purposefully selected based on their willingness to participate and their contributions to the focus group which warranted further individual probing. The researcher had planned to conduct two semi-structured interviews with the purposefully selected focus group participants as previously explained. However, as only two of the three volunteers attended the focus group discussion, both were invited to participate in an individual semi-structured interview. Only one participant accepted the invitation. The third volunteer who did not attend the focus group was contacted for an individual semi-structured interview; thus, a total of three participants were involved in the research.

Semi-structured interviews enabled the researcher to obtain valuable information that is unique to the social and cultural context of participants which might be relevant and beneficial to the investigation of Sepedi cultural views about the nature, cause/s and intervention of ASD. This information can also assist in determining to which extent knowledge and viewpoints are indeed culturally constructed. It is especially the case since the participants are seen as experts in the topic under discussion, which makes room for them to discuss their views in as much detail as they feel comfortable with (Greeff, 2005). Rich data are also beneficial since the available pool of participants used to collect data during a case study is small (Zainal, 2007). These interviews were audio-recorded to refer back to when transcribing the data (Marvasti, 2014). The researcher acknowledged the use of recording equipment before the session commenced (Gill et al., 2008). (Refer to Appendix E for the questions planned for the semi-structured interview and to Appendix F for the transcripts of both of the semi-structured interviews.)

The researcher had planned to conduct a follow-up interview for member-checking of transcripts, data analysis and findings with each of the two participants who participated in the focus group discussion and individual interviews. Member checking (Sandelowski, 2008), where construed themes after data-analyses are discussed with the participants, is an important contribution to the authenticity and trustworthiness of the study. (Refer to section 3.6.1) When interviews for member-checking were set up, all three participants claimed too full diaries and the transcripts and identified themes were password protected and emailed to two of them for verification. The second participant in individual interviews (I2) experienced logistic challenges and a hard copy of the interview transcript as well as the proposed themes and subthemes were sent to her. One of the two focus group participants (FG1; I1) submitted comments and additions to the transcriptions via email. In addition, the researcher phoned each of them to discuss possible changes and additions to the transcripts and identified themes. The other focus group participant (FG1) provided feedback telephonically. This feedback was audio recorded, transcribed and included in Chapter Four (Refer to 4.2 for more details on member checking.). The third participant (I2) did not make any changes but accepted the transcripts, themes and subthemes.

3.5.3 Observation

As one of the most important approaches to collect data in case study research include observation notes (Yin, 2013), observations were made during the focus group as well as the semi-structured interviews. Participants often communicate valuable information without expressing it verbally, which might be overlooked without conscious observation. The researcher fulfilled the role of observer while conducting the focus group discussion and the interviews (Yin, 2013). Examples of observations are emotions elicited when asked certain questions, such as anger, sadness or tension.

One of the advantages of observation is that insight can be gained about the interpersonal nature of the research (Tellis, 1997). No observations were clarified with participants during member checking, as no observations were ambiguous or originated from cultural expression. Observations were included in the field notes (refer to 3.5.4 and Appendix G).

3.5.4 Field notes

The researcher made use of field notes (Andrade, 2009; Nieuwenhuis, 2007) to document important information obtained through observation that might have been lost if the researcher did not keep meticulous records. Field notes also contain reflections of the researcher. Reflections link with the data analysis and interpretation phase of the research (Andrade, 2009). An example of researcher reflections would be to reflect whether the xenophobia reported in the newspapers influenced the responses during the interviews. For insight into the field notes containing the researcher’s observations and reflections, refer to Appendix G.

3.6 DATA ANALYSIS AND INTERPRETATION

3.6.1 Inductive thematic analysis

It is important to note that data collection and analysis are interwoven (De Vos, 2005; Nieuwenhuis, 2007), meaning that data collection guides data analysis and vice versa. For example, if questions asked and/or probes used by the researcher does not yield rich data, she would have to alter her approach to obtain richer data. (Firmin, 2008).

As stated in Chapter Two, the researcher made use of a dual method to analyse data. Firstly, data were analysed while it were being collected at the research site as a part of taking field notes (De Vos, 2005). It entailed the researcher identifying patterns and possible areas of interest in the data while on site (Braun & Clarke, 2006). She noticed and looked for patterns of meaning and issues of potential interest in the data.

Secondly, data analysis formally started when the researcher had departed from the site and listened and transcribed the audio material. She subsequently read through the focus group and interview transcripts and her field notes to get a general overview or holistic sense of what was said by the participants (Braun & Clarke, 2006; Groenewald, 2004; Lester, 1999). The researcher then wrote down ideas and possible codes that could be used during data analysis (Braun & Clarke, 2006). Atlas.ti software was used as a tool for conducting data analysis. Different codes representing different meanings were allocated to the content of transcribed data (Braun & Clarke, 2006). After the allocation of codes, the codes were analysed by taking into account the number of times they were mentioned by participants (Groenewald, 2004) and by clustering codes together to pinpoint recurring themes and related subthemes (Terese, 2013). (Refer to Appendix I for screenshots of sub subthemes as analysed in Atlas.ti) These themes were then refined by considering whether there were adequate data to support each theme, and some themes were grouped together as they proved to be more meaningful as a whole (Braun & Clarke, 2006). The identified themes and subthemes were then described with inclusion and exclusion criteria (Refer to Appendix J) and labelled (Braun & Clarke, 2006).

One of the potential challenges of interpretation is to assume a position from which one can interpret information as objectively as possible while having a connection with what is being interpreted and analysed (Willig, 2013). This challenge can be minimised or overcome by the researcher setting clear boundaries as to when she becomes too involved. For example, when she becomes aware that her emotions interfere with the manner she conducts research, she can take a step back before making any important interpretations or conclusions regarding the data collected.

A further challenge linking to such subjectivity includes personal bias or preconceived notions as to what the data represent, which poses the risk of the researcher merely analysing, interpreting or reporting findings based on these notions (Potter, 2011). For this reason, the researcher had to identify and clarify any biases or preconceived notions she might have held before starting the data collection process. Additionally, when uncertainties arose during data interpretation, or when the researcher recognised the potential to collect additional, meaningful data from the participants which might contribute to the study, the participants were consulted during member checking.

The strategy of member checking was used as it increases the authenticity of research conclusions (Sandelowski, 2012) and can prevent bias from clouding the results. Authenticity is an important requirement for qualitative research. To ensure that the proposed research is authentic, it should be fair and conducted in such a manner that the participants' opinions are all regarded as equal when interpreting the data. This authenticity renders rich data which enable the researcher to decide the extent to which conclusions can be transferred to similar situations (Howell, 2013).

3.7 QUALITY CRITERIA

Quality criteria, such as transferability, dependability, credibility, and confirmability, were pertinent to the research endeavour.

3.7.1 Transferability

Transferability denotes the extent to which research findings can be used in other settings with other participants but under shared circumstances (Anney, 2015; Wilkins, 2012). Because transferability remains a challenge in the scope of qualitative inquiry (Krefting, 1990), the researcher enhanced the likelihood of transferability by providing a thorough description of the methodology as well the context in which research was conducted using rich, descriptive data explicating working assumptions as well as employing purposive sampling methods (Anney, 2015; Wilkins, 2012). Furthermore, the reason that purposive sampling methods are especially beneficial to transferability is that participants and context are described in much detail, which facilitates transferability. Therefore, purposive sampling offers comprehensive results compared to probability sampling techniques (Anney, 2015).

3.7.2 Dependability

Dependability concerns the solidity of results over time as well as whether the research was conducted in accordance with methodological procedures (Anney, 2015; Wilkins, 2012). The researcher augmented this quality criterion by adhering to general research protocol, such as accuracy and member checking, and also to the specific research protocol approved by the Ethics Committee of the Faculty of Education through which experienced researchers approved the planned research design and research process for the study.

3.7.3 Credibility

According to Anney (2015, p.276), "[c]redibility is defined as the confidence that can be placed in the truth of the research findings." It involves the authentication of research results and whether it epitomises the knowledge gained from participants through data collection and whether these original insights were construed correctly (Anney, 2015; Wilkins, 2012). The researcher made use of member checking and reflections to enhance the credibility of the study (Anney, 2015).

Member checking can be regarded as one of the most important methods to establish credibility (Anney, 2015; Cho & Trent, 2006). It is an especially pertinent technique as it involves participants in the research process through consultation and affirmation of the precise interpretation of participants' perspectives (Anney, 2015; Krefting, 1990). One of the aims of member checking is to reduce researcher bias throughout the data collection and analysis process (Anney, 2015). The changes brought about through member checking can be viewed in Appendix H.

3.7.4 Confirmability

Confirmability denotes the extent to which findings can be endorsed or supported by fellow researchers and that results obtained are not merely fabrications of the researcher's imagination but an accurate representation of data (Anney, 2015). Confirmability can be authenticated using reflective records to tentatively make sense of data collection (Anney, 2015; Wilkins, 2012). Confirmability can also be authenticated by having a clear trail of evidence. In this study, the inclusion of the appendixes that give other researchers access to the transcripts is an example of leaving a clear trail of evidence. The researcher also enhanced confirmability by sustaining an acceptable level of distance from participants (Wilkins, 2012).

3.8 ETHICAL CONSIDERATIONS

The researcher was guided by the ethical principles as set out by Allan (2016) and the Health Professions Council of South Africa (HPCSA) (Health Professions Act, 1974) to guide ethical practice Take note that the sections below overlap in many instances and that the principles functioned as the mandate under which all research activities were conducted.

3.8.1 Respect for humanity

Respect for humanity postulates being cognisant that participants, being human beings, are worthy of being treated with physical and psychological dignity and having their rights respected by the researcher (Allan, 2016). The research endeavour itself should be designed in such a manner that these aspects are considered and that intellectual, parental, privacy and reputational rights of participants should not be violated during the act of conducting research (Allan, 2016).

The research study regarding Sepedi cultural views of ASD respected the participants' dignity in several ways, such as being non-judgemental and maintaining confidentiality.

3.8.2 Psychological dignity

The researcher guarded against violating the psychological dignity of participants by considering their individuality and unique experiences (Allan, 2016). The researcher also did not reduce their experiences as being insignificant or inaccurate, but acknowledged their responses through active, empathetic listening and appropriate responses. The researcher did not probe further if psychological distress was evident.

Furthermore, the researcher also did not attempt to impose her own values or opinions onto participants (Allan, 2016).

3.8.3 Privacy, confidentiality and anonymity

The researcher kept all information gathered from the participants strictly confidential and stored it in a secure location, for example, a locked cabinet which only the researcher has access to for hard copy information, and password-protected computer documents for electronic information. The identities of the participants have also been protected by using codes or pseudonyms (Allan, 2016; Health Professions Act, 1974). Furthermore, the researcher did not ask irrelevant questions (Allan, 2016). The researcher also did extensive research about the culture of the participants to ensure that she did not cross any ethical boundaries pertaining to cultural matters. All necessary steps were taken to ensure that the participants understood the research and had sufficient opportunities to ask questions in an environment free of bias or prejudice (Health Professions Act, 1974).

Confidentiality is especially important during focus groups, as participants may not share meanings when feeling unsafe. All members of the focus group, therefore, agreed to confidentiality.

3.8.4 Autonomy

Autonomy "refers to competent people's right to freely and voluntarily make informed decisions pertaining to their lives" (Allan, 2016, p.120). For this reason, participants must play an active and not a passive role throughout the research process (Allan, 2016). In this study, participants personally completed letters of informed consent to support autonomy. The researcher also did not involve participants who were not able to give consent.

(1) Informed consent

According to Annexure 12 of Form 223 of the Health Professions Act (1974), the participants must sign forms pertaining to informed and voluntary consent which contain all the information regarding the nature of the research, stating that all information will be treated strictly confidential and that participants have the option to withdraw from the research at any stage without detrimental consequences before participating in the research. When participants do not understand English well enough to understand the conditions for research, the researcher must provide them with information in their home language or must make use of a qualified translator for this purpose (Health Professions Act, 1974).

(2) Voluntary participation and no deception

Participants were granted adequate time and space to make choices free of influence from the researcher based on sufficient and truthful information provided by the researcher regarding the purpose and the conduct of research (Allan, 2016). Furthermore, the researcher did not pressure or rely on deception as a means of convincing participants to partake in the research (Allan, 2016; Health Professions Act, 1974). Deception includes withholding essential information from participants as to the nature and possible effects of the research on the participants (King, 2010).

(3) Justice

The principle of justice entails that any form of decision making on the part of the researcher should be made honestly and impartially to ensure equality during research (Allan, 2016). For example, the researcher avoided multiple roles and she did not select participants with whom she shared a personal relationship outside the research context (Health Professions Act, 1974) as it increased the risk of infringing on the above principle.

(4) Veracity

The researcher shielded against misleading herself and others and attempted to be as precise, honest and objective in all communication as possible (Allan, 2016). The researcher was aware of not deliberately misleading participants by clarifying whether they understood the messages communicated correctly (Allan, 2016).

3.8.5 Non-maleficence

Before commencing the research, the researcher had to evaluate the possible risk of harm befalling the participants (King, 2010). The researcher attempted to minimise any risks (foreseeable and unforeseeable) which might have been potentially harmful to participants and took the necessary steps to prevent any harm befalling the participants owing to their involvement (Allan, 2016; Health Professions Act, 1974). In this specific research endeavour, it entailed safeguarding participants by structuring questions and interactions in such a way that long-lasting suffering, humiliation and reputational damage were avoided (King, 2010). The researcher used debriefing by informing participants of where and when findings would be reported (King, 2010) and` gave participants access to a counsellor or psychologist if they needed to express or deal with any trauma that was elicited owing to interviews conducted during the research (Health Professions Act, 1974).

3.8.6 Fidelity

Fidelity entailed the researcher being loyal and trustworthy, as the participants shared personal information which might lead to vulnerability (Allan, 2016). Furthermore, the researcher did not misuse the trust of participants as a means of gathering information which the participant might not have been comfortable sharing (Allan, 2016), or breaking confidentiality or using the results for purposes not agreed upon at the beginning of the data collection.

3.8.7 Responsibility

It is the responsibility of the researcher to conduct research in a legal and socially responsible manner. The communication of research outcomes must be done in such a manner that it reduces the potential to misuse the results. The researcher will also not publish any findings that could be damaging to the group to which the participants belong (Allan, 2016).

3.9. SUMMARY

Chapter Three consisted of an in-depth discussion of the paradigmatic perspectives underlying the study, research design as well as research methods and data collection. Furthermore, an exposition of data documentation and analysis, quality criteria and ethical considerations were also included. Chapter Four comprises of a discussion of the research process as well as the results and findings. Results and findings are also amalgamated with the theoretical framework of the study.

CHAPTER 4

RESULTS AND FINDINGS

4.1 INTRODUCTION

This chapter provides an overview of the research process, an exposition of the different themes and subthemes that were derived from data collection and analysis as well as collective findings after which results, and findings will be merged with the theoretical framework of the study.

4.2 OVERVIEW OF THE RESEARCH PROCESS

Table 4.1 below represents an overview of the research process.

Table 4.1: Overview of the research process

Research process	Description
Ethical clearance	Ethical clearance was obtained from the Ethics Committee of the Faculty of Education, University of Pretoria by means of the submission of documents regarding the proposed research. (See ethical certificate bound into the dissertation at the front of the dissertation.)
Obtaining consent from the research site	The research site was conveniently sampled, and a request was written in which permission was sought to conduct research in that school. (Refer to Appendix A.)
Obtaining informed consent	After the selection of prospective participants (in this case parents of children diagnosed with ASD from the Sepedi group) through purposive sampling, letters containing the purpose of the proposed study as well as informed consent were sent to prospective participants. Completed informed consent forms were received from three prospective participants.

Research process	Description
Focus group discussion	After informed consent was obtained, data were collected during a focus group discussion, which two of the three participants attended.
Semi-structured interview 1	Data were collected at the same site from one of the participants of the focus group in the form of a one-on-one semi-structured interview, during which an in-depth discussion occurred.
Semi-structured interview 2	Another semi-structured interview was conducted at another campus belonging to the same school with the participant who did not attend the focus group discussion.
Data analysis	All the collected data were transcribed, and inductive thematic analysis occurred using ATLAS.TI software. During data analysis, codes were created for similar quotes. Initially, the researcher made use of sub-subthemes which collapsed into the subthemes and final themes. These subthemes and final themes were used to report the findings of the study after member checking.
Quality control	Quality control occurred by means of member checking. The participants were willing to do member checking but were not available for individual interviews; therefore, transcribed discussions from the focus group and the individual semi-structured interviews as well as the proposed themes and subthemes were sent by email in a password-protected format to the focus group participants for their perusal and approval. The second individual semi-structured interview participant received a hard copy of the transcription as well as the proposed themes and subthemes for approval. Participant two in the focus group sent back comments and additions on the transcriptions via email. Participants were then contacted telephonically to discuss changes and additions to the transcripts and themes. During the telephonic discussion, focus group participant one provided

Research process	Description
	feedback, which was recorded with consent, transcribed and included in this chapter.
Reporting of results	Chapter Four contains a discussion of the results and findings and integrates these results with the theoretical framework.

4.3 RESEARCH RESULTS

4.3.1 Introduction

Results are reported below as an in-depth discussion of themes and subthemes that were derived from data collected and analysed. It should be noted that observations and field notes did not provide additional data. Table 4.2 contains the codes used by the researcher to refer to the different participants and the data collected from each.

Table 4.2: Codes allocated to participants

Participant	Focus group transcription	Individual interview transcription	Member Checking
Participant 1	FG1		MC1
Participant 2	FG2	I1	MC2
Participant 3		I2	MC3

4.3.2 Background information of participants

The focus group participant one (FG1) is a 41-year-old divorced female who is an environmentalist. Her child with ASD is a six-year-old boy. Focus group participant two (FG2) is a 38-year-old married male who lives with his wife and two children. He is employed by the government in a sector that often requires travelling. His child with ASD is a six-year-old boy. Both these participants make use of private transport and reside in urban areas. FG2 was also participant one (I1) in the semi-structured interviews that were conducted.

Semi-structured interview participant two (I2) is a 30-year-old female and single mother who resides with her biological parents in an urban area. Her child with ASD is an eight-year-old boy. Her child's father contributes to his care financially, but he does not stay in the same household and seems to have a limited relationship with his son. She makes use of public transport, which made it challenging for her to attend the interview as she experienced delays.

4.3.3 Themes and subthemes which emerged from the data

Figure 4.1 contains the themes and subthemes which emerged from the data. The colour of the quotes from the transcriptions provided as evidence for a theme consistently refer to the theme of the same colour, in other words, a quote in green refers to Theme 1, red to Theme 2, blue to Theme 3, orange to Theme 4 and pink to Theme 5.

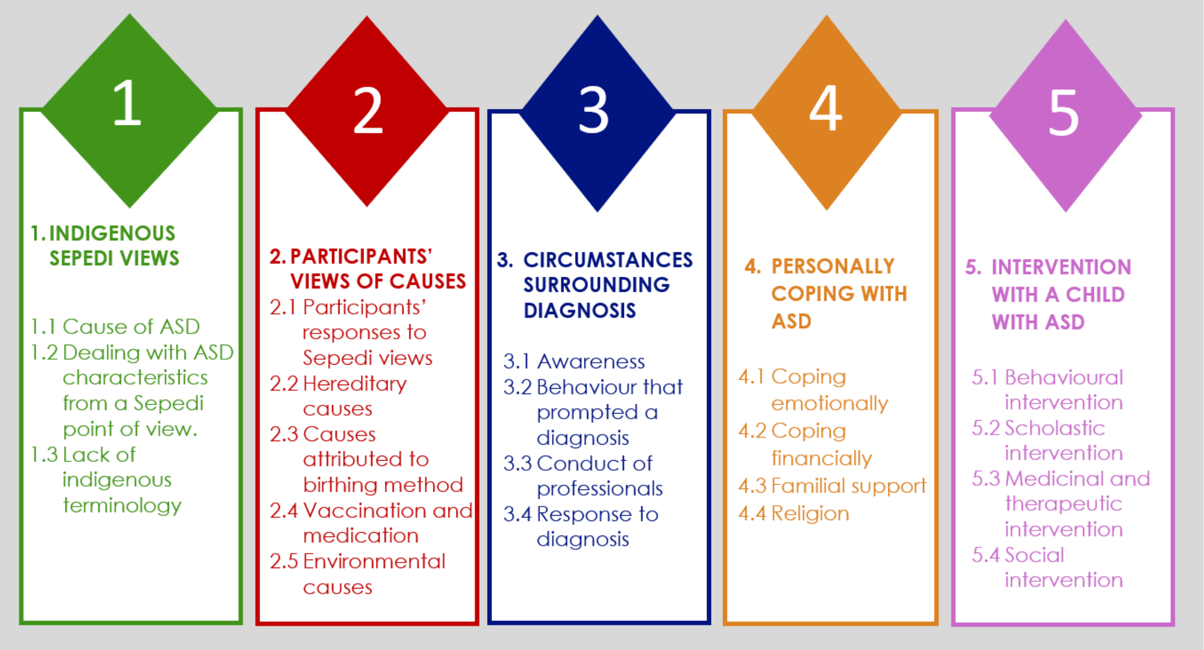

Figure 4.1: Themes and subthemes for the study

Theme 1: Indigenous Sepedi[5] views

The first theme that was derived from data analysis was indigenous Sepedi views. Even though the participants themselves did not hold these views, they told the researcher that family and/or community members expressed these views regarding their children that have been diagnosed with ASD. The subthemes discussed here are views of the causes of ASD (subtheme 1.1), dealing with ASD characteristics (subtheme 1.2) and the lack of indigenous terminology (subtheme 1.3) for ASD amongst the Sepedi people. Refer to Table 1 in Appendix J for the inclusion and exclusion criteria for Theme 1.

Subtheme 1.1 Causes of ASD

During the focus group discussion, it emerged that Sepedi community members expressed different viewpoints when they noticed characteristics of ASD. One of these views pertains to the burial of the umbilical cord of the child after birth. "[I]n Pedi we believe that where ever you are born your umbilical cord is" (Appendix D, FG2, p.126). The participant recalled others saying of South African emigrants in other countries, "The umbilical cord is flushed there and . . . in Pedi you don't flush it. . . You bury it . . . So . . . wherever you bury it is where you belong" (Appendix D, FG2, p.126).

For this reason, participants were asked questions such as, "Did you bring the umbilical cord back?" (Appendix D, FG1, p.126) and, "What did you do when you come back? Did you do some ceremonial [sic] to indicate that you are coming back?" (Appendix D, FG2, p.126). These Sepedi people sought causes of ASD in the umbilical cord which stayed in a foreign country, implying that children have ASD because they do not belong in SA but in foreign countries, based on the location of the umbilical cord.

Another cause of ASD was linked to the nickname used by the parents. Upon being informed of the diagnosis, family members "were starting [sic] to blame the name" (Appendix D, FG2, p.111) and said "maybe he doesn't want this name" (Appendix D, FG2, p.111). The reason it was linked to the cause of ASD was

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[5] The term Sepedi was used for the current study. However, both Sepedi and African can be used in some instances, as some African and Sepedi views might correspond. Please note that Sepedi and African views are not regarded as synonymous.

> because you know in our culture you are named after someone. . .he is supposed to be taking the name of my brother but you don't call him that one, we will call him [nickname] and my brother is not [nickname]. (Appendix D, FG2, p.111)

Family members suggested that the reason that child was not responding to his name was that the parents used a nickname and "[t]he ancestors don't know it" (Appendix D, FG1, p.111).

People with whom participants have contact "believe like no, we are too westernised" (Appendix F, I1, p.149) and were told "you started to do away with our culture, norms and values" (Appendix D, FG2, p.123). One participant's child was born in Europe, and he was told that "because this child is born in a foreign country . . . when you arrive . . . immediately go and see whoever traditional healer" (Appendix D, FG2, p.123). One participant stated that "from church they told me that it's my biological father and his sisters aren't [sic] getting along, so it's those things that are causing, affecting my son now" (Appendix F, I2, p.155).

Witchcraft was also attributed as a possible cause of ASD. "Maybe you were bewitched when you were young" (Appendix D, FG2, p.130). Furthermore, the participants recalled what members of the community would say about the nature of witchcraft. One participant stated that it is the "African way. They always blame that something witchcraft is there" (Appendix D, FG2, p.130).

A suggestion regarding a possible physiological cause of challenges with speech was that "there's something underneath the tongue. It can be bigger and make the tongue heavy" (Appendix D, FG2, p.131).

Subtheme 1.2 Dealing with ASD characteristics from a Sepedi point of view

Certain suggestions were made about interventions to deal with ASD. Regarding the umbilical cord of the child, participants in the focus group were offered the following solution by community members: "No, you need to go back" (Appendix D, FG2, p.126) "and take it . . .[umbilical cord – own insertion][e]ven if it's just collecting the soil from there" (Appendix D, FG1, p.126).

Regarding the nickname of the child and him not responding to the name, family members told the participant that "we must not call him [nickname] then, we must insist in calling him [child's first name]" (Appendix D, FG2, p.111) as an approach to get the child to respond to his name.
From a spiritual point of view, a participant spoke to a man who said that the pastor "is doing miracles . . . Two days is enough, take this child to them" (Appendix D, FG2, p.123) as a means of dealing with ASD.

Making a surgical incision was also suggested to improve speech. "[I]n old days when the child was not speaking, these old people knew that they open the tongue . . . Normally underneath the tongue . . . They cut something, maybe the tongue something is too close to the teeth" (Appendix D, FG2, pp.130,131). The person probably referred to the medical procedures frenectomy or frenuloplasty that is sometimes performed on children when the lingual frenulum under the tongue is cut to promote tongue length and consequently pronunciation (Kishore, Srivastava, & Mahendra, 2014).

Subtheme 1.3 Lack of indigenous terminology

During the focus group interview participants stated that "in our culture, I can assure you, autism, I can assure you, it's just an English term, it doesn't have a name . . . nobody knows about it" (Appendix D, FG2, p.116). FG2 recalled an occasion when they visited family in Limpopo province: "you go to home and you say that they said the child is diagnosed autistic and then they don't know what is that" (Appendix D, FG2, p.110). When the topic came up again later, the same participant stated that "not only in the Pedi culture, across Africa, this thing of autism" (Appendix D, FG2 p.132) to which another participant responded, "It's unknown" (Appendix D, FG1, p.132).

Theme 2: Participants' views of causes

Another theme that was evident from data analysis was the own views of the participants regarding the causes of ASD. In this section, the subthemes of participants' responses to Sepedi views (subtheme 2.1), hereditary causes (subtheme 2.2), causes attributed to birthing method (subtheme 2.3), vaccination and medication (subtheme 2.4) and environmental causes (subtheme 2.5) are discussed. Refer to Table 2 in Appendix J for the inclusion and exclusion criteria for Theme 2.

Subtheme 2.1 Participants' responses to Sepedi views

Participants heard many indigenous views and recommendations from family and community members. One of the participants responded to these views by saying "there are so many beliefs. It's just that it depends on you" (Appendix D, FG2, p.125). When people made recommendations (refer to Theme 1), he said that "I don't argue. I just said, 'Okay I'll see,' but know in my heart that no" (Appendix D, FG2, p.123), which indicates that he is aware that such recommendations will not be useful. His response to family members suggesting that he calls his son by another name was, "I refused" (Appendix D, FG2, p.111).

