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Ethical obligations that arise from the effects of cultural & religious practices and beliefs on the well-being of children with Autism Spectrum Disorder

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A thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, in fulfilment of the requirements for the degree of Doctor of Philosophy (PhD) in Bioethics and Health Law

Johannesburg, 2021

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Declaration

I, Ayanda Simelane, declare that this thesis is my own, unaided work. It is being submitted for the Degree of Doctor of Philosophy in Bioethics and Health Law at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.



_____

(Signature of candidate)

25th day of November 2021 in Johannesburg

Dedication

To my two sons Luyanda and Bukhona

To my late mother Mrs. Muntu Yvonne Msomi-Kunene

Abstract

Parents of children diagnosed with ASD in South Africa go through a multi-approach pathway to care in search of the best treatment method. This is because ASD is still not clearly understood by many African people.In general, illness in the African culture is often associated with tradition and culture, spiritual forces, witchcraft, family wrongdoings and ancestors to mention a few. Parents and families continue to search for causes and answers for having a child with ASD. Some of these questions include: *why* did they give birth to a child with ASD, *who* caused their child to get a disorder such as ASD and *how* can the disorder of ASD be treated or reversed? Some of these questions may not be answered by allopathic practitioners since the aetiology of ASD is still unknown. The shock of getting a diagnosis of ASD may be overwhelming for many parents. Often, having a child with ASD is still seen as a loss and to some, a child with ASD means a form of punishment from the ancestors or God. It is based on these reasons that parents embark on multiple approaches to treatment for their children which include traditional forms of healing and religiously informed approaches of treatment. Often, when parents seek help for their children, the medical approach is held parallel to other approaches of treatment.

This study was a bioethical analysis with an empirical component. The study aimed to explore the ethical obligations that arise from the effects of traditional and religious practices and beliefs on the well-being of children with ASD. Two distinct theoretical frameworks provided the underpinning forthis study. The first framework adopted was Uri Bronfenbrenner's Ecological Systems Theory on child development. This mostly informed the empirical element of the study. The second theoretical framework was Moral Theoretical Pluralism (Cultural Relativism and Ubuntu), an approach to moral philosophy that rejects the notion that all of our ethical obligations can be explained in terms a single (or monist) theory of right action, in favour of the position that the best arguments for how we ought to act are mostly grounded in several of the recognised moral theories. This framework mostly provided the foundation for the bioethical or normative component of the study.This study was conducted in one of SA's largest hospitals to access a rich sample of participants and practitioners with experience in helping children with ASD. Parents of children with ASD, health practitioners, traditional healers and religious leaders all involved with children with a diagnosis of ASD were interviewed to explore theirexperience and understanding of the well-being of children with

ASD. All data collected from the participants of the empirical component of the study were interpreted and analysed thematically following the objectives of the study. The study revealed that children with ASD are still largely exposed to an array of traditional methods of healing and religious healing methods by parents. In addition, the study found that the regulation of traditional health care and religious healing in SA is still under-regulated, which opens opportunities for untrained healers to enter the space which may cause harm to children. The study concludes that while some alternative treatments may be risky and harmful, some benefits come with using alternative methods. The study found that because traditional forms of treatment are culture-bound, they come with the benefit of a sense of hope for parents about their child's future. Furthermore, the use of traditional alternatives creates a sense of connectedness for parents and their families.

The study recommends that traditional healing and religious healing be incorporated into the health care system. The incorporation of these alternative methods may reduce the risk of children being exposed to some of the risky and harmful substances mentioned in this study and other studies conducted nationally. Also, incorporating other alternatives in the health care system may help reduce the burden experienced by the health care sector in terms of treating children with ASD. A more focused study on the evaluation of the integration process of other alternative forms of treatment into the health care system of care for children with ASD is recommended.

Keywords: Autism Spectrum Disorder; traditional healing; religious healing; harmful substances; parents of children with ASD; health care sector.

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The journey has been windy and heavy but with the hand of God almighty, I have come this far. There were moments where this point was bleak and seemed impossible because of the obstacles that were along the way. Certainly, I did not go through this difficult road alone.

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CHAPTER 1: INTRODUCTION

Preamble

In 2014, I conducted a research study which was focused on understanding how socio-economic status, parental stress and resilience levels of parents who were raising children diagnosed with ASD impacted child development (Simelane, 2020). The study was purely quantitative in nature with no qualitative component. During data collection process most parents were concerned about the '*why', 'how'* and *'who'* questions; they were focused on understanding why did they have a child with a condition of ASD. The question of '*why'*was a loaded question, some parents already developed their own answers to these questions. Answers ranged from parents mentioning anger from the ancestors and some understood ASD in the religious context. Participants of the study, who were also parents of children diagnosed with ASD further expanded their understanding by saying, the childs condition may be remedied provided they perfomed a particular family related ritual . Another key point to keep in mind is that the study was not qualitative in nature, I was therefore unable to probe further and understand more about the rituals and how parents understood their child's disorder of autism. It was therefore from these interactions that this particular study was conceptualised with a view to delve deep into understanding how parents approached a diagnosis of ASD. Above all, it was also important to understand the ethical obligations of some of the practices that are culture bound and religious oriented which are performed with a view of helping children with ASD. It can be seen based on the above mentioned observations that this particular study was conducted with a purpose of incorporating the qualitative components that allowed and enabled parents and practitioners working with children with ASD a platform to interact with a researcher on the known and available interventions of treating children with ASD.

1.1 Outline

In this chapter, I outline the problem that this study seeks to address and provide a short overview of the thesis as a whole. I start by defining Autism Spectrum Disorders (ASD) according to the American Psychiatric Association (APA), provide a theoretical background of the study and an overview of other chapters. A detailed review of the literature surrounding this study will be drawn from different disciplines and will be provided in later chapters. Also, I give a brief background of the problem of the study and the central objectives that are the

main focus of this study. The chapter is solely introductory and an outline of what to follow in the rest of the thesis. Later, I explain the final structure of the thesis which gives the reader a clear flow and an understanding of this study and how the chapters 'speak to each other'.

1.2 Background

ASD is a "neurodevelopmental disorder that is characterised by deficits in social reciprocity and communication and by unusual restricted, repetitive behaviours" (American Psychiatric Association, 2013) This disorder is said to affect children equally regardless of their cultural and socio-economic backgrounds (Fombonne, 2009; Tincani, Travers and Boutot, 2009)

The focus of this study was to research the use of alternative forms of treatment that are available for children diagnosed with ASD focusing on the South African context. In addition, the study sought to understand ethical obligations that arise from the effects of cultural and religious beliefs and other related practices that impact the well-being of children with ASD. Essentially, this study was a normative project, which included an empirical (qualitative) component. Normative ethics can be described as the branch of inquiry that sets out to give answers to the following questions: What ought to be done? What ought not to be done? (Sugarman & Sulmasy, 2010).

Normative ethics sets out to answer these questions in a systematic, critical fashion and to justify the answers that are given. This study explored the effects of cultural and religious beliefs and practices on children with ASD. While beneficial beliefs and practices may be supported as morally justified, harmful consequences cannot be. In other words, the key normative component of the study focused on identifying and understanding some of the known remedies that may be harmful that are embedded in some cultural beliefs and practices that may later affect the well-being of children with ASD. The qualitative (empirical) component of the study sought to establish some of how cultural and religious practices impact the well-being of children with ASD.

1.3 Conceptual Framework

This section introduces the main theories underpinning this research study. These two theoretical frameworks are briefly outlined below and will be discussed indepth in Chapter 3 of this thesis.

1.3.1 Pluralistic Moral Theoretical Approach

This study is by no means seeking to take sides between a western approach and an African approach towards helping children with ASD. However, it is taking under analysis some of the practices in the cultural and traditional sphere considering that different moral principles are adhered to by different people. In addition, the study will endeavour to understand such approaches to identify those practices that may be helpful and those that may be harmful in the development of children with ASD. For the most part, western orientated treatment approaches are mostly scientific and have no religious connotation, whereas, the African approaches to medicine are deeply rooted in tradition and religion and in an indigenous understanding of health and well being. To delve deeper into the issue under research and its relevant context of cultural pluralism, it is appropriate that this study adopted a pluralistic moral theoretical approach.

A pluralist moral theoretical approach to normative ethical analysis is distinctive because it rejects monism. Monists seek to resolve all moral dilemmas based on a single overarching principle or set of principles, which are understood as the key to answering moral questions. Thus, a monist utilitarian thinks that all moral questions can be answered by always choosing the action that will result in the best overall consequences for all parties. A monist Kantian deontologist, on the other hand, thinks that all moral issues can be resolved by always acting in ways that are respectful of persons. Pluralists reject the idea that any single moral theory can do all the work and rely instead on constructing the best arguments for action based on some kind of consensus derived from different fundamental moral theories such as cultural relativism and Ubuntu. In this thesis, I focus on the common ground between the various moral theories and cultural moral values – on the standards of ethical conduct about which there is widespread agreement. So, the ethics in this research is all framed in terms of the moral requirements not to do harm, to do good, to act fairly and show solidarity. These ethical requirements are what underlie the interview questions used and the ethical evaluation applied throughout the thesis.

An important reason for adopting moral theoretical pluralism and focusising on the common ground between moral theories and cultural moral values is because this approach is better able to accommodate and acknowledge the existence of competing culturally-grounded morals. While I do not propose a strong ethical relativist position, in which what is ethical depends solely on one's culture, I do acknowledge that cultures differ in terms of some of their ethical values and norms. Furthermore, our understanding of the moral life can be greatly enriched by giving serious consideration to the ethics of other cultures, and Western prespectives on ethics should not be assumed to be golden standard by which all other moral worldwiews should be judged.

1.3.2 Bronfenbrenner's Ecological Theory

Most developments in children, whether typical or atypical, take place within a socio-cultural context and are influenced by several transactional processes (Sameroff, Chandler, Horowitz, Hetherington, 1975; Sontag, 1996; Weisner, T & Skinner, 2007). For this reason, Bronfenbrenner's ecological model presents itself as layers of influence in the field of examining culture and disability (Canseco, 1997; Ravindran and Myers, 2012).

The ecological theory by Bronfenbrenner emphasises the child's environment, in terms of quality and context. This distinguishes it from other theories, as it looks at both nature and nurture in the child's development. Also, it puts forward a structure to assess the interplay among various systems in the ecology that have an impact on the child's development (Berry *et al.,* 2002). Within this framework, proximal and distal processes in the ecology affect the child's development. The microsystem comprises the child's direct relations such as the relationship with the mother and the father as well as the setting, which are the child's home and school. These impact the development of the child. The mesosystem constitutes the parent's relationships with others in this context and the relationships that the parents may have with the child's health practitioners. The exosystem is a more distant level to the child, however, it is crucial to the development of the child. It encompasses the availability of resources such as special schools that will see to the needs of the child, hospitals and specialists relevant to the child's condition. The macrosystem is also more distal to the child but critical.This includes the cultural beliefs, values, spirituality, government and economy. The final layer in the ecological system is the chronosystem, which takes into account that over

time things change. This theory is a good fit in understanding the issue of culture and its influence on the child's development, which allows natural interconnection between levels (micro, meso, exo, macro and chronosystems) of the ecology. To give an illustration, over time (Chrono) as cultures change and become more aware of disorders such as ASD, the government may adjust certain laws and policies (macro) which may be in the best interest of children with ASD (Ravindran and Myers, 2012).

1.4 Child Autonomy

The term autonomy is derived from the Greek term *autos* and *nomos* meaning self and rule. There are two critical conditions attached to the term autonomy, which are liberty and agency (Coggon and Miola, 2011). This principle acknowledges the principal right of people to be autonomous and be able to hold their views and make their choices according to their values and beliefs. Making health decisions autonomous is, usually, the main principle. Children do have the capacity to make decisions regarding their health. However, their decisions have limitations. Here, this is because children represent vulnerable groups and they are not as autonomous as adults are. They need protection in terms of their health and also in the participation of research studies. For a patient to exercise full autonomy, they need the capability to do so and a sense of decisional capacity. A patient's decision making is assessed given his condition, the nature and the degree of the potential risk (Kaushik, Narang,& Agarwal, 2010). On the other hand, the (South African Children's Act 38, 2005) states that a child may consent to his or her medical treatment (excluding surgery) if the child is over the age of 12, is of maturity and is mentally capable to understand the risks and benefits associated with the treatment.