Furthermore, FG2's response to the possibility of witchcraft being a contributing factor was, "I don't deny that there's witchcraft . . . but not to this child . . . myself I'm always crushing it, that, no, there's no witchcraft here" (Appendix D, FG2, p.130). FG1's views regarding witchcraft are that "I'm one person who says you can't bewitch me, I mean, unless if I want" (Appendix D, FG1, p.129). When I2 spoke about her stepfather believing in the ancestors, she said that "we need to accept it [ASD diagnosis – own insertion], not base it only on the ancestors" (Appendix F, I2, p.155).

Subtheme 2.2 Hereditary causes

Two out of the three participants held the belief that "I still feel it is hereditary" (Appendix D, FG1, p.107). These participants also deliberated their family history, and FG1 stated that "in terms of slowness, I see this uncle and I see that and this kind of things" (Appendix D, FG1, p.107). FG2 stated that there are "some in our family that have delayed speech" (Appendix D, FG2, p.116); for example, "one of my cousins as well. He delayed big time" (Appendix D, FG2, p.116).

I2 said, "[W]e asked if it was genetic or what, so they [medical practitioner – own insertion] told us that it's not genetic" (Appendix F, I2, p.156), which was different from the views of the other participants.

Subtheme 2.3 Causes attributed to birthing method

The same participants who believed that ASD is hereditary also stated that they believe the method of birth, more specifically a caesarean, played a role in their children being diagnosed with ASD. "I still believe even today that this thing of caesarean . . . I still blame it. . . " (Appendix F, I1, p.149). FG1 stated that during birth, she experienced complications. "They took forever to take the child out . . . When the child was eventually removed, the child was not crying . . . they had to put him in I.C.U." (Appendix D, FG1, p.114).

FG2 shared his own version of why he is of the opinion that a caesarean might be linked to the cause of ASD:

> I believe like if the woman goes into labour, it means that the child is responding somehow inside the womb, he tells because it's the universe, now it's time, I want to go out. I've been in this womb for this period and now it's my time . . . normally the person has grown to maturity, we can take him out. So the person never had that in memory, he was still enjoying the womb and you disturb that person's memory. So I do believe that the time that the woman goes into labour . . . that's where you can do caesarean, not the planned one . . . I do believe that the person that was inside the womb was enjoying and then you tampered with this . . . So I felt like the person was angry since the beginning because you tampered with this. (Appendix D, FG2, pp.150,151)

He acknowledged that his view was "subjective" (Appendix D, FG2, p.150) and that he still did not have certainty as to the exact cause of ASD.

Subtheme 2.4 Vaccination and medication

When asked what participants thought the causes of ASD might be, a participant responded, "I was blaming medications" (Appendix D, FG2, p.112). While being in Europe, "the paediatricians they always recommend that now it is time for this vaccine and . . . they had so many vaccinations there" (Appendix D, FG2, p.112). The participant recalled that "they start very early. I was blaming those medication as well." (Appendix D, FG2, p.112).

Subtheme 2.5 Environmental causes

Another possible cause the participants discussed was the environment that children with ASD were exposed to at an early age. FG2, whose child was born overseas, said that:

> Europe is very reserved, the kids don't play with each other . . . maybe the child was never exposed, maybe if he was born here, even if he is having this thing, born with it, it would have maybe disappeared at an early age, because it would have been within the people. (Appendix D, FG2, p.112)

Theme 3: Circumstances surrounding diagnosis

Although this theme does not directly answer any of the research questions, it is nevertheless included as the theme strongly featured in the data analysis and can be used to make recommendations regarding Sepedi cultural views of ASD. Circumstances surrounding the diagnosis of ASD in their children were also elaborated on by participants. The subthemes discussed in this theme include awareness (subtheme 3.1), behaviour that prompted a diagnosis (subtheme 3.2), conduct of professionals (subtheme 3.3) and response to diagnosis (subtheme 3.4). Refer to Table 3 in Appendix J for the inclusion and exclusion criteria for Theme 3.

Subtheme 3.1 Awareness

As data collection occurred, it became apparent that participants were unaware of the existence of ASD before it was diagnosed in their children. "I did not know what it was, but I was aware something is wrong, but I couldn't say what it is" (Appendix D, FG1, p.106). "I didn't know what was wrong with him and he also couldn't tell us what is wrong with him" (Appendix F, I2, p. 160). "[T]his thing is new to us" (Appendix F,I2, p.49). "I wasn't even aware of it until I saw the signs in my son" (Appendix F, I2, p.49). "I didn't even know what is this" (Appendix D, FG2, p.110). FG1 clarified her initial thoughts as to why her child was displaying characteristics of ASD by articulating that "I just thought it is delayed development" (Appendix D, FG1, p.106).

Subtheme 3.2 Behaviour that prompted a diagnosis

The ages at which participants became suspicious about the behaviour their children displayed varied. FG2 indicated that he realised something was amiss shortly after birth. He stated that this was the case as his son "seems like he is crying, like someone who is angry" (Appendix D, FG2, p.108). I2 started noticing characteristics of ASD at the age of three, and FG1 when her child was five years old.

Behaviour that prompted suspicion and a subsequent diagnosis for all the participants included anti-social behaviour or limited social skills as well as poorly developed and/or delayed speech. Other characteristics included I2 who recalled that her son "couldn't make eye contact with us and play on the grass or touch things" (Appendix F, I2, p.153). Her son had "meltdowns . . . [and] used to bang things, throw . . . everything" (Appendix F, I2, p.160). FG2 also recalled his son being "uncontrollable at an early age" (Appendix D, FG2, p.116).

FG2 stated that they experienced behaviour such as "when you call him, he doesn't respond" (Appendix D, FG2, p.109) and that his son had a fear of doctors. I2 concurred. Both these participants also articulated the existence of these behaviours across a spectrum but seemed somewhat uncertain as to where exactly their children were positioned on the spectrum.

Subtheme 3.3 Conduct of professionals

Professional conduct surrounding the diagnosis and the extent of explanations as to what ASD entails also emerged during data analysis. When asked if the professionals who diagnosed ASD explained what it was, participants responded, "Not really. The paediatrician said Google about it . . . he didn't explain too much about this autism" (Appendix F, I1, p.139). The neurologist "didn't sit long with us and explained" . . . I Googled it" (Appendix F, I2, pp. 153,154,). Some professionals briefly mentioned to participants that ASD is a disorder in which characteristics span across a spectrum.

FG1 expressed her frustration with teachers as they told her that "sometimes we feel we cannot tell parents because we don't know how they will react" (Appendix D, FG1, pp.106,107), to which she responded that "they shouldn't be worried about how I react.

They should give me information . . . They cannot hide information based on how will a person react" (Appendix D, FG1, p.107).

Subtheme 3.4 Response to diagnosis

Reflecting on his response to his child's diagnosis, I1 recalled conflict between him and his wife, "in the beginning, when we were trying to understand this thing . . . because they say it's hereditary . . . this quarrel that . . . it comes from your family, no, your family" (Appendix F, I1, p.149). I2 differed: "I'm not going to blame anyone, I'm just going to try and get the best help for him" (Appendix F, I2, p.157).

During the focus group discussion, the two participants recalled feelings of disappointment. "[W]hen the child is born, there is that excitement" (Appendix D, FG2, p.128) and "you have expectations" (Appendix D, FG1, p.128) "and later on you hear about this things, more disappointing, more disappointing" (Appendix D, FG2, p.128).

From a religious point of view, I1 stressed that he asked, "[W]hy did God punish us like this? (Appendix F, I1, p.148). "I'm praying. I go to church. I know I'm not perfect, but why, man?" (Appendix F, I1, p.142). He articulated that he had "many, many, many questions. . . [W]hat did we do wrong?" (Appendix D, FG2, p.110). He also recalled "reading the Bible . . . Is it because of I'm too evil? Because there is a scripture that says I will punish kids because of the wrongdoing [of the parents – own insertion]" (Appendix F, I1, p.148).

FG1 indicated that her family seemed to respond to ASD with denial as:

> they don't say anything. . . I think it is information, it is not available because even with my brothers . . . when you are in a Facebook page of autism and you post something, they said to us: 'But why are you posting about autism?' Then you tell them that, okay, the child was diagnosed and they be like: 'When?' (Appendix D, FG1, p.107)

Theme 4: Personally coping with ASD

Although this theme also does not directly answer any of the research questions, it is nevertheless included as the theme strongly featured in the data analysis and can be used to make recommendations to Sepedi parents or caregivers regarding different coping behaviours. The coping behaviours are discussed under the subthemes coping emotionally (subtheme 4.1), coping financially (subtheme 4.2), familial support (subtheme 4.3) and religion (subtheme 4.4). Refer to Table 4 in Appendix J for the inclusion and exclusion criteria for Theme 4.

Subtheme 4.1 Coping emotionally

When asked how the participants dealt with ASD, different responses regarding emotional coping surfaced. Acceptance was one of the facets mentioned by participants. Whereas I1 initially placed blame and attributed the cause of ASD to a form of punishment, he concluded that "there's not punishment there . . . we have to appreciate this is no one's fault" (Appendix F, I1, p.149). When FG2 was asked if he found answers to the vast amount of questions he had, he responded, "No, you just make peace with it" (Appendix D, FG2, p.117). During the focus group discussion, FG1 concurred and also stated that "[y]ou just accept it" (Appendix D, FG1, p.117). Even though FG2 stated that he made peace with the diagnosis, he acknowledged that "even though you make peace with it, somehow, somewhere it's very stressful" (Appendix D, FG2, p.128). A degree of realism was also observed when I2 stated that "he's not going to outgrow it . . .I've accepted it, but I don't know how to deal with it" (Appendix F, I2, pp.163, 159).

It seems that having hope is another way to cope emotionally. I1 shared that "I see a lot of potential in him" (Appendix F, I1, p.143). He elaborated by saying that this potential is what prompts him to "keep on comparing, comparing . . ." (Appendix F, I1, p.143). Furthermore, he believes that "it can [sic] be a very, very big achievement if he can develop the speech" (Appendix F, I1, p.143). FG1 expressed hope that "he will be in a private school for primary school and then he will pick up" (Appendix D, FG1, p.107) as he believed there were people who have undiagnosed ASD who still went to university despite the disorder. However, not all participants relied on hope to cope emotionally. When asked if she has thought about her son's future, I2 stated that "I haven't, because I don't want to stress myself" (Appendix F, I2, p.162).

Having answers ready for questions or explanations for behaviour seem to be another way in which parents cope. A reluctance to speak to others about their children having been diagnosed with ASD was also evident during discussions. "[I]t's very difficult to explain to someone what kind of disease is this" (Appendix F, I1, p.139). Owing to unawareness about ASD, “people is like what is that?” (Appendix D, FG2, p.125). When participants made decisions to speak to others about ASD, they would explain ASD in a simplified and shortened manner, such as “he can’t speak” (Appendix F, I1, p.140), or “having a brain disorder” (Appendix D, FG2, p.110) and/or “he’s a slow learner” (Appendix D, FG2, p.127). When asked about her child not playing with other children, I2 would respond by saying, “[I]t's a bit difficult for him to play with other kids. He has to adjust first, then he'll go and play.” (Appendix F, I2, p. 159).

Subtheme 4.2 Coping financially

Financial coping centred around own effort, relying on the biological father and relying on familial financial support. To provide financially for their children diagnosed with ASD, especially for schooling, I1 stated that “[w]e must work hard. We must do this for our kids and attend this nice school” (Appendix F, I1, p.148).

Financial support from family and the child’s father was also mentioned. “[H]is father was there financially” (Appendix F, I2, p.154) “paying school fees and also putting him on medical aid” (Appendix F, I2, p.163). The father’s family was also said to “always be there for us no matter . . . how expensive it is” (Appendix F, I2, p.155).

Subtheme 4.3 Familial support

Another method of coping with ASD was in the form of familial support. Upon being informed of a diagnosis, I2’s parents “told me . . . that we're gonna try and get help” (Appendix F, I2, p.155). I2 further stated that family on the father’s side “were all also very supportive because . . . they would go with me to the meetings, speech therapies. Whenever they're free, even if, like, finding schools they'll go with me” (Appendix F, I2, p.163).

Regarding support between a husband and his wife, I1 responded that “it makes us, our relationship very strong” (Appendix F, I1, p.149). He also stated that “in our culture in old days, this kind of things, it will be that something that will make us to divorce, but instead of that it makes us to be strong and even bond” (Appendix F, I1, p.149). Furthermore, he disclosed that his wife supported him in his decision not to attribute ASD to witchcraft.

Subtheme 4.4 Religion

Religion and prayer were personal coping mechanisms for all the participants. Individual prayer and shared prayers provided support. As a response to her mother-in-law stating that her child will never amount to anything, FG1 stated that “I will just pray and say: ‘God, if you are my God, you are going to prove to her. Let them see the results’” (Appendix D, FG1, p.129). She also stated that “I just go to church . . . I do go and I say my son is autistic . . . and they pray” (Appendix D, FG1, p.124). FG2 verbalised that “if we choose to pray together God, one day, He will answer . . . if it is meant to be like this, it should be . . .” (Appendix D, FG2, p.123). I2 cautioned that “we can try the church route, but we also need to take him to the doctor because they're also the ones that's going to explain to us what's going on. We can't only rely on church” (Appendix F, I2, p.161).

Theme 5: Intervention with a child with ASD

Strategies and methods of coping with their children with ASD pertaining to their behaviour (subtheme 5.1), school (subtheme 5.2), therapies (subtheme 5.3) and society (subtheme 5.4) arose and are subsequently discussed. Refer to Table 5 in Appendix J for the inclusion and exclusion criteria for Theme 5.

Subtheme 5.1 Behavioural intervention

Participants have established a few practical ways of dealing with their children’s behaviour. Practical ways included using a stroller to prevent the child from running around in shopping malls. I1 stated that “we had the stroller if we wanted to contain him” (Appendix F, I1, p.142). They also learnt to adjust to their children’s behaviour. “[I]f you see he doesn’t want the company of you, allow him to be alone” (Appendix F, I1, p.146). A sleeping tip from school was that “they’ve noticed it that to make him sleep, you have to pretend as if you are also sleeping” (Appendix D, FG2, p.133).

I2 said that the school taught her that “whenever he's high, we shouldn't also be high” (Appendix F, I2, p.54). Additionally, she also made changes in their daily routines and habits and the type of food he ate (Appendix F, I2, p.161). She also wrapped him in a blanket as a soothing technique (Appendix F, I2, p.158), and she has requested doctors to examine him in the car as he refused to go into the doctor's office (Appendix F, I2, p.158).

FG1 requested the school to keep her child busy with other activities during nap time, as he would be awake until the early hours of the morning if he slept during the day (Appendix D, FG1, p.133). She also used chamomile oil at bedtime to assist with sleeping (Appendix D, FG1, p.134).

Subtheme 5.2 Scholastic intervention

After having been diagnosed, all participants were advised to place their child in "a special school." (Appendix D, FG1, p.106). Experiences of school were generally supportive. The parents were uncertain as to their role in supporting their children at school, but that the school ultimately proved to be "very helpful" (Appendix F, I1, p. 145). The school apparently helped with reading, writing and behaviour, seen in statements such as "[h]e can read he can write" (Appendix F, I2, p.162), "he is progressing very well" (Appendix D, FG2, p.132), and that those at the school "have a way of dealing with him, especially when it comes to his behaviour." (Appendix F, I2, p. 160).

During member checking, some school experiences that were less helpful were offered. MC1 expressed her frustration with regards to schooling. She stated that having placed her child in a private school, "You have an expectation that the teachers are at a higher level of understanding how to deal with autistic children, but yet you get queries every day" (Appendix H, MC1, p.170). She experienced frustration with the expectations that she felt the teachers have of her.

Despite the school in general being a catalyst for positive change, two of the three participants stated that they still experienced stubbornness with homework as I2 mentioned "I'm going to call your teacher and tell him that you don't want to do your homework" (Appendix F, I2, p.162).

Subtheme 5.3 Medicinal and therapeutic intervention

After a diagnosis was made, for some children, medication was prescribed as "it was said it will calm him down so that he can concentrate" (Appendix D, FG2, p.132).

However, some participants discontinued medication as they were of the opinion that "there's no improvement" (Appendix D, FG1, p.132). These participants also had concerns about the side effects. For instance, FG2 said that others "were saying they [side effects – own insertion] are bad and that they [side effects – own insertion] are not reversible. Then we became to be cautious about it" (Appendix D, FG2, p.132). FG2 also stated that his child was "too sleepy"[6] and "without the medicine he's just normal" (Appendix D, FG2, p.132). One of the other participants was still using speech and occupational therapy, while another had discontinued speech therapy due to a lack of improvement.

Subtheme 5.4 Social intervention

Participants were found not to practice proactive social intervention in trying to teach children socially acceptable behaviour or teaching society to behave inclusively and with understanding. Instead, they employed reactive social intervention in dealing with criticism from members of society.

I2 stated that she coped socially by only going to places such as the mall with family or friends to support her with her child. "Going out for us was so stressful, because he doesn't like where it's overcrowded . . . he'll become hysterical and he'll cry" (Appendix F, I2, p.161). FG1 also stated that her child "just does not want to be around people" (Appendix D, FG1, p.118). I2 expressed her frustration with society being judgemental and asking her questions such as, "Why is your baby always here? Why isn't he playing with other kids? And why is your baby not talking? Why is he eating specific food?" (Appendix F, I2, p.159). She would then have to explain the reason for these behaviours, which made coping with ASD in a social context challenging.

FG2 also stated that his child had been labelled as spoilt and that members of their church congregation complained when his son did not comply with the cultural convention of children giving up their seats for elders. He coped with a similar situation by simply ignoring it. "Because you are not going to explain . . . if you are say this child is autistic, people is like what is that?" (Appendix D, FG2, p.125). His experiences were echoed by FG1 who stated that "my issue is the society, because people don't

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[6] Sleepiness was the only side-effect reported by the participants.

understand . . . and people just feel the child is spoiled" (Appendix D, FG1, p.124). These judgements mostly occurred during social or religious events such as attending church and/or weddings when the children did not adhere to social etiquette or the expectations of others.

Such judgements prompted FG1 to cope with her child in social situations by isolating herself. "[Y]ou isolate yourself . . . You will go there and sit there in that corner alone . . . the furthest corner" (Appendix D, FG1, p.118). She also avoided social gatherings and was of the opinion that "those who want to be angry they can be angry, but I am not going to their functions" (Appendix D, FG1, p.118). She expressed her frustration by stating, "Sometimes you just feel like people can just observe and keep quiet" (Appendix D, FG1, p.129).

Now that the themes and subthemes have been addressed, the collective findings will be discussed, also as they relate to findings in the literature.

4.4 COLLECTIVE FINDINGS AND DISCUSSION

4.4.1 Indigenous Sepedi views

Data analysis revealed that parents whose children had been diagnosed with ASD had been approached by family, friends or community members who maintain indigenous Sepedi views of the cause and intervention of ASD.

Views about the child's umbilical cord being "flushed" and not being buried as a possible cause of ASD is a view that has not been encountered in literature (refer to 5.7 for recommendations). However, Sepedi cultural views that the child's name is both a cause of, and a method for dealing with, ASD, was also found in the literature review that Taiwanese parents were known to modify their children's names as a method of intervention (Milau et al., 2018).

Results furthermore revealed that community members suggested that parents visited pastors who claimed to have the ability to perform miracles and heal illnesses. This finding is in line with research conducted by Papadopulous (2016), who discovered that Saudi Arabian parents made use of treatments performed by religious healers. These non-western views are further confirmed by Grinker et al. (2018) who found similar beliefs, namely that community members can heal others, particularly children, in a South African context.

With regards to Sepedi community members suggesting a procedure which involved cutting the tongue of a child who experienced speech difficulties Guler et al. (2018) made reference to the belief that the child's vocal cords were entrapped by spirits and that people treated these speech limitations by making incisions at the throat. Participants in the current study did not mention spirits and the entrapment of the voice but mentioned only a surgical incision.

The Sepedi participants mentioned that some Sepedi community members articulated to them that they did not follow, disregarded or discarded traditional practices and accused the parents of being too westernised, which led to their children's ASD. It was especially the case for one of the participants whose child was born in Europe. This result agrees with research conducted by Grinker et al. (2012), Mathye and Eksteen (2016) and Sage and Jegatheesan (2010) who posited that non-western communities believed that ASD was a manifestation of parents not following tradition.

Members of the Sepedi community who conveyed that the children's ASD diagnoses were the result of the parents being cursed when they were children is in line with the research of Franz et al. (2017), Guler et al. (2018), Milau et al. (2018), Papadopulous (2016) and Riccio (2011). They found that witchcraft, evil spirits and curses were viewed as the causes of ASD by some parents whose children were diagnosed with ASD in non-western contexts.

This study's finding of a lack of indigenous terminology in the Sepedi language and the unawareness about ASD in the Sepedi culture is also consistent with findings in Ghana that research participants were unfamiliar with the term 'autism' (Anthony, 2009). This lack of terminology further complicates endeavours to make people from a Sepedi culture, and probably other indigenous cultures too, more aware of ASD as the absence of known words makes explanations more difficult.

4.4.2 Participants’ views of causes

Participants’ responses to indigenous views regarding the cause of ASD, especially witchcraft, echoed with that of participants in a study conducted by Guler et al. (2018). In the current study and in Guler’s research, participants dismissed claims that witchcraft caused ASD. Participants chose to make sense of ASD and its causes in their own way by making use of their own frame of reference. It is interesting that it seems that parents with children with ASD do not attribute ASD to witchcraft but that people without children with ASD attribute ASD to witchcraft.

Findings surrounding participants’ views regarding the cause of ASD was mostly in line with the findings of current literature based on both western and non-western views. Causal factors held by participants such as vaccination, circumstances surrounding birth and hereditary factors, were also regarded as causal factors of ASD in the findings of Al Anbar (2010), Dale (2006), Dardenness (2011), Franz et al. (2017), Harrington (2006), Mercer et al. (2006), Milau et al. (2018) and Selkirk (2009). Some of the participants in the current study linked caesareans to their children’s ASD diagnoses. Franz (2017), Milau (2018) and Mathye (2016) similarly found that parents attributed the cause of ASD to birth complications.

One participant shared his interpretation of having to wait for the universe to determine the timing of the child’s birth and not interfering with this timing by making use of planned caesareans. Planned caesareans, according to him, precipitate the birth of a child who is then unhappy because it is born before it is ready to be born. A similar explanation of the cause of ASD was not found in literature, but this explanation might be linked to the participant’s views regarding fate playing an important role in one’s life and how the disturbance of this fate via a caesarean might upset the natural order (Appendix D, FG2, pp.150,151).

In the current study, one participant chose not to be preoccupied with the cause of ASD and instead decided to focus her efforts on providing the best care for her child. This finding is partially in line with findings conveyed by Dale et al. (2006) who stated that some parents chose not to become too engrossed with the possible causes of ASD as they focused on the future of their children.

According to Law (2000) and Riccio (2011), some parents remained unaware or exhibited a limited understanding as to causal factors. In the current study, all participants had views as to what could have possibly caused a diagnosis of ASD. However, despite maintaining views regarding possible causes for ASD, participants were unsure about the exact cause/s.

Before conducting the study, literature regarding parental awareness of the existence of ASD was not investigated as it was not initially covered in the purpose of the study. However, during data collection, it became evident that not only parents but the Sepedi community in general have low levels of awareness of ASD, as well as its characteristics. Participants simply recalled learners who were labelled as slow or who repeated a grade a few times as a frame of reference for previous encounters with difference. This unawareness is most likely linked to the lack of indigenous terminology, as discussed in Theme 1. As the incidence of ASD has risen drastically recently, it is also a possibility that the Sepedi communities actually had limited, if any, exposure to ASD previously, and that the necessity for ASD vocabulary was therefore also limited.

4.4.3 Circumstances surrounding a diagnosis

With regards to behaviour that prompted a diagnosis, the most common behaviours which motivated participants to seek answers included the child being anti-social or having limited social skills as well as poorly developed and/or delayed speech. These characteristics are in line with the findings of Dardenness et al. (2011) and Milau et al. (2018), who referred to language difficulties such as delayed speech and non-verbal communication as being initial symptoms of ASD. Dardenness et al. (2011) also reported that some children did not respond to their names, which was one of the characteristics that was also reported in the current study. Participants also reported speech difficulties, which was consistent with the findings of Guler et al. (2018). The initial characteristic of avoiding eye contact was also substantiated by research conducted by Anthony (2009), in which parents of children diagnosed with ASD in Ghana disclosed the same characteristic. At first, the participants in this study seemed to have been particularly troubled regarding initial characteristics of a social nature, such as their children not wanting to play with other children as well as limited ability to communicate with others. This finding is in line with a study by Dillenburger et al. (2010) conducted in Ireland that found that parents had similar concerns.

Participants conveyed that professionals did not give them an adequate explanation as to what a diagnosis of ASD meant and how they should deal with it. Professionals apparently only mentioned that they should use the internet as a means of collecting information and that they should find a suitable school for their children. Therefore, parents felt they were left to their own devices regarding how to proceed after a diagnosis had been made, which echoes findings of Dale et al. (2006) and Keenen et al. (2010). It is possible that professionals did inform parents about ASD, but that the parents were so disillusioned by the diagnosis that they did not take note of further facts. Further research may be needed in this regard.

The responses of participants upon diagnosis included blame for medication, caesareans, genes, disappointment, internal conflict or guilt associated with religious convictions. These findings are in line with that of Mercer et al. (2006).

After a diagnosis was made, participants had many questions and experienced feelings of disappointment owing to their realisation that the diagnosis imposed on the dreams and expectations they had had for their children. This finding conflicts with the findings of Anthony (2009), who reports that parents experienced relief after a diagnosis.

4.4.4 Personally coping with ASD

Because of the purpose of the study, the literature review did not include ways to cope personally with ASD. During data analysis, it became evident that participants face multiple challenges and have different coping mechanisms. These coping mechanisms include strategies such as accepting ASD, having hope for the future, being realistic about ASD, avoiding the thought of their children’s future altogether and/or not discussing ASD with others. Dale et al. (2006) found that mothers still fostered hope regarding the likelihood that a change might occur, as did the participants in the current study.

Participants coped financially by committing to work hard and obtaining financial support from family members and/or the biological father of the child. Participants conveyed mixed reactions regarding the extent of support they received from family members. Some family members were there to support participants wholeheartedly, whereas other family members were either absent or seemed indifferent or oblivious to the children being diagnosed with ASD. However, stronger familial ties and relationships as a result of ASD were also expressed by one of the participants.

Religious and/or spiritual practices, such as praying and waiting on answers from God and His intervention, were also coping strategies. Mathye and Eksteen (2016) also found that some parents believed that it was God's choice for their children to be diagnosed with ASD, as one participant also believed.

4.4.5 Intervention with a child with ASD

Regarding behavioural intervention, participants stated that methods which assisted them effectively with behaviour was being patient, being more understanding as well as adjusting to and being accepting of their children's needs. A potential difference between male and female strategies with behaviour was noted. Female participants in the study tended to make use of methods that had a soothing effect on the child, such as wrapping the child in a blanket and using camomile oil, whereas the male participant seemed to have a more practical approach to coping with behaviour, such as putting the child in a stroller when he is upset.

Intervention which supported both parent and child alike was sending the child with ASD to a special school. This particular school assisted parents by empowering them with methods to cope better at home. These intervention methods proved to be successful as their children displayed improved scholastic abilities in areas such as reading and writing. However, speech remained a challenge for some of the children.

In the current study, participants made use of medicinal as well as therapeutic intervention such as occupational and speech therapy to deal with characteristics of ASD. According to Milau et al. (2018), Asian populations also made use of speech and occupational therapy. However, participants in this study stated that these strategies proved to be ineffective and therefore terminated its use. Participants in this study also terminated prescribed medication, citing avoidance of unwanted side-effects. Prescribed medication use is common in both Western and non-Western contexts (Al Anbar et al., 2010; Daley, 2002).

Daley (2002) reported that parents in Israel made use of religious and spiritual strategies. Even though the participants in this study did not make use of formal spiritual or religious ceremonies, they did make use of prayer as a method of personally coping with the challenges of ASD.

According to Daredennes et al. (2011), several parents in Western societies employed numerous intervention methods, despite some of these methods being potentially harmful to their children, owing to the ineffectiveness of more conventional interventions and a lack of support from professionals. However, in the current study, it was noted that parents would rather terminate intervention than expose their children to alternative forms of intervention.

Participants experienced social challenges such as judgement from community members, their children being labelled as spoiled, having to explain and deal with questions surrounding their children's behaviour and feelings of general agitation regarding a lack of understanding from others. For these reasons, participants isolated themselves, avoided social situations and/or became thick-skinned as strategies for dealing with social challenges. According to Bakare and Munir (2011), Bayat (2015), Gona et al. (2015), Munsaka and Charnley (2013) and Tilahun et al. (2017), children with characteristics of disabilities or disorders in the African continent are subjected to harsh and unfavourable treatment such as being shunned, punished and/or, in some cases, put to death as the result of supernatural and ancestral beliefs. Similarly, social judgement and unsolicited advice from community members seem to be some of the most frequent social challenges faced by parents in a Sepedi culture who reside in urban areas. Studies conducted in a more rural setting might report an even harsher reality for many rural parents whose children show atypical behaviour.

4.5 MERGING RESULTS, FINDINGS AND THE THEORETICAL FRAMEWORK

This study used IKS as a theoretical framework to understand existing and new research regarding Sepedi cultural views of ASD.

During data collection, analysis and interpretation, it became clear that participants were a valuable source of information. Their unique knowledge and views come from first-hand experience of the phenomenon under study. The data illustrated that the participants' views of ASD entailed the amalgamation of cultural principles, personal views of the world based on their experiences, frame of reference and Western views on ASD. An IKS lens of inquiry facilitated a more authentic understanding of the nature and participants' lived experience of ASD which might not have been captured as accurately if data were obtained from those who did not experience the phenomenon themselves.

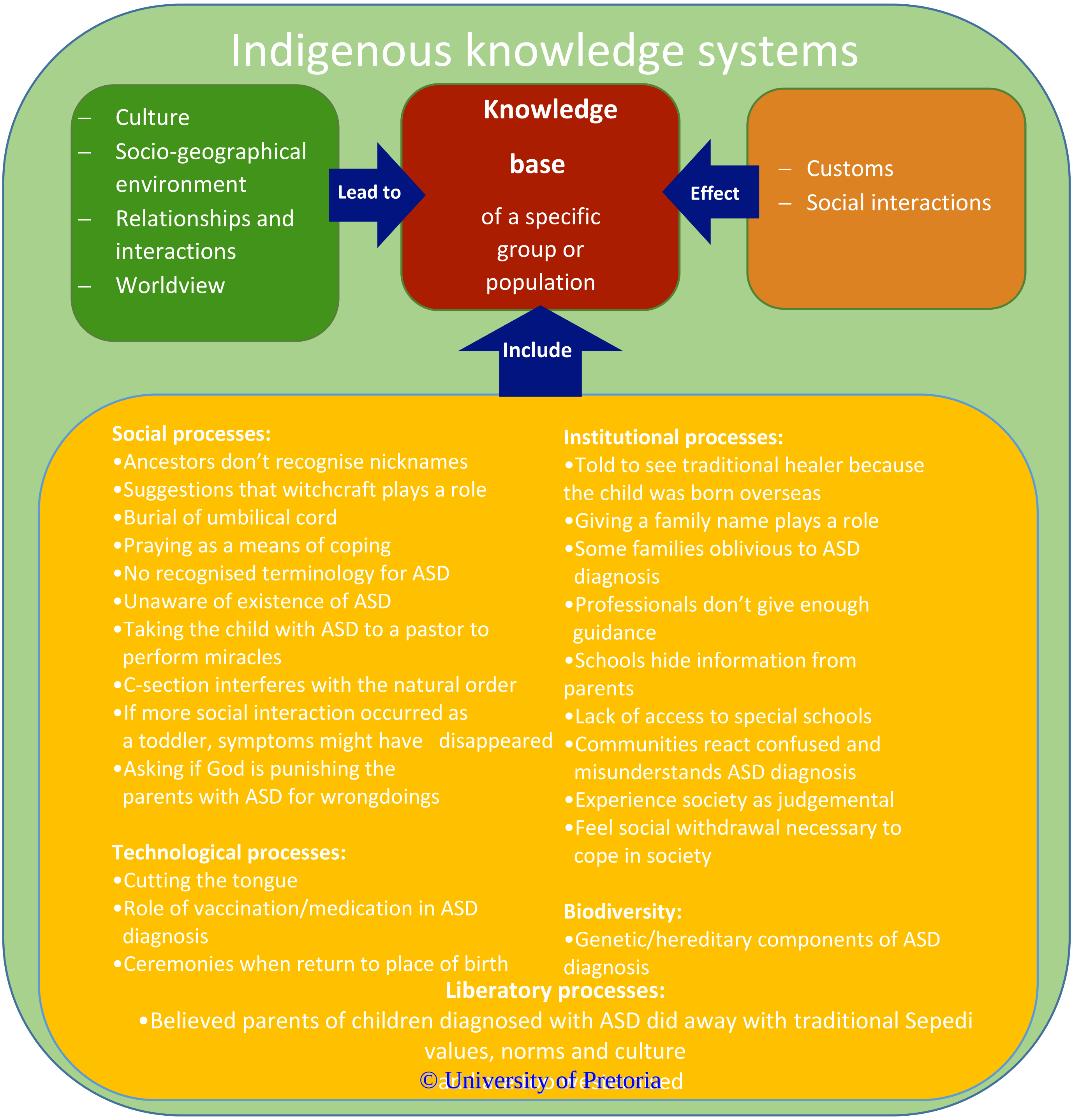
The statement made by Loubser (2005) that the essence of human existence is cultural and indigenous in nature was also evident as the participants' views and experiences contained elements of these factors. Participants accused of being too westernised and doing away with tradition as the cause of ASD was also illustrative of the cultural core that is present in the Sepedi community in which participants function. Furthermore, participants had to establish a middle ground between their own views and that of their communities to cope with and make sense of their children being diagnosed with ASD and the implications thereof. Findings revealed that the cultural or indigenous knowledge of participants is broadened or altered by external sources of information which are mostly derived from westernised sources. These findings speak to the dynamic nature of IKS.

I am of the opinion that data collected based on an IKS theoretical framework added to the known existing body of indigenous knowledge. For example, participants divulged information regarding indigenous practices such as not burying the umbilical cord
as a cause of ASD, the cutting of the tongue as intervention and a view of caesareans causing ASD, all of which are points of view that seem to be uniquely Sepedi, and

might not have been known by individuals who only ascribe to a westernised point of view. These findings speak to the flexible nature of IKS.

The five processes of IKS, namely social, institutional, technological, biodiversity and liberatory processes, as posed by Masoga (2005), featured in the responses of participants. Responses included aspects surrounding religion, spirituality, traditional healing, societal and educational structures, healing and/or traditional rituals performed by other members of the Sepedi population as well as culture, customs and traditions.

Figure 4.2 below contains an amalgamation of new insight obtained from the study and the theoretical framework of IKS as it was explained in Chapter Two.



Social processes:
- Ancestors don’t recognise nicknames
- Suggestions that witchcraft plays a role
- Burial of umbilical cord
- Praying as a means of coping
- No recognised terminology for ASD
- Unaware of existence of ASD
- Taking the child with ASD to a pastor to perform miracles
- C-section interferes with the natural order
- If more social interaction occurred as a toddler, symptoms might have disappeared
- Asking if God is punishing the parents with ASD for wrongdoings

Technological processes:
- Cutting the tongue
- Role of vaccination/medication in ASD diagnosis
- Ceremonies when return to place of birth

Institutional processes:
- Told to see traditional healer because the child was born overseas
- Giving a family name plays a role
- Some families oblivious to ASD diagnosis
- Professionals don’t give enough guidance
- Schools hide information from parents
- Lack of access to special schools
- Communities react confused and misunderstands ASD diagnosis
- Experience society as judgemental
- Feel social withdrawal necessary to cope in society

Biodiversity:
- Genetic/hereditary components of ASD diagnosis

Liberatory processes:
- Believed parents of children diagnosed with ASD did away with traditional Sepedi values, norms and culture and [illegible] westernised

Figure 4.2: Integration of Indigenous knowledge systems and knowledge obtained from the study

Because South African indigenous knowledge is characterised by a lack of text-based elements (Loubser, 2005), this study is valuable because it can contribute to the knowledge base regarding indigenous knowledge through its written format. A lack of indigenous terminology for ASD was also a finding of the study. Since indigenous knowledge thrives on oral tradition (Vogel, 2009), educating and making indigenous populations aware of ASD is thwarted by this lack of indigenous terminology.

4.6 SUMMARY

This chapter contains a detailed exposition regarding the themes and subthemes that were derived from data collection, analysis and interpretation. Collective findings on Sepedi indigenous knowledge regarding the nature of ASD, the cause/s of ASD, as well as how to intervene with ASD are discussed, as well as how these findings can be understood in terms of the theoretical framework of the study.

Chapter Five will summarise the research study, answer the research questions, discuss the limitations and give suggestions for future research.

CHAPTER 5

DISCUSSION OF FINDINGS, CONCLUSION AND RECOMMENDATIONS

5. 1 INTRODUCTION

This final chapter answers the research questions set out in Chapter One, discusses the potential value and limitations of the study and makes recommendations for practice and further research. Lastly, it concludes the dissertation.

5.2 SUMMARY OF CHAPTERS

Chapter One served as an introductory chapter and provided an explanation of the rationale as well as the purpose of the study. The research questions and working assumptions were stated. Clarification of concepts and a brief discussion of the epistemology (phenomenology) and the methodology (qualitative research) of the study were included. A short exposition of the research processes relevant to the study was also provided to orientate the reader.

Chapter Two contained a review of the literature relevant to the current study. Firstly, an in-depth explanation, including criticisms and justification, of IKS as the theoretical framework for the study was provided. Western and non-Western views of the causes, diagnosis and characteristics of, and intervention for, ASD were also discussed.

Chapter Three provided a discussion of the epistemological and methodological approaches as well as the research design. This discussion covered possible criticisms and strategies to overcome these challenges as well as justifications for the chosen approaches and research design. A description of the research design, which included multiple case studies, the selection of participants and the research site, data collection as well as the approach used to analyse and interpret data were included. Lastly, it explained the quality criteria and ethical considerations which guided the study.

Chapter Four provided an overview of the research process and a detailed discussion of the research results. Collective findings and a discussion of these findings were included before merging the results and findings with the theoretical framework of the study.

5.3 DISCUSSION OF RESEARCH QUESTIONS

This section discusses some of the answers obtained to the research questions which encapsulate the purpose of the study. The secondary question will be answered before answering the primary research question.

5.3.1 Secondary research question

As SA is a multicultural country, and boundaries among different cultures are sometimes vague, the following secondary research question was posed to elucidate, understand and contextualise the primary research question:

What are the views of some other groups in Africa regarding the nature and cause/s of, as well as intervention for, ASD?

Beliefs and practices of other African countries were explored through literature study. In many cases, where studies on African countries were not available, studies done in other parts of the world such as the East and Middle East were consulted. The difficulty to separate African views from Sepedi views is exemplified by two participants who spoke on ASD terminology in the Sepedi language. One participant stated that "not only in the Pedi culture, across Africa, this thing of autism" (reference to Appendix D, FG2, p.132), "It's unknown" (Appendix D, FG2, p.132). Therefore, the secondary research question will not be discussed separately from the primary research question. Instead, the primary question will be answered by focusing on the small sub questions contained in the primary question to give justice to the interesting and complex nature of IKS on ASD.

5.3.2 Primary research question

What are Sepedi cultural views regarding the nature and cause/s of, as well as intervention for, autism spectrum disorder?

What are Sepedi views of the nature of autism spectrum disorder?
Little is known about the nature of ASD among members of the Sepedi population (subtheme 3.1). Participants mentioned a lack of awareness of ASD several times, not only among themselves before their children were diagnosed, but also among the Sepedi population in general and on the African continent.

A lack of African terminology (subtheme 1.3) for ASD also came to the fore. Participants' only previous encounters with difference in behaviour were of fellow learners who repeated school grades (subtheme 3.1). However, these characteristics were never identified as related to ASD.

Based on their own experiences and information gathered to better understand and best support their children, participants differed as to whether ASD is a genetic disorder (subtheme 2.2). They were able to verbalise that they were aware that ASD and its characteristics fall on a spectrum (subtheme 3.2). However, it appeared as if they still had some uncertainties regarding what exactly this spectrum entailed, how it influenced their children and where their children fell on the spectrum.

Participants demonstrated an astute awareness of the characteristics which prompted them to seek a diagnosis and, in so doing, implement intervention strategies (subtheme 3.2). Both intervention strategies and current behavioural manifestations of ASD were conversed about during interviews and group discussions. These conversations brought to the fore similarities and differences in some of the characteristics of ASD in the children of the participants (subtheme 3.2). Upon discovering these differences, some participants seemed surprised about the differences in the way that ASD manifests in different individuals. It might indicate an extent of uncertainty as to the exact nature of ASD. It was also interesting to note that the criteria of the DSM-5 were mirrored in their answers, namely socially challenging behaviour and language delays (APA, 2013).

It seems as if participants made sense of information obtained during personal internet searches and the school by means of the amalgamation of this knowledge, what they experienced personally and how other members of the Sepedi population, especially family members, viewed the nature of ASD.

What are Sepedi views of the causes of autism spectrum disorder?

Participants in the current study held both Western and non-Western views of the causes of ASD. Causes of ASD were attributed to aspects such as hereditary influences, vaccination and medication as well as caesareans and birth complications. External influences, such as the environment, were also mentioned as possible causes of ASD (subthemes 2.2-2.5).

The participants' views did not coincide with indigenous Sepedi views, such as the child not being called by the right name, participants not adhering to tradition and not performing the required ceremonies, the umbilical cord of the child being flushed away in a foreign country and not buried, as well as the parents being bewitched (subthemes 1.1 and 1.2). However, one of the participants had a unique explanation for the cause of ASD based on planned caesareans. His explanation involved interfering with the universe and/or the course of nature, and in so doing, possibly facilitating or influencing ASD (subtheme 2.3).

Initial responses or views pertaining to causation included religious attributions. An example of such a view was that their wrongdoings as parents manifested as a punishment in the form of ASD (subtheme 3.4).

Participants made many attempts to pinpoint the cause of ASD through consulting schools and medical professionals as well as personal internet searches. Despite maintaining their own views of the causes of ASD, participants revealed that they still had uncertainty as to the exact cause of ASD (subtheme 2.3).

What are Sepedi views of dealing with autism spectrum disorder?

Participants evidenced several commonalities in their views of how to deal with ASD. All participants engaged in spiritual and/or religious practices to assist them in dealing with ASD (subtheme 4.4). It was apparent that they experienced many personal, scholastic and behavioural challenges with which to deal. The participants as parents dealt with ASD by altering their daily routine, becoming more patient as well as adjusting to their children's needs during social gatherings and in public settings (subtheme 5.1 and subtheme 5.4).

Finding suitable school placement for their children had also been challenging for participants (subtheme 5.2), a challenge that became evident during the focus group discussion and member checking. Participants expressed their concern and frustration with having limited options available when placing their children because of the shortage of schools that cater for the needs of children diagnosed with ASD. They experienced frustration because of the many questions about their children from school personnel. They viewed such questions as surprising because they expected school personnel to be adequately trained to deal with matters concerning their children's well-being (subtheme 5.2).

Participants also indicated that they do not speak freely about their children's diagnosis. A lack of awareness and information in the Sepedi community resulted in frustration because the participants have to explain what ASD entails every time they disclose the diagnosis (subtheme 5.1).

Participants used medication as well as speech and occupational therapy as a means of dealing with ASD. However, owing to views that these therapeutic strategies were either ineffective (speech therapy) or had adverse side-effects (medication), participants opted for the cessation of these strategies (subtheme 5.3).

Participants rely on family members for both personal and financial support (subtheme 4.2 and subtheme 4.3). The extent of this support varied between participants. Participants also deal with the financial burden of their children's diagnosis by working hard so that the children can attend a private school that caters to their needs (subtheme 4.2).

Generally, dealing with ASD included participants having to deal with suggestions from the Sepedi community regarding how to address symptoms of ASD. Suggestions entailed cutting the tongue, addressing the child by his ancestral name, consulting traditional healers and/or pastors who perform miracles as well as performing ceremonies such as collecting the soil from the country of the child's birth to indicate that they were coming back to SA (subtheme 1.2). Participants dealt with these suggestions by refusing to base a diagnosis of ASD on ancestral influences and/or witchcraft as the cause of ASD (subtheme 2.1). In some instances, participants would tell community members that they would consider their suggestions while actually knowing that these suggestions would not be of any help to their children (subtheme 2.1). It seems that for many of these urbanised parents of Sepedi descent, the shift from traditional to western understanding of ASD is occurring.

In cases where the cause of ASD was attributed to hereditary factors, some participants initially dealt with a diagnosis of ASD by blaming the family of the other parent of the child (subtheme 3.4) and/or by viewing a diagnosis as a punishment from God for wrongdoings (subtheme 3.4). Some participants stated that they eventually accepted the diagnosis without attributing blame, made peace with it and demonstrated a sense of realism regarding the fact that their child is unlikely to outgrow ASD (subtheme 4.1). Upon diagnosis, other participants decided not to attribute blame at all (subtheme 3.4). Nonetheless, some participants acknowledged that it was still stressful despite the fact that they have made peace with the diagnosis (subtheme 4.1).

Some participants also dealt with a diagnosis of ASD by comparing their children to same-aged peers, seeing hidden potential in their children and having hope that their children will still master speech difficulties and eventually progress to mainstream education (subtheme 4.1 and 4.2). Other participants avoided thinking about the future of their children as they did not want these thoughts to trigger a stress response (subtheme 4.1).

5.3.3 Conclusion of the primary research question

What are Sepedi views regarding the nature and cause/s of as well as intervention for autism spectrum disorder?

Findings from the current study illustrate that participants held views regarding the nature and cause/s of and intervention for ASD that are an amalgamation of Western and non-Western views. This amalgamation is probably caused by the fact that the participants do not reside in rural areas and had access to information about ASD via electronic media and specialists. Furthermore, the participants did not hold strong convictions of an indigenous nature regarding the nature and cause/s as well as intervention for ASD. They were therefore possibly more open to explore and consider more Western views of ASD. The fact that the parents worked in English environments where the word 'autism' is known probably also contributed to the fact that searches on electronic media brought forth information emanating from predominantly Western views, predisposing their understanding of ASD from a Western view.

It became apparent that a lack of awareness of ASD seemed to be prevalent among indigenous Sepedi populations. This lack of awareness seemed to be a challenge for participants in better understanding the nature and cause/s of and intervention for ASD. When confronted with an unfamiliar disorder such as ASD, the Sepedi community in general attempted to make sense of the disorder by making use of their own frame of reference (indigenous knowledge). They associated their own frame of reference, which pertains to other diseases, with the characteristics of ASD to find a plausible explanation for both the cause of ASD and intervention for ASD.

Even though participants possessed general knowledge of the cause and nature of ASD, they were still uncertain as to the exact factors associated with a diagnosis for their children specifically. The overall perception of participants regarding intervention and/or support strategies varied but included family and school as valuable sources of support. Therapeutic support was discontinued owing to perceived ineffectiveness or perceived adverse side effects.

The lack of terminology for ASD in the Sepedi language raises an interesting question: is there no word for autism in the Sepedi language because historically ASD was not found among the Sepedi population? Despite the genetic factor in many people diagnosed with ASD, environmental toxins, metabolic issues and lack of vitamin D during pregnancy are but some of the recent 'modern' reasons being speculated which contributed to the worldwide rise in ASD (Kočovská, Fernell, Billstedt, Minnis, &

Gillberg, 2012; Scott, Duhig, Hamlyn, & Norman, 2014). If it is indeed so that ASD historically had not been present in the Sepedi population, it may explain why the Sepedi population perceives current ASD characteristics in the same way in which any difference is viewed. Of course, such speculation can only be confirmed after more research, including genetic research.

5.4 LIMITATIONS OF THE STUDY

Since the study had to comply with the guidelines of a mini-dissertation, it had a limited scope using a small sample of participants and a simple research design. One obvious limitation centre on the small sample size. It only allows for transferability to other parents of mainly Sepedi descent who reside in urban areas and have children diagnosed with ASD in a private school. It does not allow generalisation to other groups, other living locations, other diagnoses and other schooling options. If the sample size had been more extensive, more in-depth knowledge that might have been more representative of the broader Sepedi population's views of ASD could have been obtained. For example, if participants whose children attended public and/or rural schools and resided in rural areas were included in the study, richer data regarding indigenous views might have been obtained. However, despite this limitation, valuable insights regarding indigenous Sepedi views relevant to the purpose of the study were obtained. Because the study only included participants from the Sepedi group, the extent of generalisability of these findings across other cultural groups remain uncertain.

Because of the study's short-term nature, the data obtained were based on a snapshot of the participants' views at the moment the research was conducted. During member checking, a few new insights as to what participants regarded as important also arose. It could be an indication that a study aimed at data collection and analysis over the long term might be beneficial in obtaining valuable information regarding parental growth as well as how views were altered and/or shaped by time. A different research design, perhaps some form of ethnographic research, might also have yielded other data.

The selection of participants resulted in two more limitations. Because the participants resided in urban areas, they might not have had enough exposure to ASD in the Sepedi culture. Inclusion of older participants in rural areas who are perhaps in leadership, caring or healing positions might bring relevant data about Sepedi views of ASD to the fore. It is also possible that conducting the interviews in English might have precluded the participants from expressing certain views in Sepedi.

5.5 POTENTIAL VALUE OF THE STUDY

Despite the potential limitations of the study, valuable information in the form of insight into some Sepedi cultural views of ASD was gained. The findings of the study can be applied for diagnostic, intervention and educational purposes.

Based on the limited data, it appears that the ASD diagnoses in the sample group were made correctly and that the DSM-5 regarding ASD seems to have value in a cross-cultural SA. However, based on the literature study, diagnosticians in SA need to be trained to discern between characteristics of ASD and culturally appropriate behaviour (refer to 2.4.2) regarding eye contact.

Participants also highlighted that they received little guidance from professionals[7] on how to proceed after a diagnosis was made and that they did not know what the exact implications of a diagnosis of ASD entailed. This information can be of use to make professionals more cognisant of the importance of explaining to parents the nature of ASD and how to proceed after a diagnosis. Should professionals not be able to fulfil these requests themselves owing to time constraints, they should have contact information available for parents to get the necessary guidance and support that they need. Even though participants have access to internet sources, it is important that parents get accurate information conveyed in a manner that is more context-specific to be more useful.

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[7] It may be that professionals did explain, but that the explanations were lost on the parents who had just heard a diagnosis and were trying to come to grips with the diagnosis.

The indigenous Sepedi views, especially pertaining to the cause/s of ASD and ways of intervention, can be of potential value for professionals to become more informed and cognisant of indigenous views when consulting with this specific group. These findings can potentially assist professionals in respecting and approaching these views in a way that is culturally sensitive and ethically correct.

Regarding intervention and education, participants indicated that the school played a vital role in assisting both them and their children in dealing with ASD. This finding emphasises that a shortage of schools and teachers equipped to deal with ASD is a concern in the South African context. Improved efforts are necessary from government to reserve funds to provide parents with access to schools that offer specialised education for the needs of children diagnosed with ASD. With the high prevalence of ASD, the Department of Education would do well not only to provide increased special education but also to train educators in mainstream and full-service inclusive schools how to support learners with ASD optimally in class.

Another way of support highlighted by the study relates to parents. Owing to an array of challenges faced by parents whose children have been diagnosed with ASD and a lack of awareness, the study also emphasised the potential benefit of support groups and access to information. The same also applies to family members of parents whose children are diagnosed with ASD. Initiating support groups and providing access to information are relevant to educational initiatives aimed at indigenous populations.

The Sepedi parents whose children were diagnosed with ASD were of the opinion that intervention strategies such as medication and speech therapy did not benefit their children. This finding shows that guidance regarding the implementation and maintenance of intervention strategies as well as exploring alternative methods of intervention are essential.

5.6 RECOMMENDATIONS FOR PRACTICE

Professionals such as educational psychologists, neurologists, paediatricians and other qualified professionals who make diagnoses of ASD can provide more guidance to parents and/or caregivers after a diagnosis of ASD has been made and be more cognisant of cultural views such as those that came to light in the current study.

Based on the increase in children with ASD, an investigation to determine the needs of the parents and children will be proactive. Such an investigation should do well to focus on more government special schools and training of teachers to better assist parents with limited financial means to obtain specialised education for their children diagnosed with ASD. Training of teachers in mainstream and inclusive schools to support children with ASD would likewise be proactive.

Support groups in a school or community context to assist parents whose children have been diagnosed with ASD can provide information and support with regards to dealing with ASD in personal, scholastic and therapeutic domains.

A *lekgotla* (meeting) during which professionals, community members and others affected by a diagnosis of ASD devise strategies to address the lack of indigenous terminology and educational endeavours aimed at indigenous groups may raise awareness of ASD.

5.7 RECOMMENDATIONS FOR FUTURE RESEARCH

Similar studies consisting of bigger sample sizes and participants from a variety of socio-economic backgrounds, especially from rural areas, will enrich indigenous knowledge systems regarding Sepedi cultural views of ASD. Research from an IKS theoretical framework in which participants from other indigenous groups are included may make discoveries as to the views held by an array of indigenous population. Such knowledge can inform diagnoses and support parents and their children diagnosed with ASD.

To increase variables during sampling, a different research design can be followed, such as ethnographic research. An ethnographic research design can be beneficial as it is described as being an immersive experience which facilitates an in-depth and holistic understanding of cultures and customs that are typically hidden from society (Reeves, Kuper, & Hodges, 2008). As ethnographic research is “naturalistic” (Reeves, Kuper, & Hodges, 2008, p.1), it can potentially yield valuable data pertaining to Sepedi cultural views of ASD. Findings might be a more accurate representation of views that cannot be obtained by means of conditions created during data collection using other research designs.