Where a child is not mentally capable and is of insufficient maturity, a parent may consent to the treatment of the child. Children with ASD are said to suffer from speech impairment, limitations in social interaction and a delayed theory of mind. Theory of mind is the ability to infer or understand peoples' minds and intentions (Moran *et al.,* 2011). Such limitations may be regarded as mental capability, thus, limiting the child from making full consent regarding the choice and expressing their wishes and giving appropriate consent for treatment. Parents and caregivers, thus, carry full responsibility and rights of deciding for children with ASD in choosing their treatment. An ethicist must revisit the concept of parental right as (Maclean, 2005) argues that parenthood should not be regarded as a right. The important thing is the interest, health and well-being of the child. The choice of treatment that parents make is critical

and should be made to be in the interest of the child. Whilst every child has the right to access health treatment, it is also important to be cognisant that children with ASD and other types of disorders or disabilities are not exposed to practices that are detrimental to their health.

Researchers argue that, in the case of children with mentally related issues, treatment is not only a choice that ends with the child (Koelch & Fegert, 2010). This suggests that a child is a part of a larger system (the family, community and cultural group). This larger system which is formed by a family including parents, caregivers and other extended members of the system as a whole is a part of the treatment journey of the child. Thus, there is a compromise of the integrity of the autonomy, for example, a child may not want a particular kind of treatment but the family chooses the treatment or other family members are not happy with the chosen treatment, therefore, it has to be stopped. Other factors may affect the choice of treatment such as custody of the child. A child raised by a single parent or parents that are divorced or separated-the judicial aspect may affect the child's treatment (Reading *et al.*, 2009; Koelch & Fegert, 2010). This means that each parent will be governed by a different set of principles which may largely be determined by each of their contexts and backgrounds.

1.5 Care Ethics and ASD

Research has shown that the caregiving responsibility of child-rearing is typically bestowed upon women. This notion cuts across all races, religions, traditions, cultures and in most, if not all communities, women have taken on the role of a caregiver. A common belief across cultures is that children are a gift that deserves love and support no matter who and how the child is. (Sandel, 2007) crystallises this as follows:

> "We choose our friends and spouses at least partly on the basis of qualities we find attractive. But, we do not choose our kids. Their qualities are unpredictable and even the most conscientious parents cannot be held wholly responsible for the kind of children they have".

It is unfortunate that parents do not control the charecteristics of the child that they receive. It is even worse if some charecteristics are long term conditions that require full time care. Parents take over the care for their children, but sometimes and in most cases the caring part is often left to mothers rather than to both parents. There are many implications to this which include

the fact that women often have to leave work to take care for their little one's needs. The support provided to caregivers who raise children with ASD is very limited since there are very few schools offering educational needs for children with ASD. Because of this, mothers often become full-time carers of children with ASD as a result of the disorder being a lifelong disorder. This will mean the quality of life of the mother and the entire family may be affected. For caregivers, a child with ASD may mean a complete change in the way they perceive their lives and also how they perceive the child and the entire structure of the family (Pisula & Kossakowska, 2010). The extra responsibility that is often given to mothers has some psychological consequences. The pressure that comes with caring for a child with ASD is far more than the caring given to a typical child or even a child with other developmental disabilities (Pisula and Kossakowska, 2010). Some of the concerns that are experienced by parents include uncertainty about the child's future, which may be prompted by the parents' understanding that the disorder of the child poses some limits to the child's prospects of independence (Pisula and Kossakowska, 2010). Therefore, the point of care for parents of children with ASD must not be left unattended. Several issues are linked to the process of caring for children with ASD and may be regarded as of ethical concern such as 'desperate hopes of cure' (Post *et al.*, 2013).

1.6 Statement of the Problem

Religious and cultural beliefs and practices play a crucial role in the perceived well-being of children and adults globally. Furthermore, some parents and communities still believe prayer and other spiritual and cultural practices can substitute as care or remedy for ill or injured children (Committee on Bioethics, 1997). Parents' beliefs about the nature of their childs illness of ASD vary. Some of their beliefs and practices may be due to parental frustrations, which may sometimes harmful to the child (Herbert, Sharp & Gaudiano, 2002). All children have a right to benefit from effective medical care that can prevent substantial harm, suffering or death (Committee on Bioethics, 1997). Regrettably, some parents deny their children medical care because of religious and cultural beliefs. Some try all alternatives because of anxiety and others do not inform their main health practitioners about the alternative treatment (Committee on Bioethics, 1997).

Some illnesses and disorders like ASD are not understood in the same way across cultures. Various disorders are not qualitatively the same or diagnosed the same across cultures. In the treatment and care of children with ASD, one cannot just apply an absolutist perspective or a one size fits all approach in diagnosing the disorder. ASD cannot be likened to other disorders such as schizophrenia, which present with similar symptoms across cultures. The presentation of ASD is linked to the understanding of a parent or a family. ASD cannot also be likened to a broken arm; each culture has its way of understanding the disorder and some of the understanding is usually attributed to cultural beliefs (Committee on Bioethics, 1997). It is against this backdrop that this study seeks to understand the effects of cultural and religious practices in treating ASD in the South African. The study also seeks to understands whether cultural and religious practices may be beneficial or harmful to the wellbeing of children with ASD considering the diversity that the country possesses.

1.7 Rationale for the Study

South Africa is a diverse nation comprising several different cultural groups. This is important because how people understand health and treatment varies across cultures. This understanding gets even more complicated when the cause of an illness is unknown as parents may end up using their discretion and rationalisation and they could end up making conclusions that could lead some to become desperate in their choices (Ravindran and Myers, 2012). A large amount of the population follows cultural activities and this confirms that cultural activities are a much-valued component of life experiences (Zuma *et al.*, 2016). Culture is a critical component in the health process of a child with ASD diagnosis because it means that a possibility of a delayed treatement or therapy may be possible. To give an instance, parents might associate the symptoms of ASD with ritualistic activities or spiritual forces. For the purpose of this research study the term culture and tradition will be used interchangeably.

The prevalence of ASD in South Africa is high. It mirrors that of Europe and America, with 10-20 cases per 10000 persons (Mubaiwa, 2008). The difficulties of raising a child with ASD in an inadequately resourced country such as South Africa are countless and this may be an emotionally challenging experience for parents (Mubaiwa, 2008). This is because the understanding of the disorder is fairly novel in the African continent; most practitioners working with children with ASD still have limited comprehension of the disorder, its symptoms and prognosis (Mandell & Novak, 2005; Owalabi et al., 2009). Some researchers recommend that service providers such as doctors and /or traditional practitioners ought to seek to

understand the entire family's belief system, which includes spirituality, worldviews and family values when engaging with the child (King *et al.*, 2009). Further to this, it is mentioned that if practitioners can conform to recommendations suggested by King et al (2009), this may prevent parents from holding different assumptions and views about the disorder. This limited understanding has a trickle effect on parents who receive conflicting information regarding the treatment of ASD from different sources (Mandell and Novak, 2005). It is necessary to understand the nature of cultural and religious beliefs and their possible impact on the treatment and well-being of children with ASD. It is further important to unpack the ethical obligations brought about by a multi aproach to treatment of ASD and the impact it may impose on society, caregivers, health care professionals and parents.

The proposed benefit of the study is that the findings will strengthen and illuminate the critical aspect of a trasparent referral system and access between traditional practitioners and modern health practitioners with a positive view of creating holistic assessment and treatment methods that are relevant in the context of children with ASD in South Africa. The normative arm dealt with real-world practical issues and made recommendations regarding the ethical obligations that may have an impact on society, caregivers, health care professionals and parents.

1.8 Aim of the Study

This study aims to give an account of the ethical obligations towards children with ASD that arise from the effects of cultural and religious practices and beliefs on the well-being of such children.

1.9 Study Objectives

I. To explore the nature of the cultural and religious practices and beliefs that children with ASD are exposed to and the beneficial or harmful effect of these on their well-being.
II. To articulate and normatively defend the ethical responsibilities that arise from the described benefits and harm derived from the cultural and religious practices and beliefs that children with ASD are exposed to.

1.10 Research Design and Method

A study's research design can be likened to a rough sketch or a process to be filled by the researcher as the study progresses (Devers and Frankel, 2000). This research followed an empirical-ethical research design. This is a relatively new field of study in medical research and bioethics. This approach comprises the integration of socio-empirical research and ethical analysis to answer or treat concrete moral questions (Salloch *et al.*, 2015).

The first objective of this study focused on the socio-empirical component of the study. This component of the study applied a qualitative research design to understand the research topic and answer the research questions from the perspectives of parents, health care practitioners, traditional healers and religious leaders involved with children diagnosed with ASD.

The second objective of this study focused on the central normative question that was the ultimate focus of the study. A significant proportion of the final thesis focused on identifying, articulating and critically defending the ethical responsibilities imposed on society, caregivers, health professionals and parents that arise concerning the exposure of children with autism disorders to cultural and religious beliefs and practices. This part of the project brought a philosophical normative analysis and employed the standard methods used in research.

1.10.1 Research Design

This section provides a brief high level overview of the research design and methods. The research methods are fully described in Chapter 3. For the normative component of the study the standard methods of philosophical enquiry were applied. In the rest of this section the research methods applied to the empirical component of this study are described.

Data was collected using a qualitative research approach. This research sought interviews to understand ethical obligation arising from the use of traditional and religious interventions on children diagnosed with ASD.

1.10.2 Sampling Method

A non-probability sampling method was used to source information-rich participants for this study. Thereafter, a snowballing sampling methodology was used to recruit participants. The sample was selected from the patients who attended Chris Hani Baragwanath Hospital CHBH. Parents were selected from different wards at the hospital (Psychology, Speech and Neuro Wards). The study recruited 25 parents of children with a diagnosis of ASD. Furthermore, the study sought to understand the perspectives of traditional healers and religious leaders. This was done by inviting both groups for focus group discussions. Each group of focus group had 12 participants respectively.

1.10.3 Instrument Used

Semi-structured interviews were conducted. According to (Struwig, Struwig & Stead, 2001), semi-structured interviews allow the researcher to apply flexibility when answering the interview questions. A semi structured interview guide was used to guide the process of interviews.

1.10.4 Data Collection

Data was collected using a semi-structured interview guide informed by relevant literature. The researcher utilised probing techniques such as active silence, requesting for specifications, rephrasing, reflections and paraphrasing to source rich data relevant enough to answer the research aims of the study.

1.11 Trustworthiness

This study used the four criteria by (Lincoln & Guba, 1985) to assess rigour in this research project. The following criteria were followed to improve the quality and rigour of the research:

- Credibility of data refers to the truthfulness of the data as presented by the participants and the representation of these facts by the researcher
- Dependability refers to the consistency or the replicability of the finding of the study as per previous researchers

- Confirmability refers to the demonstration that the data in this study were indeed responses from the participants and not biases or viewpoints from the researchers
- Transferability states that the data ought to be applicable in other setting or have meaning to other individuals who were not part of this study
- Authenticity deals with the ability of the researcher to which all participants' feelings and expressions are expressed in a respectable manner

1.12 Thesis Structure

This thesis is divided into six Chapters which I explain in clear detail below in this section. I further explain in detail the methods used in each chapter to get the reader acquainted with the content. This study is a multidisciplinary study that incorporates bioethics and Social Sciences.Therefore, it is an empirical study that employs relevant bioethical discussions to explain its empirical qualitative findings.

The thesis is structured as follows:

- **Chapter 2**: In this chapter, I provide a detailed literature review of current research and other seminal works around the topic under discussion. Also, I discuss relevant literature that evaluates previous research conducted in the field of ASD, traditional medicine, religious interventions and known interventions used in the treatment of ASD – their effectiveness and known benefits of the interventions. This section of the research is presented to show the relevant gaps in the literature and to highlight all sides of the topic under discussion.

- **Chapter 3**: This chapter clearly gives the reader an indication of the 2 theories that underpinned this current research project. The two theories focused on the two components of the study, the normative component and the empirical component. In the empirical component a theoretical framework used was the ecological

systems theory by Uri Bronfenbrenner. In the normative part of the study a pluralistic moral theory was applied focusing on Ubuntu and cultural relativism.

❖

❖ Chapter 4: I discuss the methodology of this study, the design, the procedures and the processes followed when this study was conducted as well as the key ethical concerns surrounding this work. The method employed during the empirical research stage of the study was qualitative. The qualitative research followed in-depth interviews with parents of children diagnosed with ASD and practitioners. The other component of qualitative research of this research study followed focus group discussions with traditional healers working in the space of ASD and also religious leaders who employ faith-based healing.

❖ **Chapter 5**: In this Chapter, I provide data findings and other graphical analyses of the results of this study. I give evidence from the interviews to support the findings of this study. Also, a brief discussion of the findings, which I subjected to thematic analysis, is provided in this section of the thesis. The data is analysed in a simplified manner to give the reader ease of reading and a better understanding of the findings of the study.

❖ **Chapter 6**: I offer a comprehensive discussion of the results from the interviews and focus groups with reference, mainly, to the bioethical literature to support the main normative objective of this research.