Studies conducted in both private and government schools can ascertain if there are differences in the extent of support received by participants whose children attend schools in the different sectors. Comparison between support offered by government and private institutions might bring discrepancies regarding support offered for children diagnosed with ASD to light. Such findings can potentially help schools adjust their approach to make them more inclusive for children diagnosed with ASD. Research to find ways to make early diagnoses of ASD and supportive therapies for children more accessible may alleviate the burden on schools to deal with learners with ASD.

5.8 CONCLUDING REMARKS

The current study obtained some interesting insights regarding indigenous Sepedi cultural views of ASD. One of these insights is that even though we live in what is described as a modern society, there still are unique, indigenous, Sepedi views that are more traditional.

Because ASD is regarded as a new phenomenon in an indigenous South African context, it is important to undertake research and educate South Africans from all walks of life by means of awareness campaigns and support programmes to parents and/or caregivers of children diagnosed with ASD.

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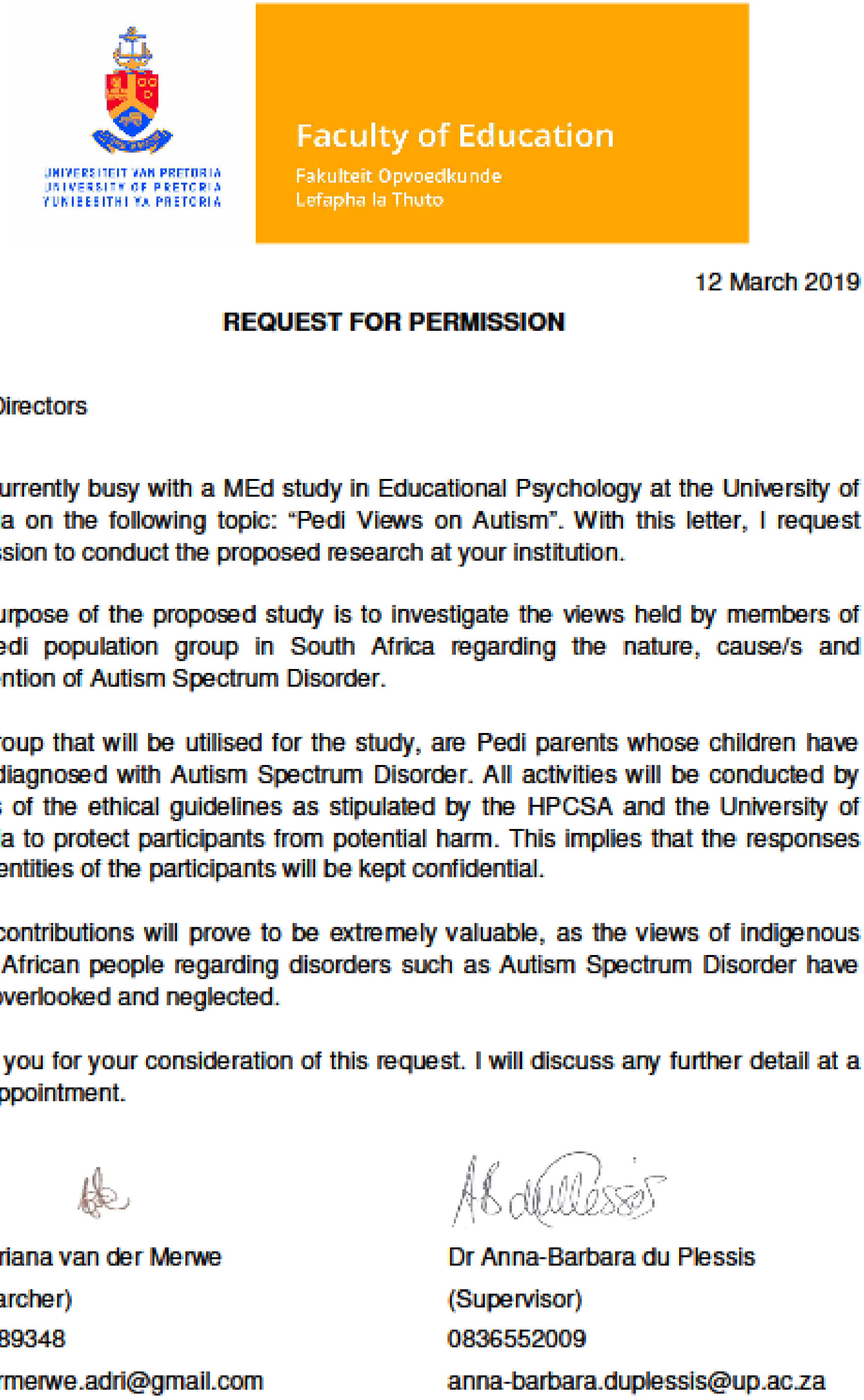
Appendix A: Request for permission – Principal



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Education
Fakulteit Opvoedkunde
Lefapha la Thuto

12 March 2019

REQUEST FOR PERMISSION

Dear Directors

I am currently busy with a MEd study in Educational Psychology at the University of Pretoria on the following topic: “Pedi Views on Autism”. With this letter, I request permission to conduct the proposed research at your institution.

The purpose of the proposed study is to investigate the views held by members of the Pedi population group in South Africa regarding the nature, cause/s and intervention of Autism Spectrum Disorder.

The group that will be utilised for the study, are Pedi parents whose children have been diagnosed with Autism Spectrum Disorder. All activities will be conducted by means of the ethical guidelines as stipulated by the HPCSA and the University of Pretoria to protect participants from potential harm. This implies that the responses and identities of the participants will be kept confidential.

Their contributions will prove to be extremely valuable, as the views of indigenous South African people regarding disorders such as Autism Spectrum Disorder have been overlooked and neglected.

Thank you for your consideration of this request. I will discuss any further detail at a later appointment.

	AB du Plessis
Ms Adriana van der Merwe	Dr Anna-Barbara du Plessis
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APPENDIX B: Invitation letter to participants

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Education

13/05/2019

REQUEST FOR PARTICIPATION AND INFORMED CONSENT
PARENTS: SITULA

Dear Sir/Madam

I am currently busy with a MEd study in Educational Psychology at the University of Pretoria on the following topic: *“Pedi Views on Autism – Two Case Studies”*.

The purpose of the proposed study is to investigate the views held by members of the Pedi population group in South Africa regarding the nature, cause/s and intervention of Autism Spectrum Disorder.

If your child has been diagnosed with ASD, your contribution will prove to be extremely valuable, as the views of indigenous South African people regarding disorders such as Autism Spectrum Disorder has been overlooked and neglected. Participation will entail a group discussion of Pedi views (lasting no longer than one hour), with the possibility of another individual interview, also lasting no more than one hour. The time and venue of the discussion and interviews will be decided collaboratively, to accommodate different daily schedules and responsibilities.

If you are willing to participate in this study, please complete the form below. Should you prefer to complete this process verbally, you are welcome to contact us to make the necessary arrangements. Thank you for your consideration of this request.

	AB duPlessis
Ms Adriana van der Merwe	Dr Anna-Barbara du Plessis
(Researcher)	(Supervisor)
0824589348	0836552009
vandermerwe.adri@gmail.com	anna-barbara.duplessis@up.ac.za

INFORMED CONSENT
PARENTS

Title of research project: **"Pedi Views on Autism – Two Case Studies"**

I, ____ the undersigned, in my capacity as parent at **Situla,** hereby agree to participate in the above-mentioned research. The research process has been explained to me. I also understand that my contribution will be treated as confidential and anonymous, and that I may withdraw from the study at any time, if I wish to do so.

I hereby give permission that a translator may be used during activities (if necessary), my responses be recorded using an audio device and notes be taken regarding activities and my responses. I also give permission that any information collected may be used for the purpose of the study.

I declare that my participation is voluntary.

I agree that the project is safe for participation. I am aware of my right to contact the researcher to refer me to a counsellor, without any additional costs to me, for additional support should I experience any emotional or other challenges owing to activities completed during the research project.

During group activities, I will treat all information shared by other group members as strictly confidential and not share this with any other individuals.

Signed at ____________________ on___________________________________2019.

Contact number: ____

____

Participant

____

Researcher
Adriana van der Merwe
(cell nr: 0824589348)

AB duPlessis

Supervisor
Dr A-B du Plessis

Appendix C: Questions asked in focus group

Focus group activity

Questions related to the primary and secondary research questions will be posed for group discussion. After the groups have completed their discussion of a question, there will be feedback to the researcher, who can again probe and discuss aspects of the answers in the group. The next question will then be posed.

1. What are Sepedi views on (the nature of) autism?
2. What are Sepedi views on the causes of autism?
3. What are Sepedi views how to deal with autism?

Appendix D: Transcript of focus group

R: Researcher
FG1: Focus group participant one (female)
FG2: Focus group participant two (male)
R: I think the first question I would like to ask you is what do you think were your views on autism when you first discovered this disorder? What did you think when your child started showing symptoms? What did you think it was? Where did it come from? Initially what did you think what was going on?
FG1: Ja.
R: I think that is a tricky one I'm jumping into.
FG1: Yes, it is very tricky. With me, I did not know what it was, but I was aware something is wrong, but I couldn't say what it is. And I just thought it is delayed development and that's when I approached the teachers to say. He was at (School's name) I was like, I was not happy with the results, he was not, the speech was not right, the speech was not well-developed. It was the speech that I was not happy about. He was doing speech therapy, but it was not helping. So, I wanted to understand from the teachers what their views is and I was referred to a special school. Still at that time I did not know what it was. And um… obviously the school - one of the therapists then sent me to a doctor, that's when they said okay there is a range of autism and he is probably that… autistic. And that's when I said, okay, ja, start looking for another school.
R: So, what age was that more or less?
FG1: He was um ….4, he was 5 actually when I started to get worried. He did not, he was at home until 3, then when he was 4, he went to crèche.
R: Oh, oh.
FG1: So for me he was like okay, we were staying in a complex there was not a lot of interaction so I was not, maybe anti-social is still an environmental thing and then at 4 he was at school, there was more changings and we said, let's give him time and it was not working. Actually he did that just one year there or two and ja, that was when I was like okay what's happening and unfortunately with the teachers as well, you have to ask them because their response to me was like sometimes we

feel we cannot tell parents because we don’t know how they will react and for me it’s like, they shouldn’t be worried about how I react. They should give me information. And then how I react to something else, they’re going to deal with it separately. They cannot hide information based on how a person will react, so I left it like that. So that’s how I first discovered that okay he is autistic. And for me, I’m divorced, so like at some point – okay actually I still feel it is hereditary, and you look at both families what could and you try to pin those things that okay, he in terms of slowness, I see this uncle and I see that and this kind of things. So I concluded that it’s hereditary and I have also concluded that even with the doctor he said that he is at a range where he can switch so I am kind like hoping that he will be in a private school for primary school and then he will pick up and then he will be able to because that’s me trying to say okay, it is hereditary. Those people that I’m saying they could be having, they could be autistic just undiagnosed, I’m looking at them to say they eventually manage to go to university. So maybe it is because we have the diagnosis if there wasn’t, no one would be bothered, you he can repeat his grade and two and eventually they just pick up and then they are like what happened… and no one knows what happened. But obviously at a later stage you’ll see those, they are anti-social a little bit and so on. So hence I say for him it was like…

R: So okay, that was the main thing that stood out to you?

FG1: Ja.

R: And what did your family members say? Or other people in your community what did they say about this? What did they say it was?

FG1: Ag, no from my family they don’t know. They didn’t, they don’t say anything. And obviously it’s because of I think it is information, it is not available because even with my brothers that are here, when you are in a Facebook page of autism and you post something, they said to us: “But why are you posting about autism?” Then you tell them that, okay, the child was diagnosed, and they be like: “When?” But they see him more often, but it’s like I don’t know what they make I have never asked. But I feel like, we don’t, there is no information and people are just like it is another disability that.

R: And Mr. (Participant two’s Surname) what is your story? Let’s hear….

FG2: Okay. Let me give you background as well as she did. Uhhh, you see, us when the child was born, I started to be curious. Immediately, immediately. No, I am not good, but I had to ask they said it's normal sometimes, you know. When the child was born within a short period of time, he was wide, wide awake like with big eyes, he open his big eyes, these big eyes, my son is having big eyes, and very, very, very wide. Like very, very bright man. And then I questioned that how possible? That time he's born outside the country we were in Europe. How is it? No, he is a clever boy, he is big, and of course he is big, don't worry about those things. He is very brilliant. He is intelligent. Stuff like that. And then he had this thing when he was sleeping, he had this thing of it seems like he is crying, like someone who is angry. Like in first weeks, even less than a month like when he is sleeping… like he is always angry. Which is something that we were questioning that, no man. I kept on calling home and I didn't know my family is church people and they would say: "You should just pray. There is nothing wrong, just pray," and then okay, it's fine. We didn't make him to sit like other kids, but at 3-4 months they start to make them, like put them to sit, we didn't do that immediately. Of course, even the hard food we didn't give, he started to eat at 6 months- food, normal food. He was just milk; he was breast feeding for 4 months and thereafter we continued with this to uhhh formula milk. And then at 6 months he started to be he be introduced to the food. And then at 6 months we put, like practised him to sit down. He sits down quicker and all of a sudden he started to crawl. People are like he is a strong boy; this is a strong boy. All of the sudden he started to stand. Ten months he's walking. And then I started to be curious about those things and then started to ask about these things. And then I went to ask a paediatrician about those things, because you know in Europe every time and again you have to see paediatricians. It is a requirement to do that.

R: Yes, of course you will do that. Do they force you to do that?

FG2: They don't force you; it is more like compulsory. Like almost in 2 weeks you have to see a paediatrician. They said no they told me: "This is a brilliant boy. He is strong, he is very healthy." And then I was curious. By 11 months he was very good in walking, like very, very good. Then I was like no, but I started to consult and people they said: "No, kids are different, some are quicker." Stuff like that.

There was another family that had twins later on, they were young. The kids, kids both girls, they walked late, everything of their motion it was always delayed. Like they walked after a year, maybe one year four months, they started to walk. And then all of a sudden, they started to know their mom, calling Mommy. You see, mommy all those things, and our child was not... was not doing that. And I was like ai no. Hey these kids are very small why is it they know how to say mommy? You see, I started to be curious, but whatever was at least giving me hope was like at least my son they say was brilliant, he walked early all these things. And they were saying normally boys get delayed. All those things, you know. Don't panic about those things. Okay, no it's fine. Now his 2 years, now he is trying to speak (makes babbling sounds), every time when we eat, we pray as well. When we tried to pray, he tried to imitate. He'll be like (makes babbling sounds). And then I started to ask …what is this now? So, the time when he was about to finish 3 years we came back and then quickly we tried to get the paediatricians here. We went to this private hospital here and we got a paediatrician there. The first thing when we get there, he said no, this is the child that we brought, we said yes and then she said: "This child is autistic." And then… What is that?

R: Ja, I was about to ask you. Did you know what it means? What…

FG2: I just say, but I may not make a final decision, the decision will be made by um what you call it…a neurologist. But when he enters here because I am a paediatrician, so I checked the child, this child is autistic. Autistic child like this, this, this, even when you call their names they don't respond, but they hear normally, but they don't respond, I said but this child he can hear, he can hear like I mean he can hear so many things.

R: He responds…

FG2: Even when you call him, he doesn't respond, he is just busy, like just busy. But I don't know why especially when you see people like this or cups like this he will be wanting to drink from here, drink here…drink here…drinking. You see. So, he said "No, okay I will send you to ENT", and then when they test the… we went there, they tested, they said no: "He can hear, he can hear properly. He doesn't have a problem with hearing" and then he said okay: "Go and Google what is autism", and then we started to Google what is autism. Hey, the disappointment ja … no…um.

R: That must have been difficult for both of you.

FG2: Ja, it was so very difficult……and then you started to blame yourself about so many things you know. Ja, like a lot of blamings and then uh…

R: There are questions, I think a lot of questions.

FG2: Ja, a lot of questions. There was so many, many, many questions…… what did we do wrong? Then you don't even get the cause, it is not clear. Somewhere on when you rely on Google they say in America it is very worse this thing and then uhhh … the paediatrician next time we went back to her she said: "You know where you are working, there are so many people- sorry to say this - there are so many kids that are more like your kids – I am not going to tell their names. Maybe if you feel free you speak about this you will discover that there are so many", And then strategically I started to ask colleagues amongst, like he mentioned in (department that participant works in) , he was mentioning some few government departments, you see uhhh….and I was like what causes that?

He was like, "I don't know. That is what I noticed that people that are coming here, government department, they are coming from this department.

FG1: Yes.

FG2: Then you start blaming yourself because I am working here. You know. It was like… What is it? Only to realise, indeed where I am working people are not talking about it some are odd, some, but you know there are so many people there. Like when people coming, like my colleagues, coming… those that we are very close you tell them that this child he is autistic he is… you find that some you know is this child or this person, in at work... it is this one, this one, they all have this. Then you start to discover. And then I went to one of the colleague that I know who this friend of ours told that because I know you you know his guy, engage him, but don't tell him that I told you but that guy was very open – but you know that my son he is eleven years he's autistic as well. And then he started to mention so many people here.

R: Wow.

FG2: Like ja, you see. And then thereafter you started to be better a little bit.

R: Ja, ja.

FG2: Um but the time that, our family is in Limpopo, you go to home and you say that they said no the child is diagnosed autistic and then they don't know what is that, of course even myself I didn't even know what is this and then I will end to cut the story short to them, I will be like it is having a brain disorder. No, you are mad, you are mad, this child, look how fit he is. He is, he can be active, how can you say this person is not normal. You know all those things, so but they will be telling you

that maybe this name, why doesn't he respond to the name, maybe this is the wrong name to him. You will have to change the name.
R: That's very interesting.
FG2: Ja …you see maybe he doesn't want this name, because you know in our culture you are named after someone. He's supposed to be like, he is supposed to be taking the name of my brother. You see, so of course in Pedi name, the name is there, but you don't call him that one we will call him [nickname] and my brother is not [nickname]. You see. So, they were saying that no we must not call him [nickname] then, we must insist in calling him [child's first name].
FG1: Eh…eh.
FG2: Then we must, you know…
R: So, they were saying you were going against tradition to call him something else.
FG2: Yes, because his name is [child's first name] [child's second name].
R: Okay.
FG2: But the one that we call him is [nickname]. [Child's first name] is another additional name that we took from my brother, elder brother. You see. And then we were saying okay, let's no longer call him [nickname], let's use this name.
FG1: Uh…
FG2: Because it seems that the [nickname] name is wrong.
FG1: The ancestors don't know it.
FG2: Ja…and it was amazing because in my families we don't too much believe in these ancestors we believe in God, but I was so very shocked…but okay, maybe he needs to be called with this name that is within the family.
FG1: Mm…
FG2: Because, (child's second name) is not a family name, not the one we gave him as parents, okay we would like to call him (child's second name) – so they were saying that no they were starting to blame the name. Okay, uhhh no we must change this name. And then I refused…I said ai no, no, no. We already…and we are happy with, we gave this name (child's second name). (Child's first name) will still remain there. Whoever feels comfortable, he can be, he can call him both names, but I am already comfortable with the name (child's second name) so we continued. And

another thing, because they said it can be hereditary as you were saying people, some were saying it can be because you rely on information, some of medications.

R: What did you think? What did you think it was?

FG2: I was blaming medications….

R: Okay.

FG2: At the beginning, but eish you know this thing of going to the paediatrician in Europe. I was starting to blame that, that you know the paediatricians they always recommend that now it is time for this vaccine and they were doing… they had so many vaccinations there, they were doing so many vaccinations, and at an early stage and then they were saying that some are still you know, and then you ask yourself stuff like but Europe

...it's not like in Africa where we are supposed to be more have more vaccinations then them. But I don't believe that they have so many vaccinations even more than us maybe. I don't know …uh…but they start very early. I was blaming those medication as well. And uh…. another thing is I was blaming the environment, the environment, you know Europe is very reserved, the kids don't play with each other. And it's cold, it's indoors.

R: No, it's not Africa, hey?

FG2: Ja. So I was thinking like maybe the child was never exposed, maybe if he was born here, even if he is having this thing, born with it, it would have maybe disappeared at an early age, because it would have been within the people…

R: Yes, yes.

FG2: Within the kids… you see, so you will just accept that there are people here unlike there where it's only us, it's cold you are always indoors when you go you don't even speak too much with the neighbours. Like you see people like from a distance, so I was blaming those things. So, another thing is like our people, most of their kids as well, some was born here, but they left with them at an early age, because we go out often, some of those kids was born outside as well. So, I have a close friend of mine as well, his kids were born in the hake? He's also autistic. So, you see I started to blame.

FG1: Yeah.

FG2: That okay uhhh… these kids that are born outside, I think that are the one that are having a problem, or those who were born within less than a year or less than 6 months, their parents will be assigned duty somewhere, and then thereafter they were starting to be somehow, because I was asking this girl of eleven years the child was born and within less than a year they have to relocate to NY, you see.

R: Oh my.

FG2: So I was starting to blame because even paediatrician was telling me that I wonder the soldiers that are normally being deployed the (specific department mentioned by participant) is having some health practitioners that are going outside, as well, and you guys that are always going outside, I don't know whether there is a link, but I am not saying, ja, because he is a paediatrician.

R: Oh ja ja.

FG2: Even saying that he notices that a lot of these kids are coming from this ministry. But when you ask the parents, they have been away with the child, or the child…

FG1: Yes, yes.

FG2: The child was born there all of them they are having all of these things …you see.

FG1: Shame.

FG2: There's a certain lady she's having 2 boys, these boys are born outside, all of them are autistic. You see. So, she's trying to understand whether this thing has to do with born outside or be relocated outside at an early age… or what is happening. Because he said this thing is happening to so so so many of them.

R: Ja.ja.

FG2: And I could not believe that there where I am working there are so many autistic kids. And if they're not autistic, these kids when they come…cultural shock there has to be Psychologists, Educational Psychologists they don't go there anymore. They are out of the system. They are not doing well in schools in most cases that is a challenge.

R: So, Ms (FG1 surname) what did you think was the cause?

FG1: For me when I was pregnant there was a time when they were taking a blood test and the doctor phoned and he said uhhh from the blood test there is an indication that the child will have down syndrome. I just felt like the results were wrong. You know they give you an option whether you want to abort or want to keep the child, but then, then you need to get the information….so though it was painful at that moment but something just said to me – you know when I went to take my blood results there was a lady that I was working with, an Indian woman, and she was a little bit old and when I left I had a feeling that they mixed us…they mixed our bloods, but there was nothing I could do, but I before I even got the result, but when I got the results I was like this results is not mine. And then we went to the scan so the scan when they were showing like okay the most of the development is fine physically, there is no evidence of down syndrome, then I left it then during birth, which is one of the things that I suspect could have caused, uhhh the baby was huge. Then they did, it was a Caesar. The doctor they made a small cut. They took forever to take the child out. I was even scared myself. When the child was eventually removed, the child was not crying. It was like they had to put him in I.C.U. and all that. So, for me I suspect something could have happened there.

R: So, during the birth….

FG1: Mmm.

R: So maybe like not having enough oxygen.

FG1: Yes…yes, yes… cause you like know normally when you are in caesar it is like, it was planned, but it was not a full where you, you, you it was this uhhh just like the one that they just uhhh…

R: Oh when they give you the injection.

FG1: Yes. You could feel…

FG2: Ja ja I know.

FG1: You could talk to them basically. And then when they…

R: Was it an epidural….

FG2: Yes.

R: So, you can't feel anything from the waist down.

FG1: Yes. So, when they talk about, like no they are struggling to get the baby out you can hear, but you can't help then after that the child was out. The paediatrician is there he is trying to pump oxygen and all that. And the, I could just faintly hear the child starting to (soft crying) because at that point I thought the child had died.

R: Of course. In which hospital was this if I may ask?

FG1: (Hospital's name).

R: Okay. Oh wow that's a hospital that specialises it's not even…..

FG2: But I also, our child was caesarean as well because he was big. Some saying because they used to measure him, like as I have indicated in Europe you always go to the paediatrician like every 2 weeks. So, they used to measure him from the stomach, and my wife's stomach was big as well. They very saying that this child is huge, he's huge, like they used to measure everything. Like they could measure from here to here, they say you see the length of the upper arm, from here, here is the centimetres are very long, from here to here it is very long, from the thigh to the knee is very long. So we don't encourage to push this child, so and the bones, you know they have systems those people, they will be like...and the bones are very heavy and indeed I wasn't convinced about their measurement all these things and indeed when he was born I could see that ja no, this child is big and the head was big like his bones like the part that you can see even, he's not meaty but he's huge even if he can come here, you can see that he is (laughs)he's no bony, he's not fat, but it's more bony. But I also had blame like the caesareans, maybe. Then I started to have this thing of caesarean, I, because you ask yourself like, what could have gone wrong here? So, you blame so many things. I've blamed caesarean, but he cried when he cried the paediatrician came to test all those things and he passed all those tests. Like you know they throw him and then he wakes up. All those tests he passed uhhh….he cried and then within a short period of time his eyes were wide open, like he is a normal person, you can like seem like you can speak he will reply and then the time when he was sitting down, uhhh… we were putting like TV. If you see something horrific on TV he was, more like scared. It was like you can see he doesn't want those things. But he… maybe by by 8 months he wanted cartoons…

R: Oh.

FG2: Ja if you change cartoons he was crying. And I was starting to ask, how does this person know the cartoons?

R: Ja …

FG2: You see. You know, I keep on asking the paediatrician so many questions about this child….like the behaviour of this child. To me I don't understand it … this behaviour. He said: "No he's very brilliant, it is very brilliant" and he hated the doctor.

R: Oh.

FG2: And at an early age he didn't even want to. Like the plays, like you can walk in anywhere, but going to the doctor, he knows to enter that room that was it terrible and when I said but this child is too young to understand.

FG1: (Laughs)

R: Mmm.

FG2: They said no kids are like this. They know they don't want doctors so… ja…and then ahhh… because he walked early, he became strong to walk faster, even quicker. When you go to shops, he was all over. Which I don't know, there was time that we had to fly back –you know in the flight there was this uhhh… what they call…uhhh where there is too much wind.

R: Oh yes…

FG1: Turbulence.

R: When the plane goes down…ja

FG2: Then you are requested to be, remain seated and all this. He doesn't want. He wants to be all over. You know, he was uncontrollable at an early age, unlike now now he's very good.

R: And how did you deal with that?