❖ **Chapter 7**: In this Chapter, I summarise and conclude this project by outlining the key points discussed in the thesis. I later conclude by putting forward recommendations that are ethical in the treatment of children with ASD, particularly, when the treatment is from traditional and religious forms of interventions. I discuss the notable limitations of the study and how this research may be generalisable and offer possible direction for future research in this field.

1.13 Concluding Remarks

In this Chapter, I have provided a general overview of this research study, the rationale and the methodology followed when conducting this study. I have given the thesis structure to understand what other chapters of this thesis will discuss and a clear logical flow of this thesis is provided in this chapter.

CHAPTER 2: REVIEW OF LITERATURE

2.1 Introduction

This chapter includes an overview of the history of ASD and it gives a detailed description of the spectrum of ASD as stated in the DSM-5. Further to this, the chapter provides clinical diagnoses and the specified symptoms of ASD as per the manual, the prevalence of the disorder, internationally and locally. Later in the chapter, widely known early interventions in ASD and their efficacy are discussed. Thereafter, the chapter narrows to the different treatments that are available to treat the disorder; this will include a discussion of cultural, religious and other forms of Complementary and Alternative Treaments (CAM) treatments that are known as treatment alternatives for ASD. To provide a clear understanding, this chapter also discussed the challenges faced by parents of children with ASD and the financial aspects attached to it. Finally, the legal and ethical considerations are discussed, prenatal testing relating to ASD and its relevance to the space of ASD. Lastly, the importance of programmes developed for community awareness is discussed.

Protection of children with ASD from harm in South Africa is becoming an issue of great concern to all stakeholders involved in caring for these children (parents, caregivers, medical practitioners, religious healers, traditional healers and government). Ethical obligations to protect children particularly those with ASD have not been clearly articulated. Although parents take the primary role in the caregiving responsibility, it is equally the responsibility of all practitioners and other stakeholders including the government to take an active role in the wellbeing of caring for children with ASD. Therefore, this is an altruistic approach to care which suggests that we all have an obligation to others to be healthy or contribute to their welfare. Without going on a tangent and opening an ongoing discussion of what altruism means, we discuss the term in the context of this research, the context is solely on the benefit of the other and not on self-benefit. A definition by Robinson & Curry (2005) states that altruism is a manifestation of caring and selflessness which is non-contingent upon reward.

The concept of caring for others is central to humans. Some philosophers and psychologists argue that there are several sources of altruistic motivation such as an altruistic personality, principled moral reasoning and internal social values (Batson & Powell, 2003). Given that parents are the first point of care for their children, they are, therefore, obliged to consider the child's best interest when they are unhealthy or require care. Parental care is often based on the

love for their children; other factors such as moral obligation, empathy or sympathy are usually a secondary reason for providing care. There is a body of literature in psychology that supports the link between love and altruism (Grote and Clark, 1998; Mikulincer, M., Shaver, P. R., Gillath, O., & Nitzberg, 2005). In developmental psychology, particularly from the standpoint of attachment theories, altruistic behaviour can be viewed from the perspective of what Bowlby called the 'caregiver behaviour system'. It is an internal system that is said to respond to the need for those dependent on us, particularly children (Bowlby, 1982). Therefore, the young are dependent on the parents for food, shelter, health care and security. These needs are critical in the development of the child and its wellbeing. In light of the vulnerability and the critical survival needs of the child, parents and caregivers remain the critical part in providing adequate care and nourishment to children.

The two aspects of vulnerability and dependability become an important part of this discussion. The aspect of responsibility forms part of the discussion because of its relation to vulnerability and dependability. The relation in these terms can be illuminated in the fact that firstly, infants and children are vulnerable, therefore, dependant on their caregiver or others to meet all their critical developmental needs. In lay terms, the vulnerability can be referred to as exposure to harm or being harmed. To be harmed is referred to as being in a situation of being in a worse-off situation than one is already facing. Therefore, the third concept of responsibility is not always a given or an obvious decision or well understood in terms of where who and to what extent responsibility should be given. However, it is understood that the concept of responsibility is one of the key elements in child protection based on the fact that not all parents are fit and resourced to care for their children which may end up leading to various exploitative situations that may be harmful to children. What is critical is to define the meaning of responsibility within the ambits of this research. There are three different forms of responsibility namely causal, moral and task responsibility (Goodin, 2016). He explains the three types clearly in his paper *Ethical Defence in the Welfare State.* He says causal responsibility is when you produce this result and moral responsibility is when you are to blame for it. Finally, he explains task responsibility by saying this is when the responsibility is your job (Goodin, 2016). While these forms of responsibilities are different, they are closely related and overlap in the context of this project. Thus, I will focus the analysis in this project on all three forms of responsibility to understand the sense of the outcomes of these responsibilities and to understand if there are consequences if and when responsibilities are performed well or performed badly. Parental responsibilities are, thus, defined in the South African Children's

Act as meaning to care for the child, contact with the child, to act as a guardian of the child and to contribute to the maintenance of the child. Based on the definition of parental responsibility according to the Children's Act, the term care was simplified and broken down by the court to mean accommodating any special needs that the child may have, in the case (J v J (A101/2008), 2008).

There have been several research projects that have argued against and for autism as a disability rather than it as a disorder of 'difference' (Baron-Cohen, 2000; Algood, Harris and Hong, 2013). Further, it is stated that ASD is considered a severe disability because of the intense lifelong effects it has on the individual and his or her family. Some researchers mention that autism is a disability because of the impaired speech, social interactions and cognitive deficit (Baron-Cohen, 2000; Algood, Harris and Hong, 2013). The high percentage of people diagnosed with ASD who have comorbidities of mental disorders and the absence of functional speech makes a compelling argument that ASD may fit in to be a disability rather than merely a disorder. Thus, I will draw on the literature from bioethics, the psychology intellectual community and the scientific literature on ASD and disability to draw a rich understanding and to form an argument that will answer the main research question of this project.

2.2 Autism Spectrum Disorder

In this section, I outline a detailed overview of the definition of ASD. I discuss the levels of ASD as outlined in the Diagnostic and Statistical Manual (DSM) 5. This will be followed by a snapshot of ASD in the context of South Africa. The cultural and religious perspectives of ASD will be outlined in this section. This section will further provide available interventions known to treat ASD locally and globally. Finally, the section will discuss the financial implications that are attached to the wellbeing of children with ASD.

The term 'autism' has existed for just over a century since the work of Eugen Bleuler on schizophrenia in the early 1900s where he used this term in some of his earlier work to describe individuals with impairment with the social world (Bleuler, 1908; Dyches *et al.*, 2004). Its symptoms have fascinated and been researched by many researchers and health practitioners over the years. Later on, the disorder was referred to as Kanner's syndrome which was a name associated with an Austrian psychiatrist, Leon Kanner (Tantam, 1988). He was a social activist and physician who worked in several psychiatric hospitals conducting work relating to Autism

Spectrum Disorders. Children presenting these symptoms were previously classified as pervasive developmental disorders in the International Classification of Diseases (The ICD-10 classification of mental and behavioural disorders: diagnostic criteria for research, 1993). Another German paediatrician, (Hans Asperger), concurrently wrote about similar characteristics in children who presented difficulties in forming friendships, had limitations in communication and showed a lack of general empathy (Asperger & Frith, 1991). The work of Asperger did not reach mainstream literature until after he died; it was only then that his literature became visible (O'Reilly, Karim and Kiyimba, 2015). Part of the work of Asperger included the identification that children with such limitations could flourish. He also mentioned that these children had some signs of genius (O'Reilly, Karim and Kiyimba, 2015). Currently, the used DSM 5 lists two major characteristics of ASD: impairment in social communication and social interaction, the second characteristic is restricted, repetitive patterns of behaviour, interests and activities (American Psychiatric Association, 2013). Some children on the spectrum present with issues of withdrawal, passive and some may be violent and highly agitated (Estes *et al.*, 2014). The diagnosis of the disorder in the African continent does not deviate from the criteria regulated by the International Classification of Diseases, tenth edition-(ICD 10) and the DSM-5. However, according to (Munir & Bakare, 2011), there are notable variations and deviations in comorbid conditions. Some children with ASD have difficulties in all aspects of language development (phonology, semantics, syntax, morphology and pragmatic).These challenges vary from child to child (Alli, Abdoola and Mupawose, 2015). Some researchers have found that ASD can be accompanied by a deficit in attention, learning and to some children, cognitive abnormalities are present (Estes *et al.*, 2014). The symptoms of ASD can present from mild to severe. Researchers and experts in the field of ASD agree that even though children are placed differently on the spectrum, a theory of mind and deficit in pragmatics is always present (Alli, Abdoola and Mupawose, 2015). Most studies in Africa have observed as high as over 50% of cases with a lack of expressive language (Belhadj, Mrad & Halayem, 2006). Furthermore, early literature by (Lotter, 1980) observed that all children who were diagnosed in Africa were 'mentally retarded' though this term has since been discontinued and replaced by the term 'intellectual disability'. All the impairments mentioned in the DSM 5 are often recognised early in childhood and are said to limit the daily functioning of children affected.

Over the years, there has been a remarkable increase in children diagnosed with ASD. According to a study by (Moore, 2008), about 1 in 1000 children were diagnosed with ASD in

the year 1994. In the USA alone, the prevalence is up to a high of 6.7 children in every 1000 during the year 2007. In the past five years, the United States Department of Health estimated that cases of ASD have increased to about 500%. The challenge of ASD has received much visibility in the research literature. Some researchers report that ASD encompasses a cluster of pervasive developmental disorders (PDD) which may pose limitations in the child's behaviour, communication and social interactions (Lauritsen, 2013). Some children may present issues with sensory perceptions while others may have other co-occurring diagnoses such as intellectual disability. Most children and people affected with ASD are unable to fully support themselves on day to day issues and require support and some level of caring and management to be effective. Preschool children with ASD have been found to present with a lack of interest in people, high resistance in adapting to change and visible stereotypes in movements (Volkmar, Paul, Klin & Cohen, 2005). Some researchers state evidence that communication challenges in children with ASD improve by school-going age.

There are notably recognisable interventions such as the applied behaviour analysis (ABA), which use the fundamentals of the operant conditioning theory which states that those behaviours that are followed by rewardable consequences are likely to be repeated. Thus, via this intervention, parents of children with ASD are coached on how to use the reward system as suggested by the operant theory to encourage them to repeat behaviours that are of benefit to them. If the reward system is repeated, research shows that there are high chances that the child's conditions will positively improve (Dillenburger, Ann and Mckerr, 2013).

2.3 Etiology of ASD

The complex nature and limited research conducted in ASD makes the understanding of the etiology and treatment of ASD a pertinent issue globally. To date, there is no consensus on the etiology of ASD. In the 1950s, autism was thought to be a result of mothers who were cold and rejected their children. The theory of refrigerator mothers was very popular at the time. So-called refrigerator mothers were said to be responsible for the lack of language and empathy in their children (Estes *et al.*, 2014). Bruno Bettelheim coined the term 'refrigerator mothers'. However, over the years, the theory became very unpopular, today there are no researchers agreeing with this theory. Another report from Kanner stated that children with ASD were likely to come from backgrounds of high socio-economic status (Kanner, 1968).

There have been claims that the disorder is likely to come from genetics and some environmental risk factors (Dillenburger, Ann and Mckerr, 2013). There is evidence that the disorder has a genetic association but not to say the disorder is a genetic disease in the way Huntington's diseases are (Estes *et al.*, 2014). The genetics of ASD is a rather complex subject. It is said that autism does not get produced from an inherited gene as is the case with Huntington's disease but is an interaction from a group of cells. Some may say ASD involves multiple factors of causes (Shaw *et al.*, 2014). Studies have suggested a strong genetic component that is related to ASD. This is shown by an increase in concordance between monozygotic when compared to dizygotic twins. Other studies have identified and associated ASD with genetic variations and some rare gene mutations. That said, not all infants with a gene will develop ASD if not exposed to the environmental factors that are known to trigger the disorder (Estes *et al.*, 2014). Some studies point out the critical prenatal period and its relation to ASD; these studies suggest that the prenatal period has some strong implications in the development of ASD (Becerra *et al.*, 2014). Magnetic Resonance Imaging (MRI) and neuropathological research studies have shown evidence of altered neocortical growth and organisation in children with ASD. Others have also associated chromosomal deletion or duplication and methylation differences. According to (Geschwind, 2008), about 10 to 15 % of people with ASD, a specific mutation gene can be identified and this is expected to increase with the improvement in technology. Some studies have documented post-encephalitic infections or sepsis preceding the onset of ASD symptoms (Mankoski *et al.*, 2006). However, there is a lot of evidence suggesting a rare occurrence of postnatal disease as a cause of ASD (Rutter, 2005). Some increase in ASD occurrence is attributed to environmental exposure which includes maternal viral infections, thalidomide and valproic acid use during pregnancy (Bölte, 2014). Further research suggests suboptimal prenatal, perinatal and postnatal conditions could be a risk factor for autism (Bölte, 2014). Other post-natal factors that became a focus of postnatal causes in ASD were the possibility that ASD maybe be a result of immunisation in children (Rutter, 2005). The measles–mumps-rubella (MMR) vaccine was one immunisation that was first suggested as responsible for the significant rise in diagnosis and causing ASD. It was argued that there was a leakage of protein into the bloodstream, therefore, causing a regressive form of ASD which resulted in loss of communication and social skills, which may have been previously acquired by the child (Rutter, 2005). After a number of studies conducted to ascertain whether MMR was indeed a cause of a regressive form of ASD in children, unfortunately, the evidence was against these claims (Rutter, 2005). The MMR claim and its association to ASD remain untrue and unproven up until this day.However, the possibility of

environmental factors is still a large area of research.

A study conducted in Nigeria that assessed the opinions of health care workers particularly nurses found that as high as 26.9% of these practitioners believed that ASD can be linked to supernatural causes (Igwe *et al.*, 2010). The Chinese belief also states that all mental related illnesses including ASD are closely related to vital and spiritual forces (Ravindran and Myers, 2012). A study conducted in Kenya found that majority of parents believed the cause of ASD to be either witchcraft, curses and/or evil spirits (Gona *et al.*, 2015). Most parents (Gona *et al.*, 2015) believed that evil spirits can invade the mind and take over the entire system of the child. They mention that the evil take over could happen prenatal or post-natal. A study conducted in Taiwan with parents of children with ASD found that about 15% of parents who were part of the study believed supernatural powers as a cause of ASD (Chen *et al.*, 2014). Some parents in the study believed karma was the cause and others alluded it was an attack from ghosts (Chen et al., 2014). This above mentioned beliefs confirm some heurmenutic approaches which place illness as a social process mediated by language and other socially learned ways about understanding behaviours related to illness. The family and the social environment are important in understanding illness. A model by Keinman (1980) explains how illness is interpreted and treated. Kleinman explains the differences that exists between lay and practitioner models. Basically, lay is charecterised by vagueness and clear bounderies between ideas and experience (Kleinman, 1980). In the African context people presenting symptoms of ASD are not unknown, however there are different ways of conceptualizing the disorder and different context mean different approaches in treating and understanding the disorder.

2.4 Prevalence of ASD

Over the past few years, there has been a debate whether or not there is an increase in the number of prevalence diagnoses of ASD (Chakrabarti & Fombonne, 2001; Nicholas, Charles, Carpenter, King, Jenner & Spratt, 2008). The initial estimates of the prevalence of ASD show figures as low as 10 in 10000 individuals with some form of ASD (Matson & Kozlowski, 2011). However, the recent figures suggest that the previous rates have increased to as high as 110 per 10000 individuals have some form of ASD (Kogan and Blumberg, 2009). As per these figures, there is no doubt that the prevalence of the disorder is increasing. It is further stated that this increase could be attributed to the shift from the previous categorising of ASD as

informed in the DSM-IV and the ICD10 system of classification (Volkmar, F. R., Paul, R., Klin, A., & Cohen, 2005; Martins, Walker and Fouché, 2013). Cases of ASD have increased by more than 500% over the last five years. Some of the resons why there has been an increase in diagnosis could be attributed to the increase in awareness and access to information to many African countries. Also, the training of practitioners about this disorder has contributed in the escalated numbers of disgnosed cases.

The estimated figures were taken from the United States Department of Health. Some researchers state that 1 in 10000 children are diagnosed with the disorder (Moore, 2008). Of the figures reported by Moore (2008), 1 in 50 children of the affected ones are between the ages of 6 and 17 years of age. Other countries such as England, Denmark and some across Asia confirm the increase of ASD (Baird, Simonoff, Pickles, Chandler, Loucas, Meldrum, & Charman, 2006; Lauritsen et al., 2004; Sun & Allison, 2010). Globally, 1 in eighty-eight children is affected by the disorder, with the diagnosis being higher in males as compared in females (Centers for Disease Control and Prevention (CDC), 2016). Early research in Africa found very few cases, which met the criteria of ASD. A rate of 1 in 145 was noted by (Lotter, 1980). Other studies in Africa conducted in Egypt and Tunisia in recent years have shown an increase to 11.5% and 33.6% respectively, which shows a very high number when compared to earlier findings by Lotter (Seif Eldin *et al.*, 2008).

2.5 Common Interventions in the treatment of ASD

Many treatments and interventions are known and exists for ASD. Some date back even to the early nineteenth century. Some of these treatments are categorised according to age groups, some for adults and others specific to children. Most literature is loaded with these forms of treatment methods. There are many contradictions even in the literature concerning the effectiveness of these treatment methods. According to Tantam, (2011), there are about 112 known to date treatment interventions that have been written about in the literature as possible treatments for ASD. Among the numerous known interventions, there are some interventions that have been flagged to cause harm to children and others have been tested and known to be efficacious.

2.5.1 Early Interventions

Early interventions have been argued to be effective in children with ASD. The contradictions exist in the literature regarding the efficacy of some of the early interventions. This section discusses some of the known interventions available to children with ASD. It also discusses the literature findings of the efficacy of these interventions on children. This section further seeks to understand some of the criticism available in the literature in regards to these interventions. Some of the known criticism is that most of these interventions are grounded in western theories of treatment. Other criticism include the financial implications that are attached to some of these interventions that may threaten acces to care to those underprevilaged and underresourced.

The disconnection in the brain, which researchers argue as a cause of ASD may be restored by providing a child diagnosed with ASD with sufficient overlearning at an early age (Tantam, 2011). Also, early interventions may improve adaptive and personal social behaviours of children with ASD (Sridevi & Arya, 2014). There is an array of information that is available for programs that are known to be effective to improve symptoms of children with ASD.

It is further stated that information is not a treatment method but an integral part of the journey and treatment of ASD (Tantam, 2011). He states that the first key information that is vital in the treatment process is obtaining a diagnosis of ASD. Usually, parents go through a series of practitioner consultations before a correct diagnosis is obtained. Some even turn to the internet to search for the underlying causes of the illness. They further state that even post diagnosis, professionals often are unable to provide parents with enough information about ASD. A project was conducted to evaluate whether information was indeed an integral part of the child's pathway to care and the project revealed a necessity for a resource material that will assist parents especially during the early stages of attaining a diagnosis (Mulligan *et al.*, 2010). Other known interventions are listed below:

- **The Walden Toddler Programme:** This programme was designed to provide early childhood education to children from the ages of 15 months including children with ASD. The programme is focused on using comprehensive incidental teaching, language development and social development with a focus to achieve social inclusion. This Walden programme is a combination of (Skinner, 1948) developmental approach and Thoreau's developmental approach which emphasise the basic principles in early child development

and its emphasis on language and social development (Thoreau, 2005). Incidental teaching is a method of Applied Behavioural Analysis that uses behavioural principles in the natural learning context (Corsello, 2005). The programme is structured and works on planned activities with a purpose to achieve individual goals. The intervention involves toys and other activities that the child may find appealing; the facilitator responds and expands on the child's requested activities (Corsello, 2005). It is designed for toddlers between the ages of 15-36 months and includes toddlers without a diagnosis of ASD. Whilst there is limited empirical research conducted on this programme, the evaluation data revealed that about 82% of children used meaningful vocabulary after leaving the programme and about 71% of children showed improved interaction with other children (Corsello, 2005).

- **Social pragmatic communication:** This programme was designed to teach social and communication skills to young children with ASD and disabilities, developed by Amy Wetherby, It is based on pragmatic communication strategies designed for children under the ages of 3 years old. Others refer to this model as an interactive model while some as a child-oriented approach (Fey, 1986; Tannock & Girolametto, 1992). This is a child development model that focuses on the relationship between a response of a caregiver and the level of a child's communication skills (Prizant, Wetherby & Rydell, 2000). The model states that language development is dependent on the interaction of the parent and the child; it also emphasises functions of communication such as questions, sharing, commenting and others (Prizant, Wetherby & Rydell, 2000). The first important step of the model is that the child initiates the interaction and secondly the parent organises the environment to encourage the interaction and all unconventional methods of communication such as eye gaze, reaching or grabbing (Ingersoll, Dvortcsak and Whalen, 2005). During the interaction, the parent encourages emotional expression such as facial expression to show anger or a happy face. The adult uses an adjusted language or simplified language to encourage communication to continue (Ingersoll, Dvortcsak and Whalen, 2005). There are limited RCT that have been conducted to support the efficacy of this approach in the literature (Ingersoll, Dvortcsak and Whalen, 2005). Other studies found very limited efficacy on this intervention of children with passive communication styles like that found on children with ASD (Fey, 1986). Indeed, there are differing views on the efficacy of this model. While there were limitations in the research conducted by Ingersoll et al. (2005), their results support the efficacy of this intervention in children with ASD.

- **Developmental, Individual Difference, Relationship-Based Model:** The model presents itself as a comprehensive developmental intervention that promotes developmental progress which focuses on helping children learn communication, thinking skills and function in an array of emotions and socially appropriate behaviour (Greenspan, DeGangi & Wieder, 2001). This model is said to target the known deficits of ASD as stated in the DSM 5, including social reciprocity, language - verbal or nonverbal, relationship building and the ability to adjust in social contexts (Greenspan, DeGangi & Wieder, 2001). Furthermore, the DIR is not just an intervention but it is a way of understanding that each child is unique and developing a programme that is tailor-made to each child's needs within the relational context of the family. The other purpose of the DIR is to strengthen relationships among all members of the family not only with parents (Wieder & Greenspan, 2001).

- **Social stories:** This intervention was developed by a school psychologist for teachers to interact with children in order to improve social skills and behavioural response in children with ASD. This method fits in classrooms and can be administered by teachers. The training is very short and can help teachers to interact with pupils effectively and readily if there are available structures to conduct this intervention. This method has been also extended outside the education setting and can be used in physical activity contexts (Sandt, 2008). Children with ASD find it difficult to understand the social situations and expectations of others in social settings; this may lead to behaviours that are disruptive for the child and also for the teacher in the classroom setting (Sandt, 2008). So, social stories are designed to provide the child with social information that will help the child understand social cues and people's perspectives (Gray, 2004). There is limited empirical research on the efficacy of this interventions, however, there are studies that have indicated the positive potential of social stories (Ali and Frederickson, 2006).

- **Remediation:** Remediation is another form of intervention that is seen as an option if early intervention was ineffective to the child or started late. Like any intervention in ASD, there are several approaches to remediation which include the use of ICT to teaching children recognition of facial emotion. Also, children with ASD are said to acknowledge facial expression recognition and present rigid behaviours (Tseng and Do, 2010). ICT is an effective intervention to help children with ASD; facial expression wonderland is one programme that is available to train children with ASD recognise faces using games (Tseng

and Do, 2010). The FEW gaming programme is based on the film called Alice in Wonderland and is targeted at children who are pre-schoolers up to grade 4. While the FEW programme is fairly new and has some limitations, a facial expression may be confusing in real life than in an ICT gaming system.

Other effective remediation approaches is the training of children on empathy. Empathy is a very important social skill that is needed in every stage of a person's life and the lack of such skills is noticeable and may impact the child in navigating certain public or social spaces (Tantam, 2011). There are several interventions targeted to teach children with ASD expression of emotions and recognition of emotions. Some of these interventions are based on interactive tools (Golan *et al.,* 2010) while others are anchored on the ABA intervention (Baer, Wolf& Risley, 1968).

- **Facilitated Communication**: The world of research is vigilant in the use of interventions in children with autism since some of these interventions are ineffective and may carry some elements of harm. So, it is important to understand the type of intervention to be administered to a child and know the integrity of the intervention before exposing a child to invalid interventions. Facilitated Communication (FC) has come under serious scrutiny by researchers and other academic communities. This was after the emergence of allegations of sexual abuse, where parents and family members were implicated and some faced conviction (Herbert, Sharp & Gaudiano, 2002; Lilienfeld et al., 2015). FC can be traced back to an institution that cared for people with intellectual and physical disabilities in Australia (Lilienfeld *et al.,* 2015). This technique was developed around 1977 by a staff member (Rosemary Crossley) who worked with children and people without speech (Crossley, McDonald & Molloy, 1980). Crossley developed this intervention to extract information from those individuals who were seriously speech impaired and physically disabled. Many of Crossley's patients were individuals with cerebral palsy (Jacobson, Mulick, & Schwartz, 1995; Lilienfeld et al., 2015). Based on the work of several researchers, this intervention was later extended to other individuals with conditions such as autism and those who were in a coma (Palfreman, 1993). Crossley's FC intervention attracted many researchers who observed the intervention and later came to their conclusions. Scholars such as Biklen confirmed Crossley's intervention as effective in his article published in 1990 (Biklen, 1990). After this article and other collaborations, FC was later integrated into the academic and clinical mainstream (Lilienfeld *et al.,* 2015). The technique gained an overwhelming interest in the academic, media and clinical spaces.