FG2: Yoh … ai it was terrible. The mother was so very shy, feeling disappointed …and then all of a sudden you know when the child start to misbehave uh… and in front of people ….and then you are requested, no but no it's you child …people they don't understand, you like they didn't understand what is happening, you know . So, it was very terrible, but in our culture, I can assure you, autism, I can assure you it's just an English term, it doesn't have a name. Uhhh …nobody knows about it. Uhhh….I tried to look in my family who can be like this, but what I've realized there are some in our family that have delayed speech. I think they were speaking, but delayed ah …and the worst part I can assure you, I had one of my cousins as well. He delayed big time, but if you see him today, but his temper he gets triggered by it. Anything else can just trigger him somehow. And he prefers to be alone….he's alone but ah …I don't know, but his behaviour was never because I'm trying to ask how was his behaviour, but except because, he is older to me by 2 years. But I know that even when we were in Primary, because we went to the same Primary. He was very,

very… eish he was somehow, his development was little bit slow ja… And uhhh but I don’t know whether … if it is autism or it’s not. Because now he is old, he’s working here, he’s here around Pretoria, but what I know he will never even face you like this. Ja, so I don’t whether, because I don’t whether, because I’m scared to be just judgemental. Ah …even myself if you look at me some of the alphabets I could not pronounce ….for quite long. Ja, uhhh but I’m not saying I’m autistic, I’m not. But it’s the speech. This thing they say hereditary, it is there in my family. Some of us are we can’t pronounce, even my mother is like this. So, people will be asking were you sucking the thumb when you were young, then I say no I have never. You know even in Primary, the teachers used to be, like making a joke, because like I could not pronounce properly. You see. So, but I was linking delayed speech with this thing in the family that we don’t pronounce other words properly maybe to him it went severe. You ask so many questions, that you don’t even have an answer …ja you see.

R: Did you at least find a few answers to these questions as of yet or are there many questions?

FG1: No.

FG2: No, you just make peace with it.

FG1: You just accept it.

FG2: Ja ja, acceptance and make peace with it, but truly speaking there is no conclusion that okay this is might went uhhh…would be like there’s a clear answer of all these questions. You still, I even today I am still asking myself what went wrong? You see. He is having his brother; his brother is having more tantrums than him. He doesn’t have tantrums. He is just autistic, but not tantrums. FG1: Okay, okay.

FG2: His brother they say he not autistic, but his tantrums are more severe.

He is the one that bumps himself, his head, every day I think I don’t know how many time he get attacked by his tantrums, you know if you see his head now you sometimes he having this… what you call them?

R: Does he rip out pieces of his hair? Ja ja mmm

FG2: Ja, because he bumps, on the floor. If he is angry, he throw himself heavily, heavily.

FG1: Ja ja

FG2: Up the point where you can even see here, something's out. He is speaking but his speech ….he is 3 and 6 months now, his speech is not yet there, but he can speak. But some you don't even hear anything. He doesn't pronounce anything properly. Uhhh …but I, we've been trying to get uhhh…help, but they say he's not autistic, just give him some time. He will develop properly. He plays, he plays him, I mean he can integrate with other kids but they say he is not autistic, but I feel his like his tantrums are too much than this one.

R and FG1: Mmm.

FG2: This one he is very good, it's just that he doesn't speak.

FG1: Mine has got tantrums, and I think one of the things that also made too long for me to realise is, you'll have functions, weddings, whatever and then you go and he just doesn't want to be there. You will go there and sit there in that corner alone and that you are not comfortable. I mean you cannot be busy whatever, and the child is sitting there and you also get frustrated.

FG2: Oh you don't deserve, you isolate yourself.

FG1: You, you.

R: Your weddings are massive.

FG1: Our weddings are massive you will just be sitting here. He just does not want to be around people, he will go and sit...

FG2: Is it?

FG1: You will go and sit to the furthest corner … so but until I was like once-once one I feel like that those who want to be angry they can be angry, but if I am not going to their functions.

FG2: Oh, but he doesn't mess up. He just isolates himself?

FG1: He just isolate. He just, when you are sitting here, this is the tent he will walk out he will go and sit…. you know just across the street, there he will go and sit there.

FG2: Is it, that is different.

R: And how did you deal with that? That must have been very frustrating.

FG1: Ja, it was frustrating … at some point you I will give him a clap, or what you may call it.

R: Ja.

FG1: So, until I was like you know if it is an event, we go there he doesn’t like it we come back. Like 2 weeks ago, I was like I let me test him in terms of noise and all that we went to Gold Reef City. He couldn’t get onto anything.

FG2: Is it?

FG1: He just like the bounce. We literally went there to bounce and came back.

FG2: So, then he’s different to ours. Ours he doesn’t isolate himself, he wants to be seen like uh... You see now at home because it’s us …he can do up and downs, but he doesn’t irritate, he can do up and downs and sit and start to sing. Whatever they are doing here during the day you can’t stop him. Whatever is done here during the day, you can’t stop him, he will continue – whether they be doing (inaudible). He will do that up until the point where you feel like hey uhhh.

FG1: It’s too much.

FG2: This is too much, no this is too much. You see if they were counting, he will be counting non-stop continually, non- stop ah …one or two you know. But he doesn’t speak he just knows whatever he was doing during the day he will be doing at home. There will be a time of course we have to support him, we join him, but you will be tired, because he doesn’t want to finish. And then… you see. And one day you’ll go to church, weddings. I’m telling you he doesn’t want other kids. He doesn’t want to see himself around kids, he wants old people. He will be with you guys here uh.. the way we chat here.

R: Ja, ja

FG2: He would want to be part of the conversation. He will be sitting here, and then he will be like (babbling sounds) and when it’s your time (babbling sounds) like and then he won’t sit down, because he wants his attention as well. So, ah …the church, I attend the Apostolic Church, you know the Apostolic Church they are not formal like the Lutheran, or Roman. You know how the settings is. I can assure you he will be in front with the priest. He’s there. He can’t sit there with the congregation. He will be there with the uhhh if he sees one pastor maybe pouring water, he’ll be wanting to do that as well. Like they know him like “Where’s your child? Your child really he is our pastor.”

R: Yes.

FG2: Yes, he is always wanting to be – he is always, and he doesn't have a problem with noises. The noise that is irritating him, like motorbikes if they irritate him too much.

FG1: Uhhh…

FG2: Like when they start to ref them too much, that's where you'll see him. Hoover, he doesn't like. Hoover is a no-no from an early when he was still crawling. Hoover is a no-no. Uhhh… machine, cutting machine he doesn't like that noise at all. It's not about that he is feeling pain. That noise of machine. Hoover, motorbikes he doesn't want, but other than that noise – when the people are singing ah he doesn't even have a problem.

FG1: But you know him sometimes I can't like, not sure, if you're …I think he gets familiar to an environment. If there could be a loud TV the Play station will loud he is fine. When you go to an environment where he doesn't feel comfortable then he will withdraw. Even if we go to the malls and he will know the mall. There was a day when I lost him in the mall and uhhh you know when you are looking for someone who you're not sure that they know their name. So, I find him uhhh… like he will go to this uhhh Wimpy play so he'll play, going up down, climb out, but he does not talk to anyone. Then when I go to Wimpy, they'll be like no there was this child. No, we saw him here. Then look for him and eventually I found him, but he does not even with other children he does not. He only communicates with my brother's kids at least he knows them.

FG2: Oh, he knows them.

FG1: But when you can now visit with your child he will not.

FG2: He speaks?

FG1: Yes, he speaks, but it's not a 100%.

FG2: Oh, oh.

FG1: Some of the things you get surprised actually that he knows. You'll be like: "I can't hear you" and he'll be like "Ah, okay".

R: Okay.

FG2: Ja ja, so it's very interesting to hear about that behaviour. His brother when you take him to this kind of jungle…

R: Ja like a jungle gyms and stuff.

FG2: Jungle gyms, he doesn't want that. TV he likes them, but of course his play is limited. He's not like other kids when they can play with that the whole day. Nah…if he can do one time second third time fourth, naah, he is fine. So, his brother doesn't want those things, he's very scared about those things. He doesn't at all. You can't put him even the Gold Reef, his brother can't do those things, but him, he likes them. Here in (mall name) they have the-that machine…

FG1: Yes, those machines the, the, the…..

FG2: No, he doesn't like it, the noise there I think it irritates him. It's too much for him, but you can see he's willing, but the noise it's too much for him. Uhhh…..but his brother doesn't even want those machines.

FG1: Okay, but with mine the (name of mall) one's he likes, I think for him he judges the danger.

FG2: Ohhh.

FG1: So, this one is like the one there outside. So, this one goes up like no no, no, because even when we go to Gold Reef City he was like – I need a train, I need a train. So, as we are walking, then the train start to go up and he was like no, but he was like it, no I don't want it.

FG2: Ja ja.

FG1: So ja, he judges and I… I do feel that he is over assertive or he's arrogant or whatever. I don't know, because you can't force him to do anything. If he tells you I don't want it, he will not do it.

R and FG2: Mmm.

FG1: And I've picked it up, even here at school when they say right, because when he says I don't want it then he will not do anything. And it is frustrating because for me thought like because it is a special school the teachers let you have your way, you know, but he'll just say I don't want it.

R: So, you briefly mentioned ancestors earlier. I know in some of the countries, especially West Africa, they still believe in witchcraft. They say that the child was bewitched and often they either shun the child or say "Now you can stay on your own, because then there's something wrong with you."

FG2: Mmmm.

R: Or a lot of them label them, they call them snake children.

FG2: Oh.

R: Or… and it's very sad, actually. So, I'm just curious… does the whole witchcraft thing still…does it exist in the Pedi culture?

FG2: Ja the witchcraft it does some people...

R: Especially with autism. I'm just wondering if it still exists. I know you said you don't believe in the ancestors.

FG2: Ja, no and uhh I never believed like that there was witchcraft on him. Even for, when you meet around people asking like… because they can notice if you go to other people like they notice that no man. What's wrong with your child? Like, because if he is sitting here you won't notice anything, but once he starts to stand up and do this kind of behaviour people starting to notice. They start to ask you whether you have ever consulted traditional healers? What are they saying? They start to ask you what have you done other than to accept the western way of going to neurologist and paediatricians….what have you done in a, in our cultural.

R: Is that friends or just community members?

FG2: Anywhere. Friends…

FG1: Relatives.

R: Oh, okay.

FG1: Whoever just feel like they can approach you, they want to help you.

FG2: They want to help you, but they want to check if really did you do something maybe …you can say that they're willing but it out of willingness, no what have you done?

R: Okay

FG2: You see that they want to introduce you to their consultation, like maybe this.

R: Oh.

FG2: Someone they will be telling you that there is a certain person …if you take him to this person, he will be fine

FG1: (She was talking and agreed with FG2 on this matter laughing)

FG2: But …ah, I don't, I don't. There's another one of our relatives, we had a family gathering somewhere in Bronkhorstspruit. So, this guy he attended this (name) Church, this (name) Church, the controversial pastor, you know it?

R: No…

FG1: Pretoria West.

R: I've heard of it, but I'm not sure what he does.

FG2: Ja, they say he is doing miracles. So, this man was telling me that I'm telling you, "Two days is enough, take this child to them". You know, sometimes I don't argue. I just said, "Okay I'll see," but know in my heart that no…ah"

R: That might have been how they would have dealt with it?

FG1: Ah….yes.

R: So in both your cases you decided not to deal with it, in that way.

FG2: Ja, because people will recommend so many things, you see. Even with my relatives would be like be ah no man you know, you guys you started to do away with our culture, norms and values. You are supposed to do this… you are supposed to do this… you are supposed to do this… you know…so to me, I just believe like you know I'm a church person, and I believe if maybe we attend the same church, if we choose to pray together, God, one day, He will answer. If it's meant to be like this, I'm that kind of person, that if it is meant to be like this, it should be, so … this is me. So this is that I will have to go and spend money at whatever Sangomas because I know people recommend so many things that, no you should do this thing. No, because this child is born in a foreign country, you should have done this, and when you arrive ….immediately go and see whoever, traditional healer. Do this and do this and I asked my mother: "Really, all this kids that are born here, did you do all these things?" Then she said "No, I have never done those things. I have never" that's why even my mother he doesn't know, like he never even recommended, he will just say that: "Pray or ask some or of the priest to pray with you", this is what we believe.

R: Mmm.

FG2: And of course, in my church we use the dialogue, you see. Like believing if maybe I pray for this water it will turn into something the child ….. .we believe in those things. You believe that this tea we can make it holy by just praying for it then you drink. You see we believe in those things. But just to go all over. Ai I have accepted that no this is the situation.

R: Mmm, so Ma'am have you, have anyone else told you the same thing also try…..
FG1: No, no, no I have no one actually said to me try 1, 2, 3. For me I think I just go to church and it's a prophetic church. I do go and see people with cases, I do go, and I say my son is autistic, my son's nose is bleeding and they pray. So that is all that I have done.
R: Mmm.
FG1: Those then still I believe. I think for me it's in my mind I'm saying it is a delayed development that is going to pass. I think I'm stuck there, that you know definitely Grade 8 he will be at a… that's where I'm stuck. But my issue is the society, because people don't understand…and people just feel the child is spoiled because at some point you just don't know what to do and sometimes he'll do the up and downs and you see he'll be crying he want this and he want it now. And people will just be like this child is so spoilt, if it was my child I would.
FG2: Be beating him!
FG1: Even in church, even in church you know you go to church and the pastors does not even say anything, the leaders they do just not say anything, but the congregation is saying: "The child cannot do this, Pastor is going to be very angry" and I don't respond. I just look at them and I keep quiet.
FG2: Ja it's like …
FG1: So, what, so must I run after him? Must I.
FG2: I know about those things. Last we went to church in Tembisa. When we arrived there, there were a lot of chairs. I said: "You sit here" it because we were …I was with his brother and his brother I said: "You, you sit here in front". So, and then when people started to come in, the majority, they feel that no kids can't occupy chairs. You see, so they wanted the chairs. He was refusing, literally refusing with his chair. So, and people started to be like…whose child is this? No some people are not teaching their kids manners …and stuff like that… and I know that because he occupied that chair, no one is going to …really check.
FG1: (Laughs)
FG2: Yoh, there was this certain time when a certain lady tried to force him. I even have to ask him, that please, please the mother is not here. I'm just with them, that

	will start to cause a problem and I'm just with them you know. But then they will be complaining that ja these spoilt kids all these things….
R:	People are very quick to judge.
FG2:	Ja, you can see this, you could see his mood he was so very very happy. Clapping hands, dancing…
R:	Ag shame.
FG2:	When we sing, when you sit down…
FG1:	I want my chair! (Laughs)
FG2:	I want this chair, up until the service is finish No one took his chair. He refused to give his chair and people are asking you like why are you spoiling your child like this?
FG1:	No, you must teach them that when an adult comes the child must stand up (Laughs).
FG2:	Yes, you know it's cultural that the young ones can't sit while the elders are not standing up. But I knew very well, because I gave him that you, you sit here nobody is going to change him. I can assure you. There was a time where they wanted the toilet. I took them to the toilet. When we came back, we found another one sitting there. I didn't say anything, but he moved that person. Just pushing and then…eish you know it was like, it hits you like eish, you know. Because you are not going to explain, because you don't know like if you are saying this child is autistic, people is like what is that? You see.
R:	So, you need to start educating people.
FG2:	So ja, you see. So, but they they they there are so many beliefs. It's just that it depends on you and also maybe your level of uhhh maybe …I want to …liberty. Your level of liberty maybe can shape you. If it is was not at that level, just imagine people recommend all these things. You'd be…
FG1:	All over.
FG2:	All over, all over. You'd be all over. So, but because it is a personal decision, but now I am not going to – some in my family was like …maybe this person, because where you were staying it was another language, maybe he is still confused. So, when time goes on he will understand that I'm no longer in that foreign land, here's my language and then he will get opened. So, you see there are so

many analyses, that no he's still confused ja… or maybe because he was born that side, and you know. You know in Pedi we believe that wherever you are born your umbilical cord is (inaudible).

FG1: Did you bring the umbilical cord back?

FG2: No.

FG1: (Laughs) That will be a problem.

R: Oh wow, that's interesting.

FG2: Ja some they believe in so many things, they believe so many things and when you believe in those things something comes.

FG1: No no it does, it does come because you can't like uh…..

FG2: But eish I don't follow…

FG1: You don't want. Yes, yes. There are things that you don't want to happen and unfortunately it's a situation that you cannot change now.

FG2: Yes, you so see. So uhm the umbilical cord is flushed there, and some would be like in Pedi you don't flush it.

FG1: You bury it.

FG2: You bury it… So, but wherever you bury it is where you belong.

FG1: Eh heh.

FG2: You see. So, people will be asking what did you do when you come back? Did you do some ceremonial to indicate that you are coming back.

FG1: Uh huh.

FG2: But don't you do those things when someone has died?

FG1: Yes

FG2: Ja but….

R: Now for some reason they've linked it to the diagnosis?

FG2: Yeees, ja they would be like: "No, you need to go back."

FG1: And take it.

FG2: Ja and some other things you know, ja.

FG1: Even if it's just collecting the soil from there. Now we are leaving…

FG2: Ja, now we are leaving, you see.

R: Okay.

FG2: Ja but you know I don't do it with that intention. I like to speak to kids like every time you get into the car. Oh now we go to (place name) let's go to (place name) we're going to (place name). I make it a song. No ah it's not like you say cultural thing. Like even when we go to sleep, I always march with them. (Sings) Go sleep, go sleep, sleep time, sleep time. That is what I do every day you know. Uhhh….because I can see that they are struggling with speech, but I make it just like a song. So, I can see how excited they do. When they go to sleep, they know that: "Oh sleeping time." (Sings) Go sleep go sleep. You know those kids, in most cases I'm always with them than their mother. I drive with them a lot man. So, I like to speak just like I speak to old people. When I drive to like now, I'm take you to school. The smaller one I don't take him to crèche. If it happens that I'm taking him …today I'm take you to crèche (Sings). (Sings) I take him to crèche. I like to speak to him like, you see. So…even when we were living there, I said: "No, now we are going home. This is not home, now we are going home," and he was very young. Like today we are going home, today we are going home. You know the real home. We are going home. But people will be asking like but no there are some other things we should have done more than that, those things. So, but I have noticed that there are so many confusion in this. So sometimes I just say that he's a slow learner, to cut it short, but no he is a slow learner, I just say he is a slow learner. And some people when you say: "This child doesn't speak." "How come?"

FG1: "What kind of a child is this one…"

FG1: (Laughs)

FG2: Why you take him to English school? You, you, confuse the child. If this child you take him to the language that you speak, but there are so many kids that are born. I always say so many kids that grow up in township they pick up. The people that grow up here in Gauteng they speak entire languages, entire, Zulu, Pedi, Tswana, Pretoria language, street language... So, but when you say that no kids are not the same you should insist on one language, insist on one language.

FG1: That language can be English mos, you see we are speaking English

(Laughs).

FG2: You know I really don't know. Ja, so some people would be like no, no, no, you're confusing the child too much. There are so many beliefs in this thing, ja too much. Even myself I don't know. It's just that I I was so very busy, too much busy. I sent the e mail to neurologist, last week to see him again. So, because I was thinking like nah man, the neurologist must scan this child for MRI, check it, what is happening in his head. You see. So even though you make peace with it, but somehow, somewhere it's very stressful, because when the child is born, there is that excitement.

FG1: And you have expectations.

FG2: Ah, yes and later on you hear about this things, more disappointing, more disappointing. So you can just imagine about the people that are, not at, like that kind of liberty their educational level is low. How they can handle this? And uhhh worst part schools are very scarce in terms of this. It's problematic. You can imagine the people that are in rural areas. First, they will attempt to take their kids to normal schools and then there after the child is not doing well. The teachers say muh uh find a kind of special school. In rural areas.

FG1: They don't even say, they just repeat a grade and repeat a grade and repeat a grade again.

R: And where is that child going to end up?

FG1: Ja.

FG2: You see mmm and then they will be like - this is a stupid child, you see, you know. Like ah …one day someone said "Hey, this one is stupid, this one is clever." You see.

R: You can't label a child.

FG2: Ja.

FG1: But those people they don't know.

R: You're not… they're uneducated.

FG2: Ja, you know, but it hit me.

FG1: Ja but it doesn't stop hitting you … you don't just say they're not educated whatever (laughs).

FG2: Ja they'll just say you're not educated. One day there was this uhhh I was even about to leave in where …we are coming from (town's name). When I was supposed to leave when tying up the belt, I was about to tie up the belt. Here comes a certain lady knowing me. I've been calling you; I've been calling you. Said no I didn't even hear anything, because it was like kind of in a mall noise area- you see.

Somewhere if you know (town's name) very well it is next to (town's name) somewhere there. Uhhh…and then he said: "There are your kids?" I said ja no these are my boys and then he said "Hello, hello," and then said: "Hi no, which one is old here? Are they twins?" I said no they are not twins, this one is older than this one. "Hello, hello hey, dumelang, dumelang." And then he said: "No what is wrong with this child?" This one is cleverer, but this one I think is more like wise, you see. Those things, but at least he never mentioned anything stupid to be done like this one in (suburb name). But she noticed something that's: "What's wrong with this one." This one is cleverer.

FG1: (Laughs every time FG2 says something) Sometimes you just feel like people can just observe and keep quiet.

FG2: Ja you see and then that's all and I was coming to Gauteng and in most cases I was with them because in most cases I'm drive with them. So, they were at the back, and I tie them with the seat belts. I no longer putting them on the chairs, I just tie them. They're no longer like before. Before they used to get out find a way of getting out the belt, but nowadays they stay still. Ah so once people start to make these comparisons about them eish – ja- no ah, it's it's…

R: No ja it hits you.

FG2: Ja …no of course they don't know about it and you don't want to explain that this is autism. They'd be like what is autism. I mean, even myself I didn't know about it. And uhhh… even during my …people will be like … you know this thing it's not like a new thing. It has been there even during our time. It's just that we did not know about it.

FG1: Yes, it has been there I mean for me it's like you even start to look and say. This cousin was ….she really "domkoppes" as people would put it or she wanted a different kind of education. And maybe coming to witchcraft, I, it's just like it has never crossed my mind that it is witchcraft. Or also I was just like I'm one person who says you can't be bewitch me, I mean, unless if I want. So, when I divorced my mother-in-law was like: "These children will never be anything," and what, what, what. And for me I will just pray and say: "God, if you are my God, you are going to prove to her. Let them see the results. So, but it was never something that I could say it is witchcraft, it has never crossed my mind. While on the other hand I've got a relative the child is ADDH and all… so they and believing that she was bewitched and the mother is trying to take the special schools and blah blah and he does not have money…and all that. But you can see that uhm okay they'll go to church, but the belief is that there is someone behind.

FG2: Ja, but anyways it's Pedi thing or African way.

FG1: It's African way.

FG2: Ja, African way. They always blame that something witchcraft is there, behind. But to myself I'm always crushing it, that, no, there's no witchcraft here. I'm telling you there's no witchcraft here. And when the child was conceived, we were not even here. You see, the child was conceived away far from home. How the witchcraft? They'll be like: "This witchcraft…this magic thing…."

FG1: Ja, this thing we can fly with you here. (Laughs)

FG2: Maybe you were bewitched when you were young, then I would be like, who was bewitched between me and my wife? Both because we met at a later stage, we didn't grow up together, my wife is coming from another area. We come from far away, like we only met here in Gauteng. So, who was bewitched here? You see like it's like you start to ask, like really? If they say there was witchcraft here. Who was bewitched? We met here in Gauteng. The child was conceived far and born very far away so how does witchcraft? You try to link the logic how this witchcraft really followed us far and then you know and then you'll be like eish…

FG1: It will go with you. It is a spirit. (Laughs)

FG2: Yes, they say it's a spirit, all this. But you know but I never, I always never believed in those things like okay no…. Anyway I don't deny that there's witchcraft….but not to this child, you see. Wherever it can exist, but I always say that and you know lucky, lucky even in my family no one believes that this child is bewitched. They might even ….what they can say is that maybe something didn't, was not properly followed. This what they can say like maybe when you lived there maybe we should have done this this this, you see, and you can see they're not even family. They want to take it from others. Guess what my sister said last week. Uhhh my sister last week phoned me and said that: "You know that I met uhhh… when we were at the bus stop, I was with this lady when we were talking about just normal things, conversation and kids. I mentioned your child. That I have this child of my brother who is 5 years who is not speaking." So the lady was advising that you know in old days when the child was not speaking these old people knew that they open the tongue, I said: “No come maybe,” because he was try to explain. He said Normally underneath the tongue they cut…

FG1: (Laughs) Yes.

FG2: They cut something

FG1: Oh my God. (Laughs)

FG2: They cut something, maybe the tongue something is too close to the to the teeth.

R: Okay.

FG2: Normally they cut something there. And it’s not for the first time to hear this. One day there was a certain lady was telling me that in the old days, when the child was delaying the speech…they used to cut underneath the tongue. Now my sister is the second person to tell me about it. I, I requested her to come. He said: “Is there something that these people.” He said: “No this lady was giving example about one of her relatives” They took this child to the doctor, even the doctors know about that there’s something underneath the tongue. It can be bigger and make the tongue heavy. Stuff like that, you know. I’m waiting for my sister to…

FG1: Ja, ja.

FG2: Come because the person was explaining, but my sister said the way this lady was explaining and then she even showed that this thing can be bigger. Then I said: “No, I’m waiting,” If she doesn’t come over the weekend I will drive, and my sister is in (suburb name). I will go and look…

FG1: (Laughs)

FG2: Try to see. You know, go and look for this thing. I try to look. I don’t really see it. Maybe there is something that I don’t see. And then I said: “Who is cutting it?”

He said: “No, even the doctors know about it” But really when they were doing the assessment why they never checked….

FG1: Look at the tongue.

FG2: Ja, it’s only when they are having fluid they will be like open and then they check with ja. Ah no, I don’t see them checking underneath the tongue. I really don’t know over the weekend I will see my sister to look at what is happening underneath the tongue. Ja…so uh, so you can see, but they are worried, big worried, because you see a very nice child who doesn’t speak. You see, he can sit down. At the beginning you know the doctor prescribed some medicine, but we don't use it. It was said it will calm him down so that he can concentrate…we don't use that.

FG1: I used and then I'm back on it and there's no improvement. I'm kind like not sure, because I feel that they are saying he does not concentrate, they're like, like I said his, you cannot tell him to do something. So, they'd be like right you'll just be like, they'll give him a pen and he'll be like… So, they said I must take him back to neurologist and the uhhh Ritalin.

FG2: Us its Risperdal.

FG1: Then they recommend that. Us he was there, but there's no improvement.

FG2: No but people when we were checking, people were talking about side effects of this medicine.

R: Oh yes…

FG2: They were saying they are bad and that they are not reversible. Then we became to be cautious about it.

R: Yes, oh ja.

FG2: And then when we were giving him, here at school he was too sleepy. You see, he was too sleepy. And then we went back to a paediatrician, because the neurologist said anything see your paediatrician will be communicating. So she said: "Reduce the dose." So, then we decided we are not continuing with it anymore. But I do believe, except the speech, he is progressing very well.

R: Yes

FG2: And without the medicine he's just normal he ah if you say sit, even here, yesterday, I was here for the feedback. He concentrates like whatever they were doing here, he would be doing at home. I know, almost everything they are doing here, and he will be adding on it at home. You see that you get tired, because he wants to repeat, repeat, repeat…

FG1: Ja.

FG2: Ja, like whatever they were doing he always wants to repeat on it, you see. Ja, so this is more something irritated, but what I can say is not only in the Pedi culture, across Africa, this thing of autism.

FG1: It's unknown.