While there was excitement about the intervention, the techniques had not gone through any controlled tests (Mostert and Mostert, 2012). The fall of the FC was seen after allegations of sexual abuse implicating parents surfaced . Some parents were convicted and served jail time after FC facilitators generated allegations of rape (Lilienfeld *et al.*, 2015). Soon after the court cases, controlled and rigorous testing of FC was done by several researchers (Bomba et al., 1996; Moore, Donovan, Hudson, Dykstra & Lawrence, 1993; Saloviita, 2014; Shane& Kearns, 1994; Smith, Haas & Belcher, 1994; Wheeler, Jacobson, Paglieri& Schwartz, 1993). Almost all tests conducted were against the effectiveness of the FC intervention in autism. Later, a consensus was reached by several organisations (American Psychological Association, American Psychiatric Association, American Academy of Child and Adolescent Psychiatry, American Association on Mental Retardation, American Speech-Language-Hearing Association, Association for Behavior Analysis, Behavior Analysis Association of Michigan, American Academy of Pediatrics, American Association on Intellectual and Developmental Disabilities, and New York State Department of Health) that FC was ineffective (Lilienfeld *et al.*, 2015). Despite all the negativity and evidence supporting that FC was ineffective as an intervention for ASD, there is still a handful of clinicians and parents who use this intervention.

2.6 Medication

While specialists in ASD do not recommend the use of drugs in treating ASD, this intervention is being used commonly as an intervention to improve symptoms of ASD. Some researchers have articulated that about 30-60% of children with ASD are taking at least one psychotropic drugs with a majority taking antidepressants, neuroleptics or stimulants including antiepileptic drugs (Ama Lam& Van Bourgondien, 2005; Green, Pituch, Itchon, Choi, O'Reilly& Sigafoos, 2006a; Martin, Koenig, Scahill, & Bregman, 1999; Oswald, & Sonenklar, 2007; Witwer, & Lecavalier, 2005). Lack of information about the disorder and its treatments are some of the reasons why there is a high number of children committed to medication intervention. Parents lack the knowledge of the possible and available treatment options for their children thus end up opting for what is available. Other research confirms that there was an association between the parent's level of education and the use of medication in individuals with ASD (Aman, Lam, & Van Bourgondien, 2005). Also, there has been a web-based survey which found that children with more severe symptoms of ASD were more likely to be exposed to medication compared

to those children with less severe symptoms (Green, Pituch, Itchon, Choi, O'Reilly & Sigafoos, 2006b). While studies have been conducted on the use of medication on children with ASD, there are very limited sources that provide statistics relating to the association of insurance or medical aid and demographic factors beyond age, sex and or even the type of ASD (Rosenberg *et al.*, 2010).

The two drugs that have been authorised by the United States Food and Drug Association are risperidone and aripiprazole for the treatment of irritability in children and youth with ASD (Wink *et al.*, 2017). Also, there has been evidence supporting the use of other psychotropic drugs for the treatment of irritability associated with ASD (Cohen, Campbell, Posner, Small, Triebel & Anderson, 1980; Politte & McDougle, 2014). It has been found that psychotropic drugs are administered and used to treat symptoms of anxiety in children with ASD. While these may work in the short term, they, however, have been found to have side effects. As stated by (Tantam, 2011), the use of psychotropic drugs in children is beneficial to parents since they calm the child's anxiety and may reduce the insistence of routine but there is currently no literature supporting effectiveness in ASD. Antipsychotropic drugs also have been prescribed to children to reduce outbursts and anger associated with ASD. Besides, these antipsychotropic do not have any supporting evidence supporting this (Tantam, 2011).There is also a rising number of concurrent use of medication (Polypharmacy) in children with ASD (Schubart, Camacho& Leslie, 2014; Spencer et al., 2013). A recent study states that there is a rising number of youth with ASD using multiple antipsychotic drugs ranging from 6.2% in 2000 to 8.7% in 2003 (Schubart, Camacho, & Leslie, 2014).Other researchers have mentioned a general concern regarding the safety and the effectiveness of the use of these drugs in children since the developing brain is sensitive and vulnerable when exposed to other biological and environmental influences (Mohiuddin and Ghaziuddin, 2013; Spencer *et al.*, 2013).

The literature contains different views about the use of medication to treat symptoms of ASD. Certain studies have found significant superiority to placebo in several symptoms (Campbell, Rapoport & Simpson, 1999). Although these studies state the effectiveness, they also state that there is an adverse side effect in using psychotropic drugs such as haloperidol. The side effects include drug-related dyskinesia, which was relatively common in children exposed to haloperidol. Also, while studies were supporting the use of selective serotonin reuptake inhibitors (SSRIs) such as fluvoxamine (McDougle, Naylor, Cohen, Volkmar, Heninger, & Price, 1996), there have been studies that found an increased rate of side effect on the use of SSRIs (Brodkin, McDOUGLE, Naylor, S Cohen& Price, 1997). Other researchers agree that

children do not respond positively to SSRIs when compared to adolescents and adults (Mcdougle, Kresch and Posey, 2000).

Functional magnetic resonance imaging (FMRI) studies, the few that have been conducted reported no differences in brain activation between children taking psychotropic drugs and those who were not on psychotropic drugs (Just *et al.*, 2007).

2.7 Interventions for Children with no Language or Limited Language

As mentioned earlier in this section, there are many interventions known for ASD. Some of these interventions include psychoeducation, care management, occupational therapy, social inclusion, speech therapy and many others. However, some interventions are known to focus on children with impairment in speech. Often, delayed speech is the first marker of autism according to many researchers (Flippin et al., 2010; Lord, Risi & Pickles, 2004). Therefore, there is an important need for children to begin language and speech interventions very early in their lives. Given several available interventions in the ASD space, practitioners and parents have difficulties in choosing the correct and effective form of language treatment for the child. The complex nature of ASD makes it difficult for practitioners to determine if a child will later develop speech as they grow older or they will need a more intensive and augmented intervention method (Flippin, Reszka and Watson, 2010). The variability in ASD has made it difficult up until this day for clinicians to develop effective guidelines to inform the treatment of speech and communication (Flippin, Reszka and Watson, 2010). Many interventions focus on communication problems in children with ASD but one of the commonly preferred interventions for nonverbal children with ASD is the Picture Exchange Communication System (PECS). PECS is designed to teach children exchange-based communication in school settings. Children are approached to give the facilitator a picture of the desired item in exchange for that particular item (Flippin, Reszka and Watson, 2010). Other researchers have stated that while there are studies confirming evidence and efficacy of PECS, there is still a need for further Randomised Clinical Trial research into the efficacy and effectiveness of PECS (Preston and Carter, 2009). Such programs may not be available in underresourced areas due to lack of funding for programs and limited practitioners to administer the PECS system.

In the early 1960s, new innovation introduced another intervention called Auditory Integration Training (AIT) for children with ASD. The summary of this intervention was to bring about

re-education to the hearing process. The intervention is said to improve abnormal sound sensitivity to individuals with ASD including those with behavioural challenges (Sinha *et al.*, 2006). An article from the Committee on Children with Disabilities (1998) mentioned at the time of publication of the article, there were no good RCT studies conducted to support the efficacy of the intervention.

2.8 Complementary and Alternative Medicine in ASD

This section discusses complementary and alternative medicine in the treatment of ASD. For the benefit of this research, African Traditional Medicine (TRM) will be discussed separately as it forms a very large part of this thesis and will be, thus, discussed separately. Also, African traditional medicine is discussed separately because of the existing debate in the literature arguing against it being an alternative form of treatment but rather a stand alone treatment method.

The use of complementary and alternative medicine (CAM) as a treatment for ASD is increasingly becoming common. There is no one universal definition of CAM but according to the National Centre for Complementary and Alternative Medicine in the USA, CAM is "healthcare practices that are not an integral part of conventional medicine. As diverse and abundant as the people of the world, these practices may be grouped within five major domains: alternative medical systems, mind-body interventions, biologically-based treatments, manipulative and body-based methods and energy therapies"(NCCAM, 2009).

Most parents who opt for the use of CAM are from high socio-economic families and can afford the high costs that are associated with these treatments. The prevalence range of parents who use CAM is very wide. It is mentioned that the prevalence range is between 32% - 92 % mainly because different studies source the information differently: some from interviewing parents and other researchers source the information from the patient files (Christon, Mackintosh and Myers, 2010). In the USA alone, the use of CAM range between 32 – 87 %, in Canada 52% and China 41% (Lofthouse, Hendren, Hurt, Arnold. & Butter, 2012). There is generaly a lack of data in South Africa concerning the use of CAM fom the general public (Peltzer, 2009). An online survey conducted by the Interactive Network on Autism (INA) reported 381 available treatments for autism of which the majority were CAM. Lofthouse, Hendren, Hurt, Arnold, Butter (2012) mention two different types of CAM that are available for children with ASD:

ingestible and non-ingestible forms. Several known CAM ingestible treatments have been known to be frequently mentioned in the literature (Melatonin, Vitamins B6 and Magnesium, Methyl B12, Multivitamin Mineral Supplements, Folic Acid, Omega 3 fatty Acid, Probiotics and GI medication, Iron Supplementation, Chelation, L-Carnosine, Ascorbic Acid, Cyproheptadine and Immune therapies). There are also several non-ingestible CAM treatments available for ASD such as massage therapy, acupuncture, exercise, music therapy, animal-assisted therapy and neuro-feedback. According to Lofthouse, Hendren, Hurt, Arnold, Butter (2012), all of the above mentioned ingestible (Melatonin and RDI Multivitamin/Mineral) and non-ingestible (massage therapy) CAM, are the methods that they recommend.Of all the mentioned above, their study recommended only two ingestible and one non ingestible. Other studies have mentioned that greater than 9% of children were exposed to harmful CAM treatment such as excessive amounts of vitamins, antibiotics and chelation (Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003). Other researchers speak of a miracle mineral solution, which made rounds in the market and it was also an available alternative treatment for ASD (Trudeau *et al.*, 2019). The miracle portion was nothing but a mixture of sodium chloride and hydrochloric acid (bleach). So far, this miracle solution has claimed one life and several injuries and still going very strong on social networks (Trudeau et.al., 2019). The USA Food and Drug association has since issued a warning about the miracle solution.

There have been some studies conducted to determine the effectiveness and efficacy of CAM treatment methods for children with ASD. The literature in this space is contradictory on certain methods for some recommendations and others may reject a particular method as ineffective. I will now focus on the known CAM interventions that have been suggested to be ineffective or those that have been found to have side effects and may be harmful to the patient.

- **Diet:** Most parents are convinced that a change in diet may improve some of the symptoms experienced by a achild with ASD. The internet is bombarded with several diet suggestions and recommendations for parents who are looking for a possible solution for their child with ASD. Whether these suggestions and internet sites are true or false, that is often the least of the concern that the parents verify. There are thousands of results that can be found if one searches for ‘diet for children with ASD’ on the internet. The availability of these results leaves parents with plenty of information to read which may become a huge task to sift through on what is real and what is not real in these results. In addition, there is a notion by some researchers stating that diet treatment for ASD is based on the unscientific and unproven hypothesis that foods containing gluten and casein may enter the bloodstream

and impede the central nervous system development (Whiteley *et al.*, 2012). As a result, children with ASD are increasingly taking gluten-free and casein-free diets. There is currently no consensus on the number of children with ASD on a gluten-free diet. However, there is a consensus on the increasing numbers of children on this diet; the number is estimated between 26% to 40% (Whiteley *et al.*, 2012). The literature,on the other hand, has seen very few well-designed trials investigating these claims. Some studies that have claimed efficacy and effectiveness of the GFCF diet presented numerous flaws in data and methodology and others have limitations that compromised the validity of their findings (Mulloy, Lang, O'Reilly, Sigafoos, Lancioni & Rispoli, 2011). Studies that protected the internal validity of their findings also had statistical flaws which also leave room for caution when interpreting the findings of these studies (Mulloy et. al., 2011). Research on efficacy and effectiveness of GFCF continues to occupy the literature, more and more contradictions of whether the GFCF is effective or not effective continues to be a topic of discussion. Mulloy et. al., (2011) studied several papers and their study concluded that the GFCF treatment is not an effective treatment of ASD and may and should only be implemented if the child experiences behavioural changes associated with the diet or the doctor has confirmed the existence of an allergy. Other studies found that the GFCF lacks evidence as an effective treatment method for children with ASD (Whitehouse, 2013). There is another body of literature stating the nutritional implications of children following the GFCF diet (Marí-bauset *et al.*, 2014). Following a gluten-free diet means that children on this diet will exclude all food items containing oats, wheat and all items with flour including bread, pasta and cereal made with wheat. The casein diet excludes all dairy items such as ice cream, milk, yoghurt, cheese and other dairy products. This type of diet is not only expensive but also requires that caregivers and parents become committed to it. Furthermore, the diet has the potential of changing the child's routine and affecting the eating behaviours which may harm the child's social life (Marí-bauset *et al.*, 2014).