FG2: It's an unknown thing,

FG1: It's unknown, because even myself I didn't know. It's not liked a physical disability, that you see and you know. Hence maybe the witchcraft thing is not coming quicker, because it's unknown. It's unknown. And with him he doesn't sleep.

FG2: Oh, is it?

FG1: Ja, he doesn't sleep. Even I had to come to school and say that he cannot sleep at school. So, when the other kids are sleeping he must do other activities, cause otherwise he will be up until 3 o'clock in the morning.

FG2: Serious?

R: Sjoe.

FG2: No, ours is… No, you'll force him to sleep. Like when he was young, he wasn't sleeping like other kids, you see the smaller one, the smaller one sleep. Hey, the smaller one sleep, he can sleep, you know. If he sleeps by 3 and wake up by 5, I can assure you 8 or 9 he'll sleep again. Ah, but this one is not like that. You have to …even here at school they've noticed it that to make him sleep, you have to pretend as if you are also sleeping.

R: Okay.

FG2: He doesn't see other kids sleeping and sleep. He want to ….he doesn't follow what other kids are doing. I think he always see himself as an adult. Even here they noticed that.

FG1: (Laughs)

FG2: You know, he likes to behave like he is an old person. Like when there are other kids playing there, he won't integrate with them, but he would rather integrate with you here. It's like let's say for example, we are here, and we then put kids in another room. He won't be there, he wants to be here, and join us. I will assure you if he comes here and there's this chair, he won't be there….and he realise that we are chatting, he will stand here. When we chat, he'll be look at you and (babbling sounds) if it's my time (babbling sounds) like that. So, if you pretend like you are sleeping and you close your eyes, he will be end up sleeping. But even in the evening he sleeps a lot.

FG1: Mine he just doesn't sleep. He will sleep with his brother and he will sleep with me, he will not. He will be up. There will be times where I, I work late. I'll be like, go back to sleep, go back to sleep sometimes I'll be like, let me switch off the lights and then leave him, but he can’t. You will go back to the bedroom it will be dark, he will just be busy…

FG2: Oh. He is sleeping alone?

FG1: Even if I can take him to my bedroom, he will not sleep.

FG2: No, ours he doesn’t want to be alone; he doesn’t want to be, you can’t go…

FG1: No, he doesn’t care.

FG2: Because we were very happy about him, so we hold like… we wrap him… we rest him like…

FG1: Like the firstborn. (Laughs)

FG2: Ja …even today you know, he doesn’t want that. And then his brother came realised that this person is taking over. You know he could even kill the brother when he was young, because he used to be the one. Now you have to take another child. So, you could see the jealous. Even today, he still wants that he can’t sleep alone, he wants to sleep next to the person. Ah, but as long as you show him that I’m sleeping he will sleep. So, but nowadays I am training him by force, to sleep. Even if we are not sleeping, I force him. Like both of them now. Go to bed, go to bed. Uhhh and I chase them with a belt, like I would be hitting the floor. Hey and then they are scared for that. I can see that he is so very, very, scared of, ja. I mean with the belt. If you just hit the floor with the belt. Yoh, he feels so very frightened, then he goes to the bed up to. Five minutes he will be gone, but if he wakes up and he find that he’s alone, yoh… he will.

FG1: Ja my son couldn’t be bothered.

FG2: Is it? He doesn’t want to alone.

FG1: He just say he will not sleep, and you will sit there. Like now I know we cannot put him to bed before 10 o’clock, otherwise 2 o’clock he is up.

FG2: Ohhh.

FG1: So, the doctor just said: “Okay whatever time 10 o’ clock and then we use the camomile oil on him because we bath him at that time then he will go to sleep.

FG2: Serious?

FG1: But he it does not even work. We just like, okay he will sleep, but 5 o’clock he is up. Monday, Sunday. Whatever he is up.

FG2: What I know, both of them the small one, when he wakes up, he complains. This one you wake him up, he's fine. But he doesn't awake himself like ah no, you have to wake him up. Like in the morning to come here, but he doesn't have a problem. The smaller one jusus, you'll really have to …hey, hey wake up, wake up. But him even though he sleeps the entire night, but in the morning when you wake him. Even in the middle of the night you can wake him you can say: "Go to toile," He'll just go, he doesn't even have a problem to wake up. He'll just wake up as like he didn't even sleep and go and pee and come and sleep again. And if he pees on the bed by mistake, you can see, you'll feel like he will show you that a-a-a. Ja you just know that something went wrong here, but that's why and his brother whose they say is not, when he goes to bed you still have to put a nappy. Ja you see, but him at this one's age he doesn't even, unless by accident. So that's why I am saying I'm trying to understand the two. The one who's not autistic according to what they say and the one that is autism. So, I do believe like this one's brains is far more, far more than this one that is not autistic, which is something else. So, I don't know uhhh…but in our culture truly speaking, across African cultures, or South African cultures no, no one understands this thing. I think lot of awareness needs to be made even in schools. I have noticed that even other doctors they just know about this thing but deepen it.
FG1: Ja,ja.
R: Okay. So, do you maybe know of someone else that I can speak to. Maybe an elder or someone else who might have been uhm exposed to, or who have dealt with autism in the past. You maybe know of anyone you can refer to me or otherwise you don't, it's also fine.
FG2: Hey, I don't know too much.
R: Mmm…
FG2: Ja, because you know when people are not speaking about their kids you never know.
FG2: You see, even our self, like I mean we don' speak often everywhere.
R: Ja ja, okay.
FG2: People that you feel comfortable with. Some is like more you don't feel comfortable, like what is? You are… a lot of questions. What is? Ja you see.

R: Ja I understand
FG2: So uhhh it's very difficult, unless maybe those who are working with kids with special needs.
R: Mmm…
FG2: It may not be autism per say, but like look now this school in (Town in Limpopo's name), they just decided to call it "stout" school. I think it is having a name. I don't know the name, but there's no other way school can just be "stout" school. You know it.
R: No, no.
FG2: There's a school in (Town in Limpopo's name). You know it?
FG1: No, no
FG2: They call it "stout" school.
R: Sjoe.
FG2: Mmm ja and some believe in our culture say that jusus you see this child of you, he's going to beat you big time. This child is going to be like who is uhhh… he's when he grows up, he is going to be one of those people that that are going to be very violent. This is going to be very violent child, you see. So ja so they always say you must start to discipline him, from now, because this one, I can assure you, if you don't start now, this is going to be this kids that are robbing people, hitting people.
Ja, you see. So, you hear all those things.
R: Ja. Thank you very much for your input, I really appreciate it. Uhm so would you mind sitting one-on-one with me for a few more minutes (to FG2). I won't keep you for another hour.
FG2: Uhm, ja.
R: Because I can see you are tired (to FG1). So, then we can discuss a few things one-on-one
FG2: Okay.

Appendix E: Questions asked in semi structured interview

Draft of semi-structured interview:

Questions will again be grouped according to the primary and secondary research questions, with possible probing questions listed below each question.

Note: The questions serve as a guiding force to direct the conversation. Probing or further questioning will be utilised to identify themes or elicit additional information regarding the topic under discussion based on the responses of the participants. Distinction will be made between general Sepedi views and views limited to Sepedi individuals.

What are Sepedi views on (the nature of) autism?

1. Your child has been diagnosed with autism. What do you understand of autism?
2. Where did you get this understanding from? (doctor, parents, magazines, internet, community?)
3. After your child was diagnosed with ASD, was it explained to you what it was?
4. With what do you agree and with what do you disagree?
5. What do your family and community say about the diagnosis?
6. What did you initially notice about your child?
7. Did you encounter any of these behaviours prior to noticing it in your own child? If yes, when, where and with whom? (keep in mind as a possible interview)

What are Sepedi views on the causes of autism?

8. When you noticed these behaviours, what did you think was the reason/s or the cause/s of these behaviours?
9. How did you respond to it?
10. How did your community or family respond to this?
11. What did they (community and family) say was the cause/s of this behaviour?
12. Did you understand what the cause was after diagnosis?
13. With what do you agree and with what do you disagree?

What are Sepedi views how to deal with autism?

14.Did you think there was a way to help or assist your child?

15. How did your family and/or community suggest you deal with your child?

16. How did you deal with the matter after diagnosis?

17.With what do you agree and with what do you disagree?

18. How did your child end up in the current school?

19. What intervention/treatment was implemented?

20. Did these / How did these interventions assist/support you and your child?

Conclusion

21. Think back about your own knowledge about ASD. What have you learned throughout your journey?

Appendix F: Transcripts of individual semi structured interviews[8]

Semi structured interview participant 1:
Researcher: R
Participant one: I1
R: So, you say they diagnosed your child with autism. Did they ever explain to you exactly what it was?
I1: Not really. We relied too much on Google. The paediatrician said Google about it and then we relied too much on Google. Ummm of course the neurologist said yes, I confirm the child has autistic. Whatever assessment he did he ja no he is autistic, but he didn't explain too much about this autism.
R: That's interesting because they should actually do that.
I1: Uhhh yes. He didn't at all.
R: Oh, okay. So, what did your family say about the diagnosis?
I1: Of course, they don't know what it is. This, a lot of my family even my parents, are in Limpopo. When we go there and say that this child is autistic, "What is that, what is that?" they ask. And then you decided to like okay make it simple to them that way. He is having some brain problems or mental problems.
R: Mmm.
I1: And they will be like: "No it can't be look at this child he is very…" because they look at his physique looks…when you say his developmental brain problem, they think of someone who is mad. I mean, this person is mad. No, not mad per se, but something on the brain is not fine. You see. And of course, when they say it's a spectrum even yourself this thing is not only one, it's a spectrum. Then you try to understand what spectrum he is here uhhh you know we only went to a neurologist only once and then we never wanted to go back. I mean we were so irritated; I even cancelled the next appointment that no I'm not going to make it because so very angry to figure out. Maybe they maybe it was too early maybe the neurologist was going to explain more uhhh because he said I can't tell what kind of spectrum but it's a spectrum of so many ja more like amalgamation of so many thing you see. So, it's very difficult to explain to someone that what kind of disease is this.

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[8] For the sake of fluency, [sic] was not used for transcribing purposes. It was however utilised to report the results of the study in Chapter Four in order to uphold academic standards.

R: Do you recount other children who were ever autistic before your child was diagnosed. Were you exposed to…

I1: I just know that when we were growing up uhhh there was some slow learner kids I just know that there were just slow learners and uhhh…

R: So, it was never given a name?

I1: Uhhh uhhh, those teachers never even gave a name and there were some who were repeating uhhh the standard maybe two times then they pass and when they pass they pass nicely then they go to another and then they repeat in old days there was no this thing of age limit that by this limit you must be out of school unlike today. You know when I did matric, I did matric with uhhh with some old people that have been failing and they even passed matric, you see. They had to repeat, for each standard they used to repeat. If they pass it's only one, two, but in most cases, they used to repeat. And even like when I was matric there was people who were repeating two times, they passed the third after the third time, you see. So, nobody knew about this and uhhh even in my, when I was young I've never seen someone who has developed speech after some time, never seen that.

R: So, when you take your son to family gatherings, how does the family interact with your son, how do they deal with this, how do they respond to it?

I1: The only place that I take my child, no no, in most cases the big family events I don't, I don't go with him because you'll find that there is some other places where you feel like you don't want to go with kids. Uhhh but smaller gatherings you can but they're always asking like: "Hey man, what is happening with this child, why he can't talk", because I always say that he can't speak uhhh that's why there's this thing because he doesn't uhhh he doesn't speak. And then it be like: "Is he a deaf?" But they know the deaf that isn't hear they can see that he can hear, that means that he is not a deaf, but then they say: "But how possible, this person hears but he can't speak?"

R: It might just be their way of trying to make sense of…

I1: Ja, ja, because the question is like because we see we see he is not deaf but why he can't speak. And nowadays it's worse because when you call his name for, he doesn't respond by sound, when you say: "(child's name)!" he come.

R: So, after he was diagnosed, did you deal with his symptoms differently than you did before.

I1: Uhhh uhhh because we just heard that he, he needs therapist (school's name) is… because we were recommended about (school's name), Google they were talking about it. There is this school called (school's name) when we Google we found the (other school's name) and of course the headmistress told you there is another one that is (other school's name) when I look (other school) was too inside it's inconvenient that because I wanted to, like I felt like I wanted to drop him, one to drop him every day to, to this school. So when were told that only therapy, and when we Googled that only therapist mmm they can do even though is seems like they are not guaranteed that it will bring the child and then, you know back, and then we asked they said ja no this is a lifetime thing, the child can overcome does not mean that it will go you see, so it will always be with him, so you see. So, we believe like whatever they do here is good, even though we are not expert, but we'll try something at school obviously. So…we believe that uhhh this uhhh intervention between the school and us at home it will be much more helpful. Even though we are not really…we can't say we are expert in training the child cause we are not even teachers, you see, so we rely on him really, whatever they were doing here we try it at home like making the recommendations that this week it is the (inaudible) and then it will be finding okay what can we do based on that.

R: Yes, okay. So initially, did you think there was any way to help your child?

I1: Any how?

R: Yes, I remember you said that he had a lot of tantrums or he had moments where he had tantrums that was very difficult to handle, at that stage did you think there was any way to help or assist your child?

I1: Uhhh, it was very difficult, the, he didn't have too much tantrums as compared to his brother…

R: Mmm, mmm.

I1: The only situation it was, but it only happened a short period of time, when you go to shops, where he wanted to run around. Uhhh, he wanted you to chase him, like you can see he is running far and uhhh I know, it was very difficult. Uhhh not knowing whether to, you feel like ey this child, you might even beat him, and all these things. You become irritated where you have to chase around the child in the shelves of the, like shops, you know. It was very very difficult, but anyway we had the stroller if we wanted to contain him, just put him on the stroller.

R: Okay.

I1: That’s all. (laughing)

R: Okay, so was there ever a point where you felt, oh my child, I can’t assist my child, what am I going to do? Did you feel helpless at any stage, or…

I1: I was kind of asking myself why God was punishing me at my early age where there was supposed to be joy. You know, I’m a religious person like ja, and then I was like I’m praying. I go to church. I know I’m not perfect, but why man?

R: And your wife? I’m wondering about how… if it was so tough for you, for your wife?

I1: It was tough for her as well.

R: How was…

I1: Ja it was of course blaming each other we’d be like: “Ja this child he inherited from your family.” I wanna be like: “Ja also in your family he he inherited in your family.” And of course, he even inherited you as well, you see. So like the blaming, blaming, blaming, blaming, blaming, blaming, because seeing that this thing can be hereditary and um once they say it can be hereditary it will be like okay then we have to blame each other that it come from your family, no it come from your family, you know, all of those things. So eish, it was tough man uhhh, really tough, but regardless of autism the thing that stresses a lot is non-verbal, you feel like no man, you know. As the father and as the boy you feel like you can be like speaking to him like a boy playing on the garden soccer with him, it doesn’t want to do those things, so, you are kind of like eish. Ja because you know I remember the Occupational Therapist asking like the autistic kids can drive a car? Because, you know asking those things can they drive a car one day? Can they, because I can see he is not going to play any sports here, can they really? I was like they can be very mechanical; they can even fix a car.

R: A lot of them are highly intelligent.

I1: Yes, and not all of them, it depends, and they were talking about Aspergers, we were reading about Aspergers…

R: Oh yes…

I1: Uhhh, on Google, there was a certain movie, one of our friends, friend, colleague said by this time watch this movie and uhhh they said there is an Aspergers child there, all those things. And uhhh there was also on Generations a last year they were promoting this thing of autism, campaign awareness.

R: Oh wow.

I1: Yes, so they were doing it there as well. Sooo, in our like of course sometimes we say this is just a drama or movie this person is normal it's not like he is an Asperger's person, so but, eish, there are so many things. Even yesterday when I was, I was asking like I have never seen an old person who is autistic, but working doing very well, even today I have never seen that person. So, she was telling us that go and have a movie called The Accountant.

R: Uhh huh…

I1: Then we will understand it. Because one day it was Saturday there was small kids with autism, they were promoting somewhere not too far that you can take your kids for he is having trampolines. This… what is the name of this…(gestures).

R: Bounce?

I1: Ja, somewhere here and then they have this climbing wall, all those things you know. So, there were so many kids there, whatever I see in comparison to my son, I saw completely different things. Some you can read from their face or their physique know that not this one you can read that there is something. But my son when he is sitting down here, not saying anything just …. You won't even notice you see. So, and I was feeling that if he can develop the speech…truly speaking uhhh it will be a big achievement. It can be a very, very big achievement if he can develop the speech. Because what I've noticed that some of his limitation is non-verbal. But I do believe like if he can be verbal all of these limitations that I see on him will be going. I see a lot of potential in him. Mmm. I see a lot of potential on him. That's why I keep on comparing, comparing, comparing, comparing. But I see a looooot of potential in him, really.

R: Mmm.

I1: Uhhh this what I see. Even for sometimes you the…the…the morale can go down, but I still feel like there is potential on this child.

R: No that's wonderful. And obviously as a parent you have to have that wish for your child.

I1: Yeees, yeeees.

R: You can't say ja he has been diagnosed now we do nothing.

I1: Ja, and another thing because I don't speak about it on everyone, people at work will be like how old is your child. Oh, he's in Grade R? Or is he going next year? You see. All these kinds of questions put you under pressure like and then you start to say eish if he was normal, he would be next year maybe doing this grade he would be like you know, all those things.

R: I think it's normal to feel like that.

I1: Mmm.

R: Because it's things that you went through yourself, you went through all of those stages so you think okay your child will also progress through the same stages…

I1: Yes…

R: And now things are different…

I1: Sooo…. I've never seen a person who is autistic and doing well, I am trying to check… Uhhh.

R: I think they're out there we just don't know it…

I1: We don't know. Ja because uhhh our paediatrician was telling us that I think she is coming in Limpopo as well, but where I didn't ask her, because she was saying that there is this old lady who is handling the community things like if there is funeral you know like how black people can do the what it's called… the clubs where they do money together and take it to the bank so that when there is kind of bereavement they can buy a cow, food for funerals stuff like that. She was saying that…. According to her….that woman is autistic, her behaviour and the way she engages is autistic but she said that lady is the one who coordinate everything but she said if something goes wrong you can see that it takes her some time to bring it back. So, she do things in order, if anything that in her order goes out of that order you can see that how…

R: Yes, it throws her off…

I1: When we were in Europe, when we were working there, there was this French lady, that lady she is so very organised she want to have things like order. If let's say for example you see like she puts the … her files like this if it happens that you move something by mistake you've messed up her day. Her day is messed, and she will leave. Mmm.

R: Basically, you said that after your child was diagnosed, did you bring him straight here (the school)?

I1: Yes, immediately, I didn't waste time, didn't waste time.

R: Okay…what did they do? What type of intervention plan did they put in place for him? So, in which way… what kind of plan did you work out together to assist your son?

I1: We didn't do it immediately, because we were still…

R: Mmm…

I1: Trying to figure out. Ja, so we said okay it's fine so because we were told that he must go to this school, they are good they have autistic kids. So, when we placed him, we came looking for the space and o wanted to see if they will take him. So, we didn't know where we were going to start, really, we didn't know, we didn't at all like ah… yoh, I think I don't know whether… Maybe I was too irritated to them, they used to ask so many questions. Then, what will be our role? They used to write that. Okay, this when you are at home like normal kids, you're to do like whatever even if it was like normal child. You know you check the homework, you play with the kids, you, you sing songs to the kids you know ah you know like…

R: So, like a routine?

I1: Yes, you see. Sooo this was what they were advising, okay no we will be give you what you should do, be doing at home, you know. And of course, they became very helpful, ja, they were so very helpful.

R: Okay, so you… is he receiving occupational therapy now as well?

I1: Outside?

R: Here? Is he receiving any occupational therapy here?

I1: They have their indoors here, they have their own indoors here.

R: Okay, so he is receiving that.

I1: Ja, he is receiving you know those type of training.

R: Oh, only occupational therapy not speech therapy or…

I1: No, they have their kinder kinetics, remember.

R: Okay, ja.

I1: They have… I think they have trained their teachers on how to do Occupational Therapist stuff like that.

R: Mmm. Okay.

I1: Um you see, but they were telling me that we might request like maybe recommend that you know have an occupational therapy from next year. Maybe if he, the person can come here to teach him how to write all these things like to make him hold the pen and all these things. That’s what they were recommending, you know, but we might request this, maybe recommend it for next year. But they said for now there’s no need, because they have their own way of training them.

R: Okay, so for how long has he been in this school?

I1: We came here, he started 2017.

R: Okay, so for two years now.

I1: Yes, it’s two years and six months.

R: And have you seen an improvement?

I1: A lot, there’s a lot of improvement. You know he can (laughs) write now, he can read. Ja, he knows A, B, C’s.

R: Okay.

I1: There was a time where you could see he will be like triangle, square. So I think they use more like groundwork.

R: So, did your household routine change a lot after you brought him here?

I1: Ja, a lot.

R: So, what is your routine now at home?

I1: No, we look at what they are doing here. Of course, the songs are always sing with him, but sometimes he get irritated when people follow him because we asked him that sometimes I don’t know when we try to sing with him. Sometimes we don’t want to disturb his mood. So, if you see he doesn’t want the company of you, allow him to be alone and sing alone. Now I can see he gets irritated a lot, by his brother, because whatever… the brother is also going to the crèche. Whatever he wants to sing alone the brother follows and he gets so very. And there is no way we can, there's nothing we can do. So, I think not the disturbances is the brother. Ja, he is a serious, serious disturbance.

R: So, I assume you've learned a lot about Autism…

I1: Ja, I've learnt a lot.

R: Ever since your child was placed in this school.

I1: I've learned a lot, even for his challenging. Remember, they are not the same, for you see they are not the same, so autism is something as they say spectrum is completely, completely…

R: Every child is different.

I1: Ja, every child is different, which is something that is a challenge when you are trying to understand, because we have this child, you'll meet another child. That you will see, that no maaara I mean… this is another what kind of autism is this now? Like when we want to that….. Even my wife said, "You know what, I think a lot of these kids, most of these kids that are here are severe. I felt like they're severe." My child has been on trampoline for quite long. He can even do this trampoline when we go to Limpopo, I bought the one at my mother in Limpopo that uh that big one. So, when they trampoline, they even sprint, sprint like you know. You know, so he's trying to imitate them, but ah you can see it's difficult to do that. It's difficult for him to roll like that, but you can see he's trying, but he doesn't want to, he doesn't, he's not able to do that. But you just feel like ah no but he's still small those….

R: Mmm, ja, ja.

I1: So, you see even my mother will be like, you'll say this person is having a mental problem. Why he can even take the old people. You see. (Laughs) You see.

R: Oh, that's what makes him unique. That makes your son who he is.

I1: Yes. So even though he likes to isolate himself, but not as like (focus group participant one surname) was saying. So, this one wants to, he can isolate himself from kids of his age, but like know when you are sitting with old people like this, no he wants to be there. He wants to be seen.

R: So, what is… what would you say, I think this is my last question…

I1: Yes.

R: So, you've been on quite a journey with your son.

I1: Eish… ja.

R: It’s been up and down and left and right and every direction. So, what will you say is the main thing that you’ve learned throughout all of this? And it can be about Autism, it can be about life. What have you learned from it?

I1: You know…

R: If you can impart some wisdom on me. As a parent um whose child has been diagnosed with autism, what…

I1: Sometimes I will always follow with people can say that life sometimes can humble you, you know. Me and my wife we have this and that. You, know, the situation that we grow up in. We don’t want our kids to grow up in that kind of situation. We work our kids must go to this kind of school. We must work hard. We must do this for our kids and attend this nice school. We don’t even mind if our kids one day they can be like maybe one of the internationalists. I said “really”. It seems like in African way you don’t want to be like, your kids be, I know in your culture maybe you’ll find like you can go and live in the U.K. while your kids are here. Are you going to cope if your child would be in U.K. or America or far, it will be like ah no we should not. You know we live in this kind of world nowadays. We don’t have to restrict our kids. So, we felt like ah, what why did God punish us like this? All of those aspirations of our kids… why? You know, all those things. Ja, so but I’ve learnt we need to teach our self so many things as well, like there are so many things that we don’t know.

R: Mmm.

I1: It’s unfortunate that when they come in a… you have to know them in a difficult way, but sometimes there this and thing that say, don’t expect nice things always. And then when you have bad things who should this bad goes too, because we are all human beings, we deserve the best. But why, like if not you, then who?

R: That’s true.

I1: You see. So, at the beginning there was, you know, I was saying I am reading the Bible like why God is punishing me. Is it because of I’m too evil? Because there is a scripture that says I will punish kids because of the wrongdoing.

R: The forefathers, and they will be cursed to the tenth generation?

I1: Yes, you see then I was asking like, what did we do wrong really… to be punished like this? Really. And then I said no, but anyway there's not punishment there. If not us then to who, I know there's nothing really punishment. But the issue of witchcraft, I know it's there. Some people believe like no, we are too westernised and then why we don't follow the procedures. So, I crushed it from the beginning. Ja, it was something that we, even like when I was telling my wife. She supported me and she stand behind me that… let's not put witchcraft here.

R: So maybe it actually brought the two of you closer in a certain way. Would you say it brought the two of you closer, the family closer?

I1: Oh, me and her?

R: Yes.

I1: Ja, we you know as a couple's sometimes, you there's some other things of disagreement you know. You quarrel and stuff like that, but we feel like they think of our path. You know, both of us were raised by single parents. We'll be like, you know we don't want our kids to be like that. Ah… you know and ah we just feel like no, we have to appreciate this is no one's fault, this is our child. So, ah ja I know I can assure you it makes us, our relationship very strong. And ah lucky you know in our culture in old days, this kind of things, it will be that something that will make us to divorce, but instead of that it makes us to be strong and even bond worse, you. I know even in the beginning, when we were trying to understand this thing there was thing of like no because they say it's hereditary. It comes from your family. No, it comes from your family, you see. And then she'll be like you know like this quarrel that you know no it comes from your family, no your family.

R: It can't be my family…

I1: Yes, you see. Ja, there were these kind of things at the beginning, you know. But I still believe even today that this thing of caesarean, if kind of not…ah I still blame it, ja, I still blame it the caesarean I…

R: Ja, and what I can understand from what Mrs. (Focus group participant surname), also said. She also said it's something with the birth of the child.

I1: Ja, ja ah. I do believe like when the woman goes into labour it's natural. It's supposed to be like that. During labour I do believe like it's like because it's a natural thing it's supposed to be like that. Something because it's natural, something is developing there, you see. So, the child is developing the intelligent, the brains developing very well, because he know now this is my time and then this is where the labour. And when you decide to cut it short the woman doesn't go into labour it's my other reasons. It's my analysis.

R: Of course, I'm interested, that's why I'm here. I'm interested in your analysis.

I1: It's not scientific, it's my own, subjective ja…

R: No, that's what I'm interested in.

I1: I believe like if the woman goes into labour, it means that the child is responding somehow inside the womb, he tells because it's the universe, now it's time, I want to go out. I've been in this womb for this period and now it's my time. Normally with caesarean they will be like okay but this period, normally the person has grown to maturity we can take him out. So, the person never had that in memory, he was still enjoying the womb and you disturb that person's memory. So, I do believe that the time that the woman goes into labour, stuff like that, that's where you can do caesarean, not the planned one. And then of course they argue, you know, sometimes the one is emergency. We don't want that to be emergencies.

R: Ja, ja, then you obviously can't.

I1: Now I said, "No, wait for this emergency? Because you are professionals, you are doctors."

R: Yes, yes.

I1: Deal with this emergencies, because now the child is telling that now is my time, I want to go out. I mean you will agree with me the water will go out, telling that no okay this woman needs to go to hospital, it's about time. So, then lady will be in labour pains. This labour pains I do believe that is like the natural way. The brain and everything of the child is completely now developed. This is my thinking, I do believe like the child was enjoying to be in the womb, not yet time to be… and then you bring the child. And then there's another friend of ours, he had his… there's so many people that go for caesarean and planned one their kids they're not autism. So, you see, you see…

R: They start to think about your analogies.

I1: That's why I say it's just subjective, but I do believe that the person that was inside the womb was enjoying and then you tampered with this, you see… So, I felt like the person was angry since the beginning because you tampered with this. So, I do believe like…

R: Yes.

I1: The woman must go into labour pains; water fall and that's when you can operate and do caesarean. Not the planned one, that they look at the weeks and then they say, "but this weeks is a developed person and ja he can be taken out."

R: Oh, yes.

I1: Stuff like that. This is my own analogy. This is my own making.

R: Well thank you, I appreciate that, thank you I really appreciate that.

I1: Ja, no my pleasure. I'm looking forward for your…

R: Ag thank you so much.

I1: Your final ah…

R: Oh yes, I've got a lot of work ahead of me, but I'll… Thank you so much.

I1: Ja, I really appreciate that there are people that are interested in making research about these things.

R: No, it is very important.

I1: Yes.

Semi-structured interview participant two
R: Researcher
I2: Participant 2
R: For me autism is something that is very interesting and as I'm sure you know there's a limited amount of information. People don't know about it and that is why I'm doing this study.
I2: O, okay.
R: It's a way to create awareness.
I2: Ja, ja.
R: Basically.
I2: And we should like also in townships we should promote it as well.
R: We have to.
I2: Not a lot of people are aware of this.
R: Exactly.
I2: They don't know how to deal with it also.
R: Yes, and that's why I brought in an expert because I'm not an expert you are the expert and that is why I'm speaking to you. Because you have first-hand experience. I have some experience but it's different to be a parent, than it is to be an educator or psychologist or whatever the case might be. So, yes so that's why I said I'm calling in the experts and asking them how they experienced it and especially Pedi views because in a lot of African countries I know they exclude children who are autistic, they call them snake children. Yes. They say that they are cursed and that there is witchcraft involved.
I2: Ja, ja.
R: So, I want to investigate a few things whether those things, you know also exists in South Africa. But we'll get to that part. Okay, so you will see that I'll be taking notes as well. But of course, I'll be listening to what you're saying as well so I'll be multitasking.
I2: Okay.
R: So, your child has been diagnosed with autism, right?
I2: Yes, since he was 5 years, mostly since he was 5-year-old.

R: Okay and what do you understand, what does autism mean and what do you understand behind that meaning?

I2: Well, I have first saw it on TV with 20 breaks thing? But I didn't know much about it until I found out that, when my son was 3 years old, he wasn't speaking but he was walking, but he was like doing everything besides speaking. Then I took him to the clinic then they referred me to the speech therapist, so we went for speech therapy and occupational therapy. So they told me that maybe it might be autism, so like within that time we, he wasn't at most yet, but there was sign of him, because he couldn't make eye contact with us and play on the grass or touch things or even adjust to people like he was so not socially towards other people.

R: So, he was reserved, hey?

I2: Yes, very reserved.

R: Okay so, oh those where the first things that you noticed, hey?

P: Yes.

R: Okay and did they ever explain to you what autism was after they diagnosed him?

I2: Not much, but I, like I Googled it.

R: Okay, okay.

I2: But they told me not to like so much on Google because some say that I think it's how many kinds, it's high function and low function. But he has high function, because now he can read, he can write, he can be able to play with other kids. But at first it was very difficult, because we didn't know how to handle him especially with his behaviour, he couldn't tell us when he's, where he's hurting or what is going on if he's hungry or what, so that was a bit stressful.

R: Yes, I can imagine. Especially at the beginning.

I2: Um. And ja, at the age of 5 where, there was a, I took him to a local crèche. So, I asked them if they would be able to handle him and I explained that he is not like any other kids, he doesn't talk but when he wants something, he would rather show you. Be patient towards him, then they said no they will handle him. But within 3 weeks they already suspended him, by the age of 3 years.

R: Which age?

I2: 5

R: 5? And how old is he now?

I2: He is turning 9 in September.

R: Okay, so he is turning 9. Okay and as I understand it you are a single mother.

I2: Yes, I am a single mother.

R: That must have been very difficult.

I2: Last year was the worst year of my life, like to handle to this thing. Like his father was there financially, even now, he's still here financially. But he finds it very difficult to accept, he's like I don't know if he is trying to deal with it or what but he I think he is a bit ashamed of him because he won't spend time with him. He'd rather say that take it lets take our child to his parent’s house, then I'll see him there, he won't ask to bring him to his place, because he doesn't want his friends to know. Yeah.

R: O, okay. So, who diagnosed him, initially?

I2: Dr (surname of doctor)?

R: Okay, so is it a doctor, is it an Educational Psychologist or a?

I2: He's a Neurologist.

R: A Neurologist? Okay and did he explain to you what it was, or not really?

I2: Yoh, he was, I think he was a bit mean.

R: Okay, ja? Sure, you can, you can say, it is not as if I'm going to him.

I2: But hey, yoh, he was a bit mean I felt like he was a bit impatient with us. He like, he didn't sit long with us and explained. He told us that we are babying him, we should be more firmer towards him and I like, we asked him how can we do that when we don't understand other? How do we do that? Like we need to find a common ground between us, how do we communicate? How like from here do we go, how do we get help?

R: Um, and what did he say?

I2: The only thing he told us that the schools that he goes to, those are the the kind of help that you can get.

R: Okay, so everything that you know, is mostly based on internet sources?

I2: Ja.

R: Okay, and other parents?

I2: Other parents? Uh, there is a friend of mine, but his son has Ceribal paralysis. So, we communicate, she also has, like she knows how to deal with such things.

R: Okay so wow that must have been very difficult for you. What did your family and your community say after the diagnosis, how did they react? What was their response and what did they say?

I2: Um. My father, my stepfather actually. He's the one that believes in, in the ancestors and but we, like my mother and I we don't believe in such things and at this day and age we know that there are this kinds of spectrums so we can't all say no that it is witchcraft and stuff. But my family have been very supportive. Because even when I come to the meetings at school, they come with me and also when I used to take him to the speech therapist um his grandparents would also come with me. Also, my friends they were very supportive.

R: Okay, so in general community and family and…

I2: Yeah, because we talk about it, my neighbour, she has a son who has vitaligo. So, it's new to us, it was that thing, that no, the ancestors are punishing him, then we Googled it but it's just this skin condition, these things we need to be aware of it and we need to accept it, not base it only on the ancestors but we also need to be aware of these things.

R: Okay, so those family members that still believe in the ancestors, what did they say? Was the cause of his autism?

I2: Uh...It was, I had to go to church, from church they told me that it's my biological father and his sisters aren't getting along, so it's those things that are causing, affecting my son now. I'm like how, because it's not even my fight, it's their fight and I don't even know what their fighting about? My biological and I we are not even close, we don't have a relationship at all, so how is this affecting my son?

R: Exactly, and how are you supposed to solve it then?

I2: Yeah, like how do I get help from them when they aren't even not on speaking terms. Like how do I go to them?

R: Okay so after he was diagnosed, how did the family advise you to deal with, with his condition.

I2: They just told me to be strong and like whatever, they will always be there for us no matter how difficult it is and how expensive it is, but they will always be there.

R: Okay so before, so you say initially you noticed that he didn't make eye contact and he didn't communicate as well…
I2: Yeah, he also didn't have any social skills.
R: Okay and before you saw these signs or these behaviours in your son, have you seen it somewhere else before?
I2: No.
R: Never?
I2: Never.
R: Not in school, not in your family?
I2: Like I wasn't even aware of it until I saw the signs in my son, then that was when I got a wakeup call.
R: Okay so when you went to your family and you said: “Okay, my child has autism” did they know what you were speaking about?
I2: No, they didn't know. Because this thing is new to us. I am actually first one in the family to have an autistic son.
R: So, there aren't any other family members, so everyone you know, all of them. No family members who struggled. So, you're trying to think? Ja?
I2: Yeah, I'm trying to think but so far no one.
R: Okay, okay so when you first found out that he has autism what did you think was the cause?
I2: We asked about it, we asked if it was genetic or what, so they told us that it's not genetic. But uh what Dr (surname of doctor) told has was that, there is a 70% chance that even if we have another child, he might be autistic. So, like that thing, it always stuck to us, that yoh, what if our like our child become, we have another autistic child, how do we handle it? When we're struggling with this one. Because every day is a learning curve for us, every day.
R: So, before he was diagnosed what did you think was wrong?
I2: Nothing, because he, he started walking at 10 months and he then one day, 3 months he had like everything like everything was one time but I had a concern that why isn't he speaking at this age, that's when I had to take him to the clinic.
R: Okay so that's when you started asking yourself…

I2: What's wrong with him?

R: Yes, yes. Okay, so okay so, you didn't really know exactly what was going on, you just knew it wasn't normal.

I2: Yes.

R: For a child of his age, basically.

I2: And I asked my mother if, when I was young, was I also like this, and she said no. Then I also ask from his father side, how was his father? Then his mother explained that no, his father started talking when he was 4 years old.

R: Oh, okay.

I2: Ja, okay. I became a bit relaxed but then it was a concern for me because even the books that I was reading, at this age your child should be at least be making a sentence. But at the age of 3 my son wasn't making any sentence, only calling us by our names. That's it.

R: So, did you at any stage ask yourself if you did anything wrong or if you know, I know a lot of parents feel that it is their fault or that they're angry. What emotions did you experience?

I2: Well, for me like I took it as if I didn't want to delay my child so I'm not going to blame anyone, I'm just going to try and get the best help for him as possible because I like I think what if I did something wrong, because I followed every instruction in the book from birth and then this thing comes, I didn't question myself, I don't know.

R: So, was it a full term pregnancy?

I2: Yes.

R: Was it a normal birth?

I2: Yeah, he is a post mature

R: Okay, so he was actually born after 40 weeks? So, a natural birth I assume.

I2: Yes.

R: Okay, that's interesting, ja, because some people feel that it might be because of the C-section or whatever the case might be. Okay, that's interesting. Okay, so basically, how did your child end up here, at this specific school?

I2: Well I took him to, he was in (name of school) first.

R: Oh, okay.

I2: So, they're the ones that referred me here, to this school.

R: Okay and what did they do the moment you brought him here? In which way did they start to support him?

I2: Well, he first went for this test, this test first. Where they go to grade 2 or start again in grade 1. Then the first 3 weeks for him it was difficult to adjust, because he wasn't even coping and that was also difficult for me because I just came out of a relationship with his father so I think, I thought maybe I was being strong for him, but apparently I wasn't, it's like he was also affected by that, that's why maybe he wasn't coping.

R: Okay and since then? How has...

I2: Since then, his doing okay, ja.

R: So, has it improved since he has been here? Did they give you anything that you must do with him at home?

I2: The only problem we have with him at home is when his sick, we can't go to the doctor. He is afraid of doctors, like literally afraid of doctors. And he can read if this is a surgeon, he won't go.

R: Okay, so how do you deal with that?

I2: Yoh, It's very stressful. Like every time when he becomes sick, I also become frustrated, because he doesn't want to, just because of one bad experience, so he doesn't want to go to any doctor, any doctor.

R: So how do you, so what do you do? How do you...

I2: The last time that he was sick the doctor had to come to the car and examine him.

R: Oh, okay.

I2: And he is also afraid of when the weather changes, when it becomes cloudy, thunderstorms. Yoh. He won't move, he'd rather come to you, you must wrap him with a blanket and cuddle him. So, I even told them at school so they're aware of that, even at home it's like that.

R: And when you have for example a family gatherings or weddings or how do you manoeuvre that or how do you deal with that?

I2: At first it was difficult because people were judgemental like, why is your baby always here? Why isn't he playing with other kids? And why is your baby not talking? Why is he eating specific food? So, like every time we have to explain.
R: And when you explain to them how do they...?
I2: They're, like “Oh, okay so it's like that”, so they know how to deal with him, they know how to accommodate him.
R: Okay, so what do you say to people? When you first meet them, and they start asking questions? What's going on? What would you say to them?
I2: Oh, but firstly when you see him you won't notice that he has autism, ja. But as time, like you'll see okay there is something different about this child. Then I have to explain, no he has autism like it's, it's a bit difficult for him to play with other kids. He has to adjust first, then he'll go and play like that is what I tell them, be patient, if he doesn't want any food don't force him food, he'll eat at his own time.
R: And when you say, so I assume its people also from a Pedi background, so when you say to them that it is autism, do they know what autism is?
I2: Yeah, now they know, what autism is.
R: But initially?
I2: Because, like from our side, we have I think 3 or 4 teachers, so they are aware of this.
R: Okay, sorry. I just want to check. So thus far you say it's been really effective. So, when your child started to show symptoms. Did you think there was any way to help him? Initially, did you think you know you can help him; did you think there was a way to assist him? Or did you feel a bit helpless or how did you feel at that stage?
I2: At that stage I didn't feel helpless because I didn't care about who's going to say what about him because I told myself this is my son and I'm going to do what's best for him. Whether it's his father or my friends or anyone but I'm going to do what's best for my son. But later onwards that's when it kicked in, okay. I've accepted it, but I don't know how to deal with it, how do I deal with it?
R: And who helped you with that?
I2: My family.
R: Mmm, okay and the school?

I2: Also the school, yeah. The school plays a big role in his life. Especially last year at (school's name), I used to communicate with the teachers and ask them okay now I'm gonna tell this one to do his homework, how do we move forward from that. Then the teacher said no it's fine I'll talk to him tomorrow and tell him that: "You have to do his homework when you get home" like they have a way of dealing with him, especially when it comes to his behaviour because sometimes you don't know what to do? You don't know whether to yell at him or spank him or what? Because we're also trying to understand him.

R: So what does he do that makes you, you know, question how to react. What else does he do to...?

I2: Like they showed us that whenever he's high, we shouldn't also be high. We should just try to come down and like looking him in the eye and tell him that whatever that you're doing is wrong, you need to go and fix whatever mess that you made. That's how we communicate with him.

R: So, when you say, when he's high is that like tantrums?

I2: Yeah, the meltdowns. Because he used to bang things, throw shoes and everything, whatever he finds he throw it.

R: Okay and then when that first started you didn't know how to deal with it.

I2: No, I didn't.

R: How did you deal with it at that stage?

I2: Like it was so frustrating because I didn't know what was wrong with him and he also couldn't tell us what is wrong with him. So how, how do I calm him down?

R: Okay and who do you stay with?

I2: I stay with both my parents.

R: Okay and they've been supportive? And when he was diagnosed what did they say?

I2: Ah they told me that it's not the end of the world and that we're going to try and get help also. But like I said, my stepfather is the one who believes in the (inaudible) he also went to the like ancestors' ways, but I nah, I'm too scared of that so I couldn't deal with that.

R: Okay so what did he do? Did he go to a Sangoma or what?

I2: I'm not sure if he went there or what he usually doesn't talk about it.

R: Yeah, but what did he suggest? When he got the chance to suggest anything what did he say?

I2: He said that we should take him to church and see what's wrong with him and I'm like okay fine we can try the church route, but we also need to take him to the doctor because they're also the one's that's going to explain to us what's going on. We can't only rely on church.

R: Okay and the church he's referring to is it Christian? Is it...?

I2: Yes, he's a Christian.

R: Okay, so did he want them to pray for him? Or...?

I2: Yeah, to pray for him. Then we did that and like just to accommodate him and show him okay fine whatever help that's coming I'm willing to accept it, yeah.

R: Okay… And routine? I assume you had to change your entire routine at home after he's been diagnosed.

I2: Like the food, that we eat. But now he eats everything so. Even like we had to chance things like sleeping time, also the type of food and what else? Like going out. Going out for us, was so stressful, because he doesn't like where it's overcrowded, like he'll become hysterical and he'll cry. So, whenever we have to go to the mall, I make sure that I don't go to the mall with him alone. It's either I'm with my mother and sister or I'm with my friends, so that they can help me out and make him feel comfortable that it's safe you are here with us, nothing is going to happen to you.

R: Okay and when you're alone how did you, you know, deal with it? How did you manage it?

I2: Yoh, like I wouldn't stay more than 30 minutes in the mall. Whenever he starts, I have to go home with him. Just to accommodate him.

R: So again, then he would throw tantrums or cry or shout or throw things.

I2: Ja, he would cry and become very scared when he sees lots of people. Also getting on a bus, like even today I didn't think he'll ride a bus because he is also scared of that, but he'll say “Oh, there's a bus” and I'm like okay fine let's go inside it, no he doesn't want to go inside the bus.

R: Okay, that's quite interesting. It's interesting how the children differ. Because they have one description of what it might be and then another child might show something else. So, you say he has high functioning autism? So how do you understand that, what do you think that means?

I2: It's not that server because he's like now he can play with other kids like he's socially like how can I put it?

R: So, he used to be very reserved, ja?

I2: Ja, now he is not shy any more he can play with other kids, he can make conversation.

R: And his schoolwork? How's he doing there?

I2: His school work, ja, so far so good, yeah. He can read he can write, but stubborn when it comes to homework.

R: Ag but most kids are stubborn.

I2: Like we have to force him and like every time when he doesn't want to I'll be like okay fine I'm going to call your teacher and tell him that you don't want to do your homework, that's when he'll start doing his homework.

R: Okay and so do you talk to a lot of people you know, when they see your child and they ask, you don't mind explaining to them what it is?

I2: Uhhh hu (no).

R: Okay, because a lot of people might say it's something else to try and avoid the entire discussion of what it is.

I2: You can't avoid it. Because there are no signs, even when you are pregnant there is no signs you might have an autistic child.

R: Ja, okay so I think like one of the most important questions that I want to ask you is, obviously this is a journey, for every parent it's a massive journey, and it's a big responsibility and it's difficult. In your journey with your son what have you learned?

I2: I've learned to be more patient with him and like try and accept whatever challenge is that coming our way because it is really not easy, ja.

R: Ja and the future? How do you see… have you thought about that?

I2: I haven't, because I don't want to stress myself.

R: Yes, of course, so you're taking it...

I2: Ja, step by step.

R: Ja and then you're going to see how things work out. Okay, is there anything else that you'd like to share with me? Anything interesting that someone might have told you within the Pedi community about autism and about what they thought your son, or your child had. I'm not sure if it's a boy or a girl.

I2: Well he's from his father's side they we're like they were also in denial because they said no he's going to outgrow it and I'm like no, he's not going to outgrow it. But we all have to adjust to him.

R: So, you say you think the father is embarrassed?

I2: Yes.

R: Why do you think that is… or ashamed?

I2: Because of the way he treats him, ja. He doesn't have any relationship with him. The only relationship that he has with him is by paying school fees and also putting him on medical aid. His parents are the ones that's playing the role like even these holidays, they're the ones that took him for the holidays.

R: Oh, okay. So, do you think it is because of the autism? Or?

I2: What, according to what his aunt told me, is that we need to give him time to accept and like maybe he should go and see somebody. Because he hasn't dealt with it and I'm like we are all in this situation, how am I dealing with it? Like he also needs, it's his son, he must also take responsibility, not only with money. But he must show him that he loves him unconditionally no matter what.

R: So, I assume you've tried speaking to him about it.

I2: Yeah, a lot, so it's like speaking to a brick wall.

R: Ja and you think the main reason is...autism?

I2: Ja.

R: So at least his family is involved.

I2: Yes, his family is involved.

R: Okay, so they're all, so what did they say to you, what did his side of the family say when you said okay this is what's going on.

I2: No, they were all also very supportive because like I said they would go with me to the meetings, speech therapies. Whenever they're free, even if, like, finding schools they'll go with me. For them it's not something new, like the way they took it was like it's nothing new towards them. It's only their child that, he refuses to accept his son.

R: Oh okay wow, that's amazing.

Appendix G: Field notes, observations and reflections during the focus group

Date: 20 June 2019

Time: 15:00

Setting:

- Private room (office) and the private school
- Curtains closed
- Adequately lit
- Discussion took place with participants and researcher sitting in a circle around a coffee table with the female participant being seated to the right of the researcher and the male participant to the right.
- Noise levels varied according to the activities of the learners (remember during member checking of transcript: important to check noise levels to ensure that valuable information is not lost due to noise)

Participants:

FG1: Female

- Divorced
- Self-employed: Environmentalist
- Busy schedule

FG 2: Male

- Married
- Government employee
- Busy schedule

Observations:

Male	Female
Well-dressed (work attire: black and white suit) **Introduced himself immediately and started asking about the other participant's child** **Talkative and enjoys sharing with the group** **Frequent eye contact**	Well-dressed Asked about the nature of the research before discussion commenced Arms folded most of the time Leans on one side Hands clasped at times Laughs and makes jokes (unique sense of humour)

Frustration evident when discussing challenges **Uses gestures** **Smiles** **Laughs – good sense of humour** **Disappointment evident when speaking about the plans they used to have for their son** **Comfortable** **Open body language** **Not afraid to voice opinions** **Took the lead in the discussion** **Consults female participant to confirm whether she has had similar experiences or that their thoughts were aligned** **Agrees to participate in a one on one interview with the researcher**	Seems to find some of the traditional views amusing Tired (yawning, mentioned this beforehand) Initially a bit reluctant to talk, needed more specific probing Lead by male participant and researcher Eye contact established later in the discussion Occasionally hums or nods in agreement Frustration and/or irritation evident when she discussed schooling as well as social challenges faced
General	
Collaborated well **No conflict** **Parents seemingly not getting the support they need** **Seems like an unnatural setting for the participants: might not be used to talking openly about their child being diagnosed with ASD, especially with a stranger (member checking where participants have the opportunity to voice opinions one to one might prove to be valuable)** **Fact that they showed up might show a willingness to talk to others**	

Reflection:

Today I conducted a focus group discussion as well as one semi-structured interview with research participants. It was truly enlightening to gain a glimpse into the lives of parents whose children were diagnosed with ASD. Initially the focus group participants seemed a bit uncomfortable but became more at ease as the discussions progressed. This might be the case as all those who were involved in the group discussion were unfamiliar with one another. The participants' children attended the same, quite small, private school which might cause one to assume that they have met one another before. This made me realise that there possibly exists a lack of communication and/or support amongst parents whose children have ASD as it is commonplace not to discuss the diagnosis with others. The male participant mostly led the discussion and the female participant contributed based on what he discussed as well as further questioning. Initial reluctance to communicate with me might possibly be due to us speaking different languages and coming from different cultural backgrounds.

One of the aspects that was especially striking to me was the challenges that parents with children diagnosed with ASD face daily and how those who do not have children diagnosed with ASD take seemingly simple daily tasks, such as going grocery shopping, for granted. These challenges exist across cultures and therefore a diagnosis of ASD might serve to be an opportunity for people to unite and support one another irrespective of their culture. What I could further gather from participants is that supporting a child with ASD is especially challenging within a South African context due to resource constraints. This information was gathered from participants who are fortunate enough to enrol their child in a private school where they can receive support and despite this support still experience challenges to manage day to day life. I could not help but try and imagine the feelings of helplessness that parents in rural areas might experience when their children are diagnosed with ASD due to financial challenges as well as limited access to resources.

A lack of awareness as well as unique cultural views regarding ASD also piqued my interest. One would think that current technological advances and the influences of the Western world on South Africans might prompt the extinction of traditional views. However, this is not the case as these indigenous views are still very much alive. Indigenous views which might seem ridiculous to those who come from a Western background still serve as a frame of reference and seems to be the reality for indigenous groups in South Africa.

Semi-structured interview participant two:
Date:12 July 2019
Time: 15:00

Setting:

- Quiet classroom after school
- Well-lit
- Participant seated across from researcher

Participant:

- Female
- Single mother
- Unmarried
- Stays with her parents
- Late due to public transport delay

Observations:

- Casually dressed
- Seems a bit nervous at first
- A lot of questions and prompting before responses
- Spoke more freely about what she seems to be passionate about such as support received from family members, lack of emotional support from her son's father as well as daily challenges
- Does not use a lot of gestures
- Sits with handbag on her lap
- Friendly with the researcher after the discussion

General:

Interview of a shorter duration
Unfamiliarity and language might have been barriers

Reflection:

Today I conducted the second semi-structured interview with a single mother whose child has been diagnosed with ASD. Initially she also seemed reluctant to share information, which corresponds with the notion of previous participants that in indigenous cultures there exists a reluctance to talk about ASD and their experiences. A lack of awareness of ASD within indigenous groups within South Africa was also concurred.

I realised the importance of not making assumptions during research endeavours. For example, since she is a single mother, one might run the risk of assuming that she does not have adequate financial and/or familial support. However, the support that the participant received from her and the child's paternal family was inspiring. It truly reminded me of Ubuntu within indigenous African groups and how they support one another through tough times. She experienced similar challenges and noticed similar symptoms than the other participants. Despite contributing financially, the participant expressed a lack of emotional support from her child's father. This emphasised the importance of not only financial but also emotional support for parents of children diagnosed with ASD.

What was interesting is that where participants in the other interviews showed concern for the future, this participant chose to focus on the present as a way of supporting him best. This made me realise that even though one has the same culture, individuals still have their own unique views and approaches toward life and therefore culture is merely a factor which guides and not dictates views.

This participant also expressed her concern regarding a lack of access to schools in South Africa, especially rural areas, which are equipped to support children with ASD. Therefore, this was a concern for all the participants involved.

Appendix H: Member checking

Focus group participant one:

This participant agreed with the themes and subthemes chosen but communicated the following as something that was important to her regarding coping with her child with ASD scholastically. The information was obtained from a telephonic discussion which the participant consented to having recorded. Below is the transcription of the telephonic discussion with this participant.

MC1:	"Access to autistic schools is very difficult. You can't like have an expectation because it's not necessarily a private school. You know when there is a public school and a private school, you know that the curriculum is different, you expect better from a private school because of it being private. I don't have an option; I can only take him to a special school, and you get frustrated. You have an expectation that the teachers are at a higher level of understanding how to deal with autistic children but yet you get queries every day. You don't know what to do and they expect you to do something, why do you expect them to be the specialist and it's really frustrating. The second thing is the school readiness. When school readiness is done, or how it is done, they allocate an hour. They come and do the school readiness, in that hour is a new person who is independent, the child really is not yet comfortable, and I find it very unfair to use that to say that he is school ready or not school ready. And I am not even in a position to say I can argue the results, because I also don't want to jeopardise the future of the child. You just have to accept what you're being told, but when you think they need familiar surroundings and so forth. So you ask yourself whether the school readiness is necessary to be done by an independent person who comes to school for that day, and they do school readiness and they tell you he did not want to respond to anything and therefore the conclusion is that the child is not school ready because he could not achieve a specific score. Some of those frustrations, you don't know how to act as a parent."