2.9 The Diagnostic Process of ASD

The first early attempts to diagnose ASD as a broader group of developmental disabilities dates back to the work of Kanner (1943). Initially, the work of Kanner focused on describing the symptoms that best characterised the condition through observations. This informal assessment process has led to low validity in the diagnosis of ASD according to the Kanner approach

(Matson et al., 2007). Seeing the idiosyncrasy in the earlier diagnosis methods, there has been efforts and increased research to improve ASD diagnosis tests. The critical moment in the conceptualisation and diagnosis of ASD came in the 1980s when the DSM III recognised autism disorders as a separate category.This was almost 40 years after Kanner's paper (1948). ASD diagnosis includes clinical observations and interviewing of the child, where applicable, parents or caregivers are interviewed and asked to complete an ASD checklist (Matson et al.,2007). Since the diagnosis of ASD is based on behavioural criteria, a diagnosis can, therefore, be made by different professionals using tools that are relevant to their profession (Graf, 2019). The use of a diagnostic tool has become the central core for diagnosing ASD (Matson et al., 2007). Research has shown that a reliable diagnosis can be made between 2-3 years of the child's age (Baird *et al.*, 2003). Several assessments are conducted in the diagnosis process by practitioners. Some of these assessments are medical and others are through assessments. Some doctors go over and beyond with assessments and others are guided by their exposure in the field of ASD as well as caregivers' explaination of the child's condition.

Autism research has increased through the years; more researchers are entering the space, as a result, more screening and diagnostic tools have been developed over time. Screening tools are used to identify many developmental delays. Some tools are used to identify the existence of ASD. Others, may be specific to a particular delay such as limitations in language and speech. Screening tools alone should not be used as a diagnosis as they do not provide conclusive evidence of the delay. Tools vary; they may be administered by teachers, nurses, professionals, psychologists and doctors. While the diagnostic tools are of critical importance in providing a conclusive diagnosis of the child, they are hard to access in low-resourced countries for professionals (Durkin *et al.*, 2015). The unfortunate part of these tools is that they are expensive; they require knowledge and training for those who will administer them (Durkin *et al.*, 2015). It is important to discuss the issue of culture that has long occupied the research literature over time. Tests need to be culturally relevant and tested in the context of each culture even if they will be used in English. Different cultures interpreted certain phenomena differently. For example, eye contact which forms part of the symptoms of ASD may mean different things in different contexts. While there have been studies conducted to understand the adaptability of certain tests in South African contexts (Chambers *et al.*, 2016), practitioners need to take into account the diverse cultural aspects that are available in parents and their understanding of ASD.

2.10 Challenges in Parenting children with ASD

As a challenge to parents and families, ASD is ranked the most stressful neurodevelopmental disorder of all (Gray, 2006). According to the description of the disorder on the DSM 5, children diagnosed with this disorder face challenges of speech, communication and a deficit in social communication. These challenges are apparent from as early as the child is two years old, up until the individual reaches adulthood. Parents with a child diagnosed with ASD are more involved in the child's life than other parents with children without an ASD diagnosis (Hartley, Barker, Seltzer, Greenberg, & Floyd, 2011). As a result of these challenges, taking care of children and adults on the spectrum may be demanding and place enormous stress on parents and families. Alarge number of challenges begin from the time parents are faced with looking for a diagnosis and an understanding of the problem of the child and this later progresses to the emotions that arise after receiving a confirmed diagnosis. From childhood to adolescence, parents shoulder almost all the child's responsibility from deciding the right treatment programme as well as the course of treatment which can be a daunting responsibility (Krauss, Seltzer and Jacobson, 2004). Early literature confirms that the presence of a child with autism has a negative stressful effect on the entire family life; it affects siblings and the marital situation of parents (Koegel, Schreibman and Loos, 1993; Van Rooyen, 2016).

Challenges parents face range from more than usual doctor visits, the administering of medication for the child as well as the financial attachments that are associated with raising a child with ASD (Lee, 2009). Since the demands linked with raising a child with ASD are high, mothers have been found to have more than usual caring responsibilities when compared to their counterparts. These stresses are linked with family activities such as going shopping and taking family trips (Koegel, Schreibman and Loos, 1993). Also, parents face a bombardment of a series of intervention after intervention suggested by different practitioners which bring about additional parenting responsibilities (Myers, Mackintosh & Goin-Kochel, 2009). Some children are unable to function without the help of their parents; they require assistance on communicating with others, promoting autonomy which can also bring about some level of strain on the parent (Osborne *et al.*, 2008). Some research states that parenting a child with ASD limits a parent in living a fulfilling life because of a rigid and structured life caused by parenting demands that are associated with ASD (Meirsschaut, Roeyers & Warreyn, 2010).

There are three significant sources of stress experienced by parents (Sharpley, Bitsika and Efremidis, 1997). The first source mentioned by Sharpley is the permanency of the child's

condition. Some researchers may refer to it as the loss of a healthy child. Oswin (1991), on the other hand, mentions the concept of a 'perfect child'. It is normally expected that all parents plan for a healthy and perfect child when expecting a new member of the family. However, this is not always the case; some children experience a myriad of defects, impairments, disabilities and other forms of illnesses. Thus, it is mentioned that from the time the child is diagnosed with a disability, in this instance ASD, the family goes through a crisis of having to mourn the loss of a 'perfect child' (Oswin, 1991). Other researchers state that this loss is often followed by a series of negative emotions such as shock, grief and also the loss of previously held expectations of a healthy child (Goldberg *et al.*, 1995).

The second source of stress is the negative treatment and disapproval of the child's behaviour from those around the child (family members, teachers, community members). Often ASD is not widely known to most people and this may result in a negative reception of the child by those who are not familiar with the disorder by showing disapproval towards the behaviour of the child.

Another source of stress is the lack of support professionally (Sharpley, Bitsika and Efremidis, 1997). The issue of professional support continues to be a problem for parents and also in the health sector. There are very few expert professionals focusing on ASD and this poses a problem for parents. Governmental programmess and interventions continue to be a public health issue. This is not only a problem in SA but is a cause for concern in other countries like Australia (Dabrowska & Pisula, 2010). The stress experienced by parents is critical because it may affect the adjustment in caring for the child and their needs. The process of how a parent copes with stress associated with the child's behaviour and the condition usually leads to successful adaptation.

Despite these above-mentioned challenges, parents and families thrive and often cope successfully with ASD in the home. There are, however, various factors that contribute to parental adjustments such as the sex of the parent, support and coping activities (Bristol, 1984; Gray & Holden, 1992; Gray, 2006).

2.11 Culture and ASD

Research on ASD in Africa was introduced many years after the paper by Kanner in 1943 titled "*Autistic disturbances of affective contact*" (Munir & Bakare, 2011). The work by Longe and

Asuni and that of Lotter were among the first work published in Africa on the subject of ASD (Bakare & Munir, 2011). This work included issues of cross-cultural perspectives on childhood ASD, cultural factors and cultural environment. Generally, in Africa, illnesses like ASD have been labelled as "western illnesses". The notion of western illness comes from the fact that western countries are over-industrialised and the technology is very advanced which in turn affects the environment. Another belief was that the illness occurs in countries where nuclear families are dominant as compared to the idea of family in Africa which is extended and larger (Baker & Munir, 2011). To al large extent, African families still believe in the notion that 'it takes a village to raise a child'.These differences in approaches and understandings of the approaches are part of the objectives of this research project.

Denialism of the existence of the disorder in Africa went on for years until Sanua opened a debate and discussion with his paper titled "*Is infantile autism a universal phenomenon? An open question*" (Sanua, 1984). Many researchers started answering Sanua's question through research and evidence of the existence of ASD. This has unfolded in many studies confirming that indeed ASD exists in Africa and the rest of the world. However, with the acceptance of the existence of the disorder emerged other questions of the causes and the treatment of the disorder. There are many issues of ASD in Africa that remain obscure due to the value and the belief system that is strongly embedded in culture and tradition.

According to (Grinker, 2008), generally, Africans are less likely to consult the services of a psychiatrist in matters related to mental diseases and disorders but more likely to pursue traditional healers because of their cultural beliefs, which are embedded in historical experiences. Most parents make decisions about the diagnosis of the child's condition based on their background, which includes cultural background. This way of thinking is unlimited to South Africa but is the norm for parents in other African countries the same.

Parents' interpretation of the disorder influences the type of treatment the child will receive. Those who believe in traditional treatment will seek treatment by consulting traditional and spiritual healers and those who believe in spirituality or religion may make offerings to God or take the child for arduous ceremonies. While some of these alternatives may be harmless, there is an obligation on designated caregivers and professionals to be aware of the potential for some of these practices to be harmful (Tidbury, 2014).

As mentioned, the cause of autism is unknown, however, research has shown that proper early intervention with evidence-based treatment is the most effective way to improve the condition

of children with autism spectrum disorders. Yet, some parents continue to contest the opinions of experts staying firm in their beliefs of culture and religion. Parents who limit therapeutic opportunities available to the child may indirectly be causing harm to the child by limiting the child's future opportunities. Children rely fully on their parents to make decisions for them that are in their best interests as well as making the right decisions for their wellbeing. Often, we assume that parents have the child's best interest at heart but it is equally important to note that not all individuals/parents are equipped to make good choices for their children. It is known that some parents are poor in their parenting and this may put the child in danger.

In the context of South Africa, the issue of culture goes beyond just a practice. It is embedded in the country's democratic laws that promote 'one law for one nation' and this allows for cultural diversity and constitutional protection of cultural practices and beliefs (Comaroff and Comaroff, 2004).

Traditional medicine in South Africa still plays an integral role in the health of many citizens. In 1995, there were 200 000 traditional healers compared to 25 000 modern doctors (Truter, 2007). The majority of South Africans (60- 80 %) consult the services of a traditional healer before seeking medical assistance from a primary health care professional (Truter, 2007). In the context of families and parents who live with a child with a disability, traditional practices and ceremonies are inevitable in most African families. Parents experience a great deal of emotion when they discover that their child has a disability. They may accept the disability or any form of the handicap but after the condition becomes apparent and reality sets in, the question of witchcraft as an underlying factor often comes to the foreground and parents begin to seek traditional treatments (Berg, 2003). Families do what they perceive best for their child based on their environment (Ravindran and Myers, 2012; Ennis-Cole, Durodoye and Harris, 2013). The family's interpretation of the disorder influences the type of treatment the child will receive. While most of these alternatives are harmless, there is an obligation to designated caregivers and some professionals to be extra vigilant to the potential for some that are harmful (Tidbury, 2014) .

Globally, different cultures, groups and communities have their understanding of illness, its causes and treatment. Several major traditional medical systems are used by non-Africans (Chinese, Arabic, Hindu etc.) that can be categorised as traditional or ethno-medical based. Therefore, Africans and their approaches to illness are not far different from other alternatives. The distinction from other approaches is that each African community within the

larger community has its medical system for example traditional medicine in Nigeria is not necessarily the same with that used in South Africa in the treatment of illness in general. The use of plants as medicine is the common denominator when it comes to African treatment methods (Mahomoodally, 2013). Also, there has been a notable lack of understanding of African Traditional medicine and the role of traditional healers. These misconceptions and misunderstandings, according to Sindinga, Nyaigotti-Chacha and Kanunah (1995), emanate from the negative presentation of traditional medicine during the colonial era. The negative presentation of African approaches portrayed all traditional ways of healing as witchcraft and a particular form of black magic (Sindinga, I., Nyaigotti-chacha, C., Kanunah, 1995). Up until this day, the term 'witchcraft' has been closely associated with any form of traditional African medicine. The term'witchcraft' is defined as any approach or administration of mystical powers used to harm others (Mbiti, 1969). A lack of theoretical formulation on the medical system in the African approach can be another source of the misunderstanding of the African approach to healing. There are several definitions of traditional medicine in the literature, which explain the concept and distinguishes them from other ways of treatment. Traditional health care relies on a combination of knowledge and observations that originated within a culture used to diagnose an array of illnesses that are physical or mental within a community (World Health Organization.Programme on Traditional Medicine, 2001; White, 2015). The practice of traditional health care in the African continent has become a very popular practice.The traditional health industry has grown to become one of the multimillion-dollar industry in the health care sector (White, 2015). In addition to this, (Kofi-Tsekpo, 2004) defends the term 'traditional alternatives' by stating that it is not synonymous with'traditional health care'. He further defends this by saying this is the African indigenous way of health care and not an alternative.

There is a common notion that highlights that majority of Africans believe in supernatural powers and ancestors (Samuel Danquah & Asare, 2017). The understanding of illness in the African context is communal and family oriented when compared to the western approach to Illness. According to the model by Kleinman (1980) puts strong emphasis on culture as an influence to understanding illness. The model acknowledges that people are not the same and they may have inconsistences in their approach to illness. In South Africa there are varied approaches to illness within different cultures and different groups however it is important to explore those approaches that are common in the treatment of ASD.

In 2001, the World Health Organisation released an article titled '*Legal status of traditional medicine and complementary/alternative medicine*'.This article states that there is still a very large number of Africans who rely on traditional health care alternatives even after the introduction of the western form of medicine. While the number of Africans who use traditional treatment methods is high, this does not mean that the biomedical approach has been completely abandoned by Africans. Most Africans utilise both African treatment together with western treatment for the same illness at the same time or for different illnesses depending on the person's illness. This pluralistic way of medicine is common in Africans.

Africans regard good health as a combination of the mental, physical, spiritual and emotional wellbeing of oneself, his family and the community at large. There is limited research conducted on the use of African traditional medicine and ASD in South Africa. Studies mentioning the use of TRM on children with ASD are often not focused and specific to ASD.Those that mention ASD and TRM often are targeted at studying children with disabilities in the general sense (Tigere and Makhubele, 2019). The history of traditional medicine is not one that carries the African face only. Traditional medicine is a global phenomenon; it has traces in the East (Chinese and India) and the West (Native Americans). In many African countries, the use of traditional medicine is apparent. In Sub-Saharan Africa, a very high percentage of the population consult the services of traditional practitioners (Ebersöhn, Sefotho, MMampane, Loots, Omidire, Sherman & Nxumalo-Tsebe, 2014). The question of understanding illness in the African context is centred around the 'who' and the 'why' questions (Nwoye, 2015). Often, Africans focus on understanding who caused the illness and the question of why did the illness happen. Often, the answers to these questions are structured in such a way that there is a categorisation of illness. The answers are divided into two categories: to understand whether the illness is natural and whether the illness is supernatural (Mthombeni & Nwoye, 2018). Illnesses that are uncommon or have unknown causation are said to be caused by supernatural causes. ASD may be grouped with these forms of illnesses (Mthombeni & Nwoye, 2018). African beliefs around illnesses that are caused by supernatural causes are believed that they can be cured or treated through traditional methods of treatments. A study conducted in South Africa (Limpopo) revealed that most parents directed most blame to witchcraft as a cause of the child's disorders (Tigere and Makhubele, 2019). The study objectives were to understand the parental experiences of children living with disabilities. The study also included parents of children with a diagnosis of ASD. The findings of the study showed that parents look for a cure in all possible interventions including divinity and African

traditional medicine. As a result of the search for a cure, parents end up out of pocket because of the expensive interventions that are available. There is much secrecy that surrounds the use of ATMs in African communities.Therefore, children may be exposed to hazardous treatments due to a lack of transparency in this approach. Denial of the use of ATM from parents does not necessarily exclude the use of ATM (Luyckx *et al.*, 2004). Based on the literature surrounding the use of ATM, the use of indigenous forms of healing remain an integral healing social resource in Africa. However, more work still needs to be done on the standardisation of this approach and to find proper synergy between western and ATM approaches to healing ASD.

2.12 Religion and ASD

Different scholars define religion differently. A definition that fits all contexts adequately is difficult to find. However, there are phrases in most definitions that are common such as 'an ultimate context for meaning and value' and some will say how individuals organise to cope with social change and other threats to the environment'(Kenan, 1997). Now that I have defined the term religion, I want to link this discussion with mental health related discussion. Religion, in the mental health discourses, to a large extent, has been seen to lack empirical substance. This is regardless of the literature in psychiatry and psychology where patients have been found to have high levels of religiosity (Dein, 2018). Some studies have found and confirmed that patients do not only necessarily use religion just for their own life or health but also to deal with life stresses (Dein, 2018). The research by Dein further argues against the assumption which states that religion is irrelevant to clinical psychiatric practices. I am also for the same argument which argues that religion may be better used in the case of children with ASD and not completely be rejected as lacking empirical evidence. Literature is divided into the association of mental health and religion such that some studies demonstrated mixed findings in anxiety where some showed less anxiety with religiosity and others showed great anxiety with religiosity. There is also another body of literature suggesting that individuals who are religious, not only Christian but Islamic, Hindu and Judaism have better indices of mental health (Abu-Rayya, Abu-Rayya & Khalil, 2009; Dein, 2018)

The issue of mental disorders and religion dates back to the time of the renaissance where some people were persecuted as demon-possessed and killed by the inquisition (Koenig, 2001). Many researchers and mental health professionals have acknowledged the concept of religion

and asserted that it may provide a worldview on the purpose and meaning of life (Koenig, 2001). Theorists such as Freud gave their view on the association of mental health illnesses and religion saying that religion has the power to stifle neuroses and it can be one of the methods for sublimating the instinctual drives (Koening, 2001).

According to a study by Koening (2001), which studied over 630 articles to find out the association of religion and mental health, nearly 80 percent of the articles reported positive association between religion and constructs such as happiness, positive effect, morale and other indicators of well-being. Of the 100 articles, only 18 found no association between the constructs under research. About 16 studies examined the relationship between religion and psychotic and disorders. Of these studies, 4 found decrease symptoms among more religious participants. All these studies suggest that religion is a much needed intervention to some people whose belief system is grounded in religion. Thus, the idea of religion as an intervention to ASD remains relevant and central to this date.

A growing number of people and patients profess their belief in God or a particular higher power. According to Gallup and Lindsay, up to 75% of American people say they pray daily (Gallup, G., & Lindsay, 1999). Over 69 % said they were a member of a church or synagogue and of that 69%, about 40% said they attended church regularly. The number of South Africans who mentioned their affiliation with the Christian religion has risen to as high as 79.8% as mentioned in the 2011 census. This number has rapidly almost doubled when compared to the 1911 percentage of 45.7 %. The figures and arguments discussed in this section provide a compelling case for religion as a critical resource to parents who are faced with a momoth task such as raisng a child with ASD. For decades, the topic of spirituality and religion has been scarce in scientific journals to the extent that psychologists considered it to be immaterial or an improper topic for scientific research (Miller and Thoresen, 2003) .

2.13 Prenatal ASD testing

New scientific knowledge states that pregnant mothers may be able to know if the baby they are soon to deliver may or may not likely to have autism spectrum disorders (Chen, Wang, J., Shao, Gao, Xu, Yu, & Jia, 2014). This type of testing could improve early interventions and even help reduce parental guilt and offer parents an indication in regards to the child's health and condition (Johannessen *et al.*, 2017) . Such tests may mitigate the feelings of shock that many parents go through after a child's diagnosis of ASD is obtained. This many also alleviate

adverse feelings of ‘loss of a healthy child’ experienced by parents and the unending quest of finding answers such as why did the child have ASD and how can the disorder be reversed.

While this new scientific discovery seems like a breakthrough in the ASD space, there are notable harmful results such as family conflict resulting from understanding that the child inherited disease-causing gene however this test offers parents the option to decide whether to carry the child full term or terminate the foetus if the decision is within the value system of the family (Johannessen et.al., 2017). This dissertation acknowledges the ongoing debates on the topic of abortion which are critical and relevant. Some debates are based on the rights of the foetus and there some who even argue against the use of contraception. The starting point does not necessarily overlook all the ethical debates in terminating pregnancy but it is guided by the South African law which has granted everywoman the right to decide about her pregnancy and to choose the eventuality of the pregnancy. Currently, in South Africa, it is the right of every woman to decide whether to keep the pregnancy and carry it to full term or opt to terminate it. The modern scientific knowledge of pre-natal testing may be able to empower and prepare mothers for the possibility of bringing a child with ASD or give them available choices. Based on the available scientific technology and the country’s laws which allow termination of pregnancy, women, therefore, should have the right and the duty to selectively choose pregnancies that they want or the ones that they do not want using the help of science in their decision. Conducting a prenatal test does not necessarily mean that the mother is weighing options for termination but this means that the mother is preparing for the unborn child adequately.While the law in South Africa may permit this act, African communities and their attitudes and beliefs around pregnancy and termination are still strongly against the act and culture to a large extent is considered relevant when a woman considers to terminate the pregnancy.

The ethics of the prenatal test can be viewed similarly to that of down syndrome, however, autism and down syndrome need to be understood in a different light. Many factors need to be considered with this new prenatal testing without falling on to the deployment of the phrase ‘Playing God’ and other legal and social implications. Other ethical considerations such as religious, societal and individual autonomy and community values system are important (Johannessen *et al.,* 2017). One positive factor is that parents may be able to prepare for the child before they are born and plan for all challenges that come with having a child with ASD. Secondly, having a child with ASD is not at all doom and gloom since some children with ASD may be regarded as high functioning children within the spectrum. Thus, the moral cause of

termination in the case of ASD should be completely independent of other cases such as down syndrome. While all prenatal testing may pose the risk to a foetus, however, the ethical questions around prenatal testing are on-going debates that do not start nor will end with testing for ASD.

2.14 The financial Costs related to raising a child with ASD

Having a child with ASD comes with numerous challenges which include financial related costs. The rising medical costs, living expenses such as caregiving responsibilities like special nannies and scarcity of schooling facilities are among some challenges linked to finances faced by parents. Access to quality medical care is closely attached to financial responsibilities. Even when parents have financial resources to access quality optimal care for the child, they cannot escape the responsibility of parenting which may result in taking time off from work (Zablotsky *et al.*, 2014). Research argues that autism is positioned amongst the most expensive disabilities which requires parents to be well resourced financially (Clasquin-Johnson and Clasquin-Johnson, 2018). The cost of raising a child with ASD is three times that of a typical child according to (Dillenburger, Ann and Mckerr, 2013). Furthermore, the cost of raising a child with ASD can be estimated to as high as $3.2 million (Lokhandwala, Khanna and West-Strum, 2012). This figure is exorbitant for many parents internationally even worse in SA, a society with unemployment as high as 29 % according to Statistics South Africa. The increase in diagnoses of children with ASD has opened more space for research in the field of autism. This has brought about an array of treatments and therapies for this disorder which most of these therapies come with financial attachments.

2.15 Community awareness and public education of ASD

Public awareness programmes have a goal to change public behaviour and attitudes towards a particular phenomenon, to improving quality of life through organised activities (Seymour, 2018). There are several different techniques that this could be achieved such as the use of media and public engagement methods (Seymour, 2018). The use of media has been found to have a great influence on policymakers and also on people to change behaviour (Cugelman, Thelwall and Dawes, 2011). The downside of public awareness campaigns is that they require a lot of resources mainly funding and are not guaranteed to be effective (Seymour 2018). The

World Autism Awareness Day (WAAD) in April which is celebrated on the second day of April is but one of the ways of promoting community awareness and ways of educating the public about the disorder. According to (Ahmed,Bath, Sbaffi & Demartini, 2018), WAAD conducted a successful campaign on twitter which was evident based on the increase in the volume of tweets during this period. Even though the authors were unable to provide evidence on the individual impact of the campaign, the study suggests that there was an increase in public awareness (Ahmed, Bath, Sbaffi & Demartini, 2018). Globally, the month of April is marked as the autism month to raise public awareness. There is also another large campaign celebrated in many countries such as the Autism Speaks *light it blue campaign*. Many of these campaigns have played a significant role in influencing certain legislations to be introduced such as the Combating Autism Act of 2006 in the USA, the Autism Act 2009 in UK and the Autism Act (NI) (2011) in Northern Ireland.

The 'autism epidemic' has been making rounds in the media and popular public domains for a while. However, it is unknown how much the general public is informed and knows about the disorder in general. A study by (Tipton and Blacher, 2014) indicates that while there is a comfortable amount of general knowledge of the existence of the disorder, there is, however, concerning misinformation around the causes of the disorder.

2.16 Ethical and Legal Position

The goal of protecting children from a harmful environment and to prevent possible abuse of children is to offer physical protection to the child, to ensure that the right form of treatment is afforded to the child and to promote good and healthy well-being for the child (Racusin and Felsman, 1986). Human children are the most dependent children of all creatures under the sun. For human children to survive, they need the care of others. There is an obligation to biological parents, communities, the state-assigned organisations such as orphanages or other legally appointed guardians to play a role in the protection of children. It is important to understand that approximately 40% of the South African population are living below the poverty threshold (Statistics South Africa, 2013). The issue of poverty in South Africa is not one that will be eradicated overnight. It is also known that there is a link between poverty and the abuse of children. There is a growing body of literature stating that children with developmental impairments are exposed to different forms of abuse (Westcott, & Jones, 1999). Other researchers state that children in special schools had a high rate of maltreatment when compared with children in normal schools (Sullivan and Knutson, 2000). Often, the literature

focuses on the physical and sexual forms of abuse in children. It is further stated that child neglect remains the most common form of child maltreatment (Stokes and Taylor, 2014). It can be characterised as a failure to provide care, a safe environment and basic life needs. The difficulty is, child neglect is not very simple to define. It is neither an academic exercise (Dubowitz, 2013). Child neglect is often viewed as a by-product of families living in poverty. Dubowitz (2013) lists different forms of neglect that are critical in child care. The general expectation is that parents are mainly responsible for meeting the basic needs of the child. Other stakeholders (schools, hospitals, societies, professionals, family, community) that are involved in child development are also equally expected to meet the needs of the child. Dubowitz further says, delaying or failing to provide health care needs for the child's needs could be classified as neglect (2014). He states that when a parent does not seek help, appropriate care for the child or delays starting the treatment could be regarded as child neglect. I argue in the case of ASD that seeking early intervention such as language and social skills could improve the case of a child and offer rapid and positive response when started early (Franz& Dawson, 2019). While no one factor in the case of child development may constitute or amount to neglect, issues of family status, parental status and socio political components are relevant and should be considered. However, parental omission in providing appropriate care that could improve the life of the child may be regarded as neglect in its own right.

The Constitution of South Africa states that all persons belonging to a particular culture or religion should not be denied the right to enjoy and practice their culture or religion. The law also includes the use of the preferred language (Constitution of the Republic of South Africa, Section 31 (1), (a)]. Further to this, the law states that every child has a right to be protected from different forms of abuse, degradation and any form of maltreatment [Constitution of the Republic of South Africa, Section 28 (1), (d)] (Constitution of the Republic of South Africa, 1996). It is important to note that while the practice of culture is a right, also and equally the right of any childis of paramount importance. Children's Act [38 of 2005] states further that children are not to be subjected to social-cultural and religious practices that are detrimental to their well-being. The act does not necessarily refer to and not deal necessarily with children with ASD. It refers to children in general under the age of 18. However, if a cultural ritual or practice were deemed harmful to a child with ASD, it will be prohibited by the Act. Children have been victims of abuse in all sorts of contexts; it is even worse if a child has a disability (Oosterhoorn, R., & Kendrick, 2001). Cultural treatments are a known phenomenon. However, concerns arise when the child experiences a complication due to the use of cultural treatments

when there are other available known safe and provenly effective forms of treatment. Furthermore, Dubowitz mentions that there is a consensus, generally, which recognises that what constitutes child neglect is not at all culture-bound (2014). Often, parents opt for alternative medication for their children in a search of a cure for their child with ASD. It is important to understand that the some alternatives that are used by parents ought to produce better outcomes when compared to mainstream treatment and secondly yield a high quality of life for the child and finally, not cause any form of harm or complication to the child's condition.

2.17 Concluding Remarks

This chapter provided a brief review of the literature that is relevant to the topic under discussion. The chapter begins by defining ASD, its background and the description of the disorder as defined using main literature in the space of ASD. Background of the local and global landscape of the disorder was also discussed in the chapter. Furthermore, the contrasting views for understanding illness in the western and African context were relevant to understand and to allow the reader to follow the discussion of the research and to realise the two parallel forms of healing available in the African context. Also, there is a discussion of the known alternative treatments and their efficacies. The chapter concluded by discussing the process of diagnosing children with ASD and providing a discussion of the ethical aspects surrounding ASD.

CHAPTER 3 THEORETICAL FRAMEWORK

3.1 Introduction

The previous chapter discussed the literature relevant to this project. It highlighted pertinent headings and argued relevant points that influence child development particularly a child with ASD. This particular chapter will focuss on discussing the theories underpinning this currect project.

The first theory discussed in this research study is a theory by Bronfenbrenner which covers the empirical component of this study and it looks at child development in different environmental layers. It also offers a simulteneuos way of looking at the child and the environment and how these systematic contexts interact. The theory states that child development is influenced not only by the childs' biology but by the immediate environment as well as the interaction of the larger environment. This theory recognizes the nature and nurture approach of child development, in that,it acknowledges the child's surroundings and the context and recognizes that as the child develops the complexity of the childs' surroundings become more and more complex also. This theory places the development of the child in five defferent layers namely: microsystem, mesosystem, exosystem, macro system and chrono system.

Table 1: Theoretical Framework

Empirical	• **Bronfenbrenner Ecological Theory of Human Development**
Normative	• **Moral Theoretical Pluralism** • Cultural Relativism • Ubuntu -The African Philosophy

The second part of this chapter discusses the theoretical framework used in the normative component of the thesis. As suggested in Chapter 1, the main theoretical position that was adopted was what can be called moral theoretical pluralism. This is a view that recognizes the value in more than one moral theory or worldview and focusses on ethical requirements that

all of these perspectives hold in common as the basis for judging what is right or wrong. It also recognizes that there are differences across cultures when it comes to moral values and norms, and is able to be open to what can be learned from diverse cultural normative perspectives, because it does not hold any one moral theory or worldview as inherently right or better.

This study takes the approach that norms, ideas, values and virtues are diverse. The research also acknowledged that within a single culture or a group of people there may be different but permitable moralities. In order to approach this type of diversity and wide range of views , morals and values this research will underpin the normative component of the study on the two normative theories i.e. Cultural relativism and Ubuntu (Connectedness). The concept of Ubuntu, Botho, Hunhu in Africa is a common philosophical concept which can be directly translated as meaning: humanness or connectedness. The concept of Ubuntu has much criticism in the literature, that the concept can be vague in its meaning. This research approaches the concept of Ubuntu from the fact that it represents communal rationality, ideas and human excellence and is the known approach and worldview of most indegeneous African people from the Sub Saharan region and a way they use in raising their children. The theory on cultural relativism argues for the recognition of cultural differences and acknowledgement of the intricate way culture evaluate processes and how particular judgements are made. It is based on these definitions and understandings that the theories selected are a best fit for this particular study.

3.2 Bronfenbrenner – Ecological Systems Theory

The ecological theory by Bronfenbrenner is a widely used theory particularly in understanding child development in many disciplines. This theory was developed in the 1970's by Uri Bronfenbrenner. The theory has transformed or rather improved over the years from the first publication in 1977 until 2005, this theory has been in a continual improvement process (Tudge *et al.*, 2009). Bronfenbrenner's theory puts into emphasis that the childs environment is a critical influence in the childs development. The theory emphasizes also on the environment of the organism in this case of the child, how they experience it whether direct or indirect. The changes in the childs environment influences development and how a person copes with the changes is critical in understanding the person. The main environment includes the family which is the main and the initial environment in influencing the childs development,the family

is also the first basis and the critical part for early intervention in the treatement of the child. The family as mentioned earlier determines the type of intervention to be administered to treat the child therefore becomes the main focus in this study. In his early work of 1979,Uri Bronfenbrenner gave prominence to the environment and divided it into four interrelated systems and this will be discusses below in this chapter. His improved version of the theory added a fifth system which he called the chronosystem, he was also more concerned with differentiating between the concept of the environment, proximal processes and the concept of time and how all these concepts related to human development (Ashiabi and O'Neal, 2015). Based on the short definition and discussion of the theory, this theory does not purport to highlight how human development occurs but rather to illuminate the critical conditions and processes that influence human development (Ashiabi and O'Neal, 2015).

3.2.1 The Micro System

All immediate contact to the child such as family, school, peers, neighbourhood, health services etc. form part of this level. At this level the relationship is bi-directional, both the child and other factors have the means to influence the relationship. This level is critical for making decisions for the treatment of the child. This research looked at this level in terms of the childs environment and the family. The family of the child played an intergral role in the choice of treatment for the child. Parents and extended family menbers formed part of this level as they were closely involved in the development of the child. The bi-diretionality of this level means that, parents also have to change in order to accommodate the needs of the child for example: seek information on the needs of the child, get help from either therapy or other family structures on how to deal with the challenging childs needs.

3.2.2 The Meso System

This level is regarded as the connection level. This is where there is a connection of the micro level and the parents of the child. These interactions have a significal influence in the childs development. The example of these connections are the childs teacher and the parent. Other connections can be the church and the child or even the neighbourhood and the child. Basically this layer is the link between the micro and the exosystem.

3.2.3 The ExoSystem

This is a larger layer where there is and interaction between the microsystem and the child. In this layer the child may not be directly involve but the interaction of this layer impacts the child. This layer is the society and its institutions: the government and the laws, education system, politics and the economy.

3.2.4 The Macro Level

This layer is the outer layer but has a cascading influence to the childs development. This layer includes norms and values of the culture and sub-cultures.Parental beleifs greatly influence the development of the child. How parents interprete the disorder is largely embedded in the family's beliefs and cultural background. As mentioned earlier in previous chapters, parental beliefs have a significant part in determining and understanding the disorder of their child (Ravindran and Myers, 2012).

3.2.5 Chrono System Level

Over time a number of changes may take place in the family or in the lives of the parent but more importantly in the society and its institution. More information may be available to parents about ASD due to more government awareness programs and other factors. Family situation may improve or change which could allow the family to better handle the childs situation more better or the opposite could be true.

The above stated theory by Uri Bronfenbrenner has been used widely (Ravindran and Myers, 2012; Van Rooyen, 2016) to understand ASD and provides a good framework for this current study.

3.3 The Moral Theoretical Pluralism

Moral ethicists hold the view that a single moral theory should guide all of our actions. In other words, we should be able to work out what is right or wrong by applying just one over-arching guide to right action. As Elinor Mason writes: "Traditionally, moral philosophers recognize three different ways of thinking about morality: the deontological way, the consequentialist way, and the virtue ethics way, although there is debate about the cogency of these

distinctions…. Monists claim that there is only one ultimate value. Pluralists argue that there really are several different values, and that these values are not reducible to each other or to a supervalue. Monism has the advantage of relative simplicity: once it has been determined what the supervalue is … much of the hard work has been done. On the other hand, monism may be too simple: it may not capture the real texture of our ethical lives. However, pluralism faces the difficulty of explaining how different fundamental values relate to each other, and how they can be compared." (Mason 2001)

In adopting a moral theoretical pluralist position I am able to draw on all moral theories, not just the traditional Western theories of utilitarianism, deontology and virtue ethics to reflect on the normative aspects of my thesis. So, some of my normative thinking has been informed by Ubuntu and Cultural Relativism. These two theories will be discussed below as theories that will underpin the study under moral theoretical pluralism.

3.3.1 Cultural Relativism

Thre is on going deate in the literature discussing the concept of relativism, it is important to be specific that this research focused on cultural relativism and not moral relativism. But before entering into a discussion of cultural relativism one should revisit the fuction of culture in particular for the benefit of this research study. According to (Kwast, 1981) culture is a patterned way of doing things. The article further provides another definitions stating that culture is similar to a superglue that attach people together. The article further mentions that when people are binded together a sense of identity is formed. Identity therefore brings about continuity and unity that is impenetrable (Kwast, 1981). Thus, cultural relativism is a way of understanding cultures using that particular cultures point of view and not imposing any form of judgement or interrogating the worth of other cultures. Some argue that there are specific ways of making cultural judgements and evaluations (Lakatos, 2018). This research acknowledged the on going discussion of weak or strong cultural relativism and the application of human rights. The approach that this study is taking is that which explains that cultural relativism is framed from the respect of other ways of life (Lakatos, 2018). The DSM –V has redefined the term ASD and simplified it to remove a number of extraneous variables. It defines the concepts as a set of observable behaviours of which could be analysed differently in different cultures. Thus, cultural relativism refers to the ability of understanding others cultural

practices without judging and without measuring them according to other known standards that are set by other cultures. In this research project, the concept of cultural relativism became central in understanding the treatment choice of the child decided by the family without measuring it to the popular and already known treatment methods of ASD. According to (Sutton, 1998) relativism is complicated when it comes to issues of health. It is even worse when it is the health of children that is involved:

> Such [difficulties with tolerance of] child care practices were complicated by the fact that for myself and for the Kalymnians these practices often entered the realm of medical authority, that is, they seemed to escape the category of 'culture.' While I would not dream of passing judgment on the Kalymnian use of protective talismans for the evil eye, it was quite another matter when the practice at hand seemed to enter the realm of health rather than belief. (Sutton 1998: 132–133)

The issues of child health is complex and one that opens a number of debates not only the cultural debate but also touches on consent, childrens rights and the interest of the child. Whilst cultural relativism was central in this reseacch project, it was equally important for the researcher not to heighten personal or own convictions but to keep at all times that the participants' world view was always respected. The child's well being was a central matter to be taken with care in this research study. The dichotomy