Sections of the above statement were included in Chapter Four to take into account information obtained from member checking.

Focus group participant two:

After being sent the password protected full transcription of the focus group discussion, focus group participant two agreed with the proposed themes and subthemes. However, he made a few additions and comments on the information contained in the transcript. Additions will be indicated in red and comments in green.

Information or comments on transcriptions contributed by Focus Group participant two:

	Original transcript	**Additions/comments**
MC2:	Ja, it was so very…	Ja, it was so very difficult…
	There was so many many many questions…	There was so many many many questions one has to ask, like…
	…where I am working people are not talking about it some are odd…	… where I am working people are not talking about it some are old kids, (or grown kids)…
	…but that guy was very open, but you know that my son…	At least that guy was very open – and he indicated this, but you know…
	I said ai no, no, no. We already gave and we are happy with…	We already gave him a name to call (Child’s name)…and we are happy with…
	…because it he would have been within the people	…because ~~it~~ he would have been within the people…to play with…
	So I was starting to blame because even paediatrician was telling me that I wonder the soldiers that are normally being deployed the Department of Health is having some health practitioners that are going outside, as well, and you guys that are always	Here I was trying to indicate that sometimes I blame for our son to be born outside SA. But the Paediatrician indicated that their officials in (department in which participant works) and other officials from the (other

	going outside, I don't know whether there is a link, but I am not saying, ja, because he is a paediatrician.	department mentioned by participant) and some other health practitioners that are in most cases deployed in foreign countries like in my Government department. But the Paediatrician did not want to link this as the cause.
	The child was born there all of them they are having all of these things …you see.	In most cases, most of the child born outside SA are having some *more like psychological* challenges.
	…these kids when they come…back home is having some cultural shock, and there…	…these kids when they come…back home is having some cultural shock, and there…
	He was very, very … eish	He was very, very shy… eish
	And uhhh but I don't know whether if it is autism or it's not.	And uhhh but I don't know whether that behavoiur… if it is autism or it's not.
	He is speaking but his speech he is 3 and 6 months…	He is speaking but his speech is also little….he is 3 and 6 months…
	His brother when you take him to this kind of jungle…	His brother when you take him to this kind of jungle, he resists to use them unless his elder brother uses them…
	…certain person if you take him to this person, he will be fine…	certain person somewhere else who help people (normally they refer to traditional doctors) if you take him to this person, he will be fine

	…but know in my heart that no,…ah"…	but know in my heart that no, I won't do that consultation …ah"
	… and I know that because he occupied that chair, no one is going…	… and I know that because he occupied that chair, no one is going to use it (the chair)…
	…but he moved that person…	…but he moved that person off the chair…
	You'd be…	You'd be like going all over the world…
	You know in Pedi we believe that wherever you are born…	You know in Pedi we believe that wherever you are born your and also your umbilical cord fell, then you are belonging there…
	Ah so once people start to make these comparisons about them eish – ja- no ah, it's…	Ah so once people start to make these comparisons about them eish – ja- no ah, it's it's…difficult to handle.
	I'm waiting for my sister to…	I'm waiting for my sister to…maybe come and check the child tongue.
	I will go and look…	I will go and look for what my sister is referring to…
	…when they were doing the assessment why they never…	…when they were doing the assessment why they never checked for it…
	You have to…even here…	You have to make him sleep…even here…
	…now this school in (Town in Limpopo's name)…	…now this school in (Town in Mabogane/Soshangube name)…

Semi-structured interview participant one:

After being sent the password protected full transcription of the focus group discussion, semi-structured interview participant one agreed with the proposed themes and subthemes. However, he made a few additions and comments on the information contained in the transcript. Additions will be indicated in red and comments in green. When the participant suggested deletion, those sections were not included in Chapter Four.

Information or comments on transcriptions contributed by semi-structured interview participant one:

	Original transcript	**Additions/comments**
MC2:	He didn't at all…	He didn't at all. Maybe is because they have both realized that we don't understand what is that. In short, they just indicated that Autismchild's have delayed speech and they don't have eye contact.
	I just know that when…	Not really, I just know that when…
	…the standard maybe two times then they pass and when they pass, they pass nicely then they go to another and then they repeat…	…the school standard (grades) maybe two times then they pass and when they pass, they pass nicely then they go to another.
	"Is he a deaf?" the deaf that isn't cannot hear and they can notice that my son sees the is able hear…	"Is he a deaf?" But they know that in most cases a deaf cannot hear, and they can notice that my son is able hear…
	And nowadays it's better-because when you call his name he responds, when…	And nowadays it's better because when you call his name, he respond even

		though he doesn't respond verbally, when…
	…both the… because we were recommended about (school's name), Google they were talking about it…	…both the paediatrician and neurologist … recommended about (school's name),
	…and then we asked they said ja no this is a lifetime thing; the child can overcome does not mean that it will go…	…and then we asked they said ja no this is a lifetime thing, even if the child can overcome some of spectrums does not mean that it (ASD) will go…
	Even though we are not really…we can't say we are expert in training the child cause we are not even teachers, you see, so we rely on him really, whatever they were doing here we try it at home like making the recommendations that this week it is the …… and then it will be finding okay what can we do based on that.	What I was trying to say here is that, we are not experts, neither teachers, but we will try our best to assist him at home. In most cases we rely on school recommendations and programmes they do during the day/week at school.
	You become irritated…	You become frustrated …
	…garden with him, doesn't want to do those things…	…garden with him, it's unfortunate that he doesn't want to do those things…
	Even yesterday when I was, I was asking…	Even yesterday when I was here with the speech therapy, I was asking…
	I have never seen an old person who is autistic, but working and doing very well, even today…	I have never seen an old person who is autistic, working and doing very well in life, even today…
	…they were promoting somewhere not too far (school) that you can take your kids as they are for, he is having	…they were promoting somewhere not too far from here (school) that you can

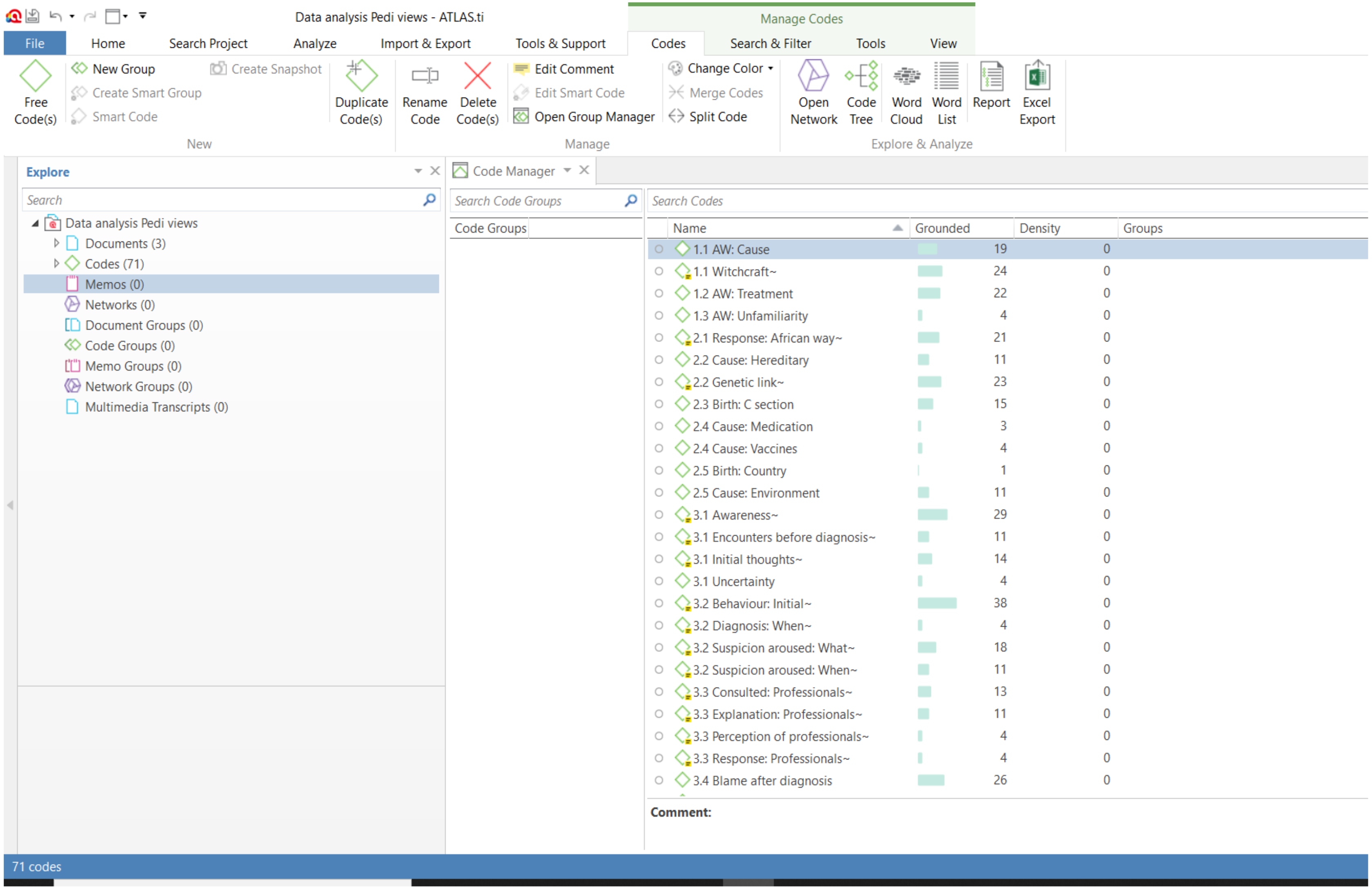
	trampolines. This… what is the name of this…	take your kids as they are having trampolines. This… what is the name of this…
	…they were promoting somewhere not too far (school) that you can take your kids as they are for, he is having trampolines. This… what is the name of this…	I was referring to place called Rockvalley.
	Now I can see he gets irritated a lot, by his brother, because whatever…he does, his brother is also going to the crèche.	Now I can see he gets irritated a lot, by his brother.~~,~~ His brother is also going to the crèche.
	Whatever he wants to sing alone the brother follows and he gets… And there is no way we can, there's nothing we can do. So, I think the disturbances is the brother.	Whatever he wants to sing alone the brother follows and he gets so very angry about that. And there is no way we can, there's nothing we can do. So, I think now the disturbances is his brother.
	…so, autism is something as they say spectrum is completely, completely…	…so, autism is something as they say spectrum is completely, completely different…
	But you just feel like ah no but he's still small…	. But you just feel like ah no but he's still small and some of those kids spinning are older to him….
	We don't want our kids to grow up in that kind of situation. Our kids must go to this kind of schools…	We don't want our kids to grow up in that kind of situation. We work very hard that our kids must go to this kind of schools…

Semi-structured interview participant two: (MC3)

Semi-structured interview participant two was given a personalised hard copy of the transcript as well as proposed themes and subthemes as it was a logistic challenge for her to schedule another face to face meeting or full telephonic discussion. She was phoned by the researcher and asked if she understood what the themes and subthemes entailed and whether she agreed with these themes as well as what was contained in the transcription. She agreed with the themes and subthemes and did not express any concerns with regards to the content of the transcriptions.

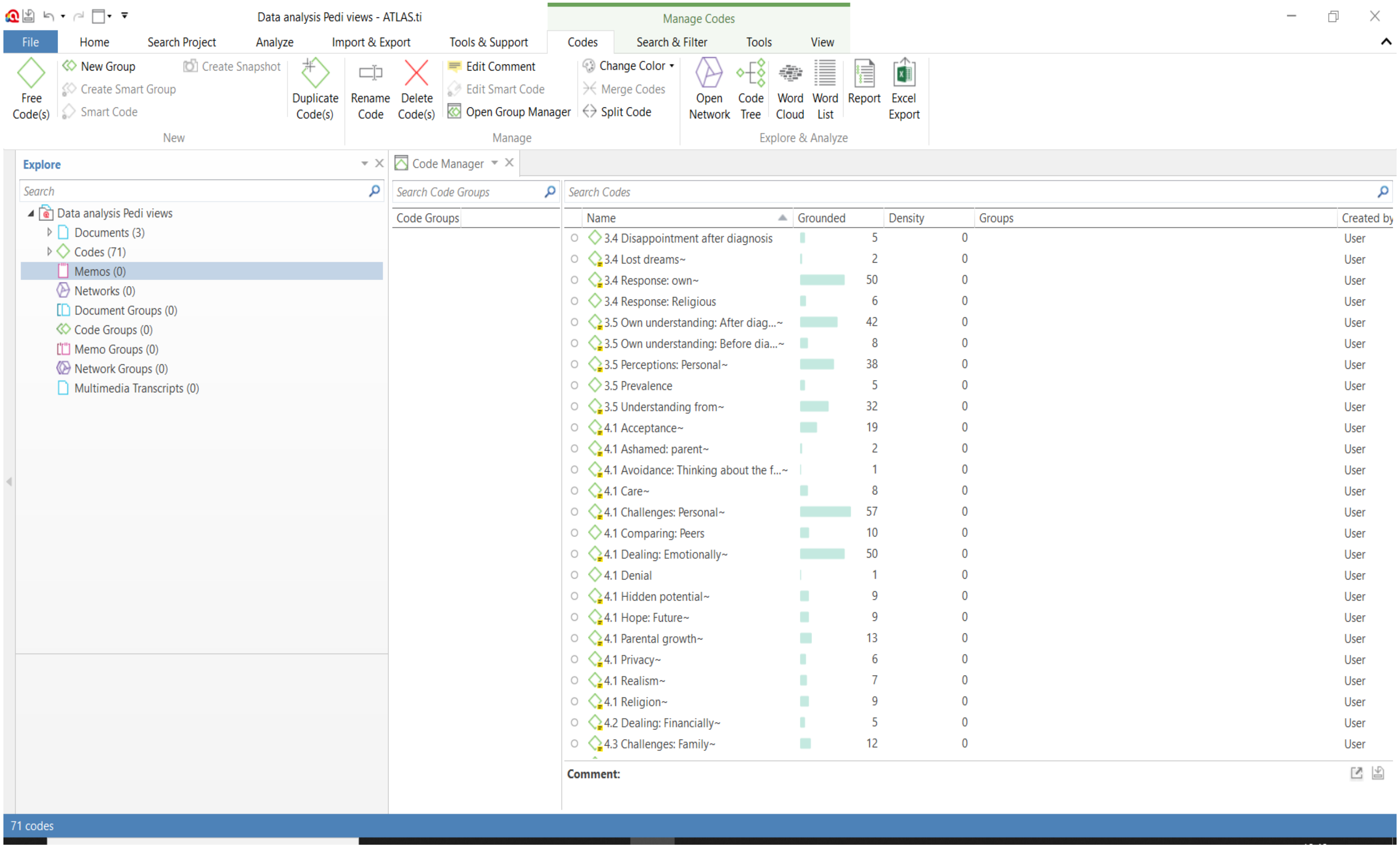
Appendix I: Screenshots of Atlas.Ti analysis

ATLAS.Ti codes which served as sub subthemes

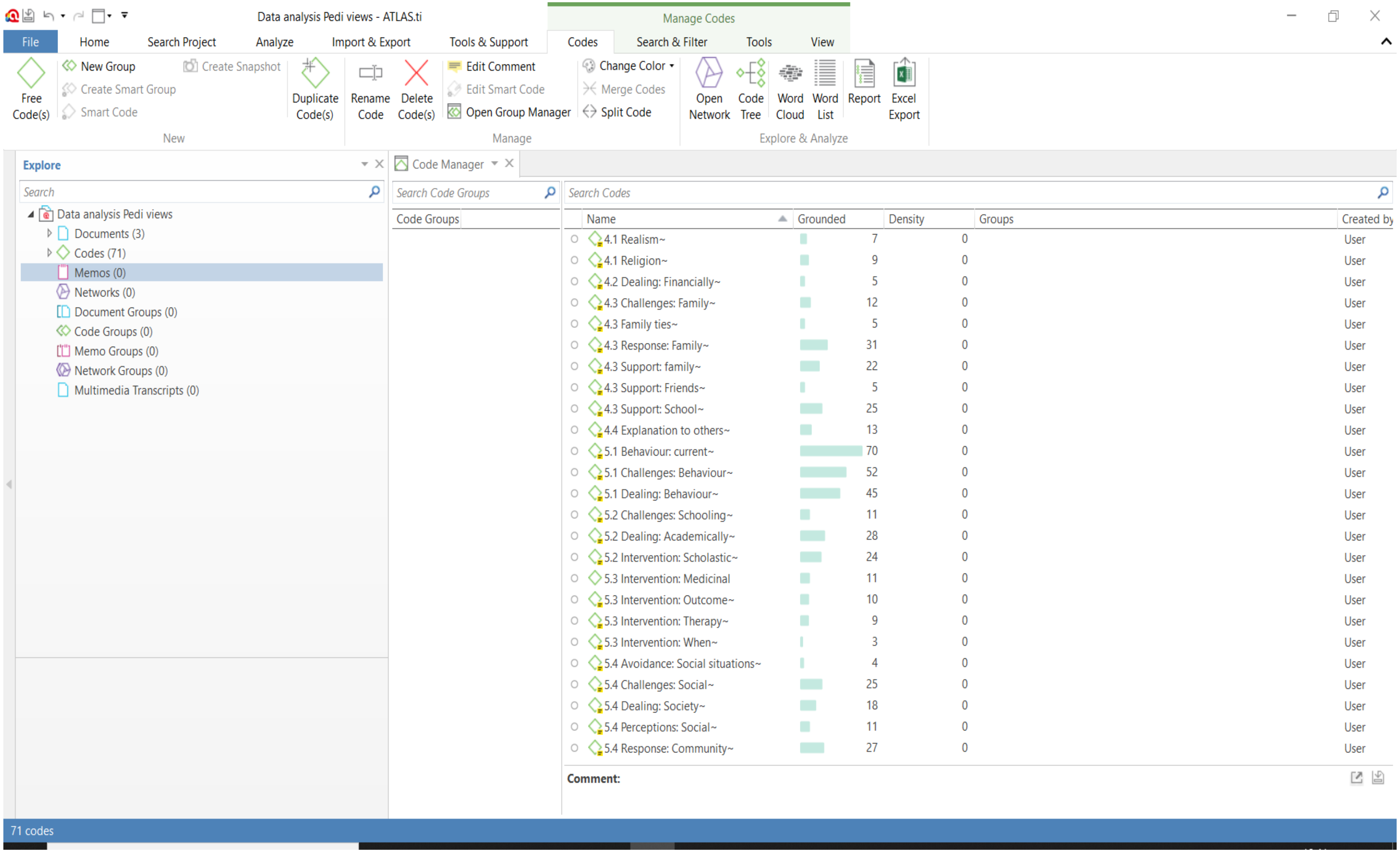


- Data analysis Pedi views
  - Documents (3)
  - Codes (71)
  - Memos (0)
  - Networks (0)
  - Document Groups (0)
  - Code Groups (0)
  - Memo Groups (0)
  - Network Groups (0)
  - Multimedia Transcripts (0)

Name	Grounded	Density	Groups
1.1 AW: Cause	19		0
1.1 Witchcraft~	24		0
1.2 AW: Treatment	22		0
1.3 AW: Unfamiliarity	4		0
2.1 Response: African way~	21		0
2.2 Cause: Hereditary	11		0
2.2 Genetic link~	23		0
2.3 Birth: C section	15		0
2.4 Cause: Medication	3		0
2.4 Cause: Vaccines	4		0
2.5 Birth: Country	1		0
2.5 Cause: Environment	11		0
3.1 Awareness~	29		0
3.1 Encounters before diagnosis~	11		0
3.1 Initial thoughts~	14		0
3.1 Uncertainty	4		0
3.2 Behaviour: Initial~	38		0
3.2 Diagnosis: When~	4		0
3.2 Suspicion aroused: What~	18		0
3.2 Suspicion aroused: When~	11		0
3.3 Consulted: Professionals~	13		0
3.3 Explanation: Professionals~	11		0
3.3 Perception of professionals~	4		0
3.3 Response: Professionals~	4		0
3.4 Blame after diagnosis	26		0



Name	Grounded	Density	Groups	Created by
3.4 Disappointment after diagnosis	5	0		User
3.4 Lost dreams~	2	0		User
3.4 Response: own~	50	0		User
3.4 Response: Religious	6	0		User
3.5 Own understanding: After diag...~	42	0		User
3.5 Own understanding: Before dia...~	8	0		User
3.5 Perceptions: Personal~	38	0		User
3.5 Prevalence	5	0		User
3.5 Understanding from~	32	0		User
4.1 Acceptance~	19	0		User
4.1 Ashamed: parent~	2	0		User
4.1 Avoidance: Thinking about the f...~	1	0		User
4.1 Care~	8	0		User
4.1 Challenges: Personal~	57	0		User
4.1 Comparing: Peers	10	0		User
4.1 Dealing: Emotionally~	50	0		User
4.1 Denial	1	0		User
4.1 Hidden potential~	9	0		User
4.1 Hope: Future~	9	0		User
4.1 Parental growth~	13	0		User
4.1 Privacy~	6	0		User
4.1 Realism~	7	0		User
4.1 Religion~	9	0		User
4.2 Dealing: Financially~	5	0		User
4.3 Challenges: Family~	12	0		User



Name	Grounded	Density	Groups	Created by
4.1 Realism~	7	0		User
4.1 Religion~	9	0		User
4.2 Dealing: Financially~	5	0		User
4.3 Challenges: Family~	12	0		User
4.3 Family ties~	5	0		User
4.3 Response: Family~	31	0		User
4.3 Support: family~	22	0		User
4.3 Support: Friends~	5	0		User
4.3 Support: School~	25	0		User
4.4 Explanation to others~	13	0		User
5.1 Behaviour: current~	70	0		User
5.1 Challenges: Behaviour~	52	0		User
5.1 Dealing: Behaviour~	45	0		User
5.2 Challenges: Schooling~	11	0		User
5.2 Dealing: Academically~	28	0		User
5.2 Intervention: Scholastic~	24	0		User
5.3 Intervention: Medicinal	11	0		User
5.3 Intervention: Outcome~	10	0		User
5.3 Intervention: Therapy~	9	0		User
5.3 Intervention: When~	3	0		User
5.4 Avoidance: Social situations~	4	0		User
5.4 Challenges: Social~	25	0		User
5.4 Dealing: Society~	18	0		User
5.4 Perceptions: Social~	11	0		User
5.4 Response: Community~	27	0		User

Appendix J: Inclusion and exclusion criteria for all themes

Table 1: Inclusion and exclusion criteria for Theme 1 – Indigenous Sepedi Views

Theme 1	Criteria for inclusion	Criteria for exclusion
1.1 Causes of ASD	Indigenous African and Sepedi cultural views communicated to participants by friends, family and the community regarding possible causes of ASD.	Views communicated to participants by friends, family and the community regarding possible causes of ASD not pertaining to indigenous African and Sepedi cultural views.
1.2 Dealing with ASD characteristics from a Sepedi point of view	Indigenous African and Sepedi views communicated to participants by friends, family and the community as to what the participants can do to deal with characteristics of ASD.	Views communicated to participants by friends, family and the community as to what the participants can do to deal with characteristics of ASD not pertaining to indigenous African and Sepedi views.
1.3 Lack of indigenous terminology	Views obtained from participants which illustrate a lack of indigenous terminology related to ASD.	Views obtained from participants which do not illustrate a lack of indigenous terminology related to ASD.

Table 2: Inclusion and exclusion criteria for Theme 2 - Participants' views of causes

Theme 2	Criteria for inclusion	Criteria for exclusion
2.1 Participants' response to Sepedi views	Views obtained from participants regarding their response to indigenous African and Sepedi views.	Views obtained from participants which do not relate to their response to indigenous African and Sepedi views.
2.2 Hereditary causes	Views obtained from participants which illustrate that they attribute ASD to hereditary factors.	Views obtained from participants which do not illustrate that they attribute ASD to hereditary factors.
2.3 Causes attributed to birthing method	Views obtained from participants which illustrate that they attribute ASD to birthing methods.	Views obtained from participants which do not illustrate that they attribute ASD to birthing methods
2.4 Vaccination and medication	Views obtained from participants which illustrate that they attribute ASD to vaccination and medication.	Views obtained from participants which do not illustrate that they attribute ASD to vaccination and medication.
2.5 Environmental causes	Views obtained from participants which illustrate	Views obtained from participants which do not illustrate that they attribute

	that they attribute ASD to environmental factors.	ASD to environmental factors.

Table 3: Inclusion and exclusion criteria for Theme 3 - Circumstances surrounding diagnosis

Theme 3	Criteria for inclusion	Criteria for exclusion
3.1 Awareness	Views obtained from participants surrounding their awareness of ASD before and at the time of diagnosis.	Views obtained from participants not related to their awareness of ASD before and at the time of diagnosis.
3.2 Behaviour that prompted a diagnosis	Views obtained from participants surrounding initial characteristics of ASD which prompted a diagnosis.	Views obtained from participants which are not related to initial characteristics of ASD which prompted a diagnosis.
3.3 Conduct of professionals	Views obtained from participants regarding the conduct of professionals towards participants when a diagnosis was made.	Views obtained from participants not related to the conduct of professionals towards participants when a diagnosis was made.
3.4 Response to diagnosis	Information obtained regarding participants' responses to a diagnosis of ASD.	Information obtained not regarding participants' responses to a diagnosis of ASD.

Table 4: Inclusion and exclusion criteria for Theme 4 - Personally coping with ASD

Theme 4	Criteria for inclusion	Criteria for exclusion
4.1 Coping emotionally	Views obtained from participants as to how they cope emotionally with a child with ASD.	Views obtained from participants not relating to how they cope emotionally with a child with ASD.
4.2 Coping financially	Views obtained from participants as to how they cope financially with a child with ASD.	Views obtained from participants not relating to how they cope financially with a child with ASD.
4.3 Familial support	Views obtained from participants as to how family members assist them to cope with a child with ASD.	Views obtained from participants not regarding to how family members assist them to cope with a child with ASD
4.4 Religion	Views obtained from participants how they use religion as a method of coping with a child with ASD.	Views obtained from participants not related to how they use religion as a method of coping with a child with ASD.

Table 5: Inclusion and exclusion criteria for Theme 5 - Intervention with a child with ASD

Theme 5	Criteria for inclusion	Criteria for exclusion
5.1 Behavioural intervention	Views obtained from participants as to how they cope with their child's behaviour.	Views obtained from participants not relating to how they cope with their child's behaviour.
5.2 Scholastic intervention	Views obtained from participants as to how they cope with their child's scholastic needs.	Views obtained from participants not relating to how they cope with their child's scholastic needs.
5.3 Medicinal and therapeutic intervention	Views obtained from participants as to which methods of intervention they currently or previously used to support their children with ASD.	Views obtained from participants not relating to methods of intervention they currently or previously used to support their children with ASD.
5.4 Social intervention	Views obtained from participants how they cope with the responses of society to their children with ASD.	Views obtained from participants not relating to how they cope with the responses of society to their children with ASD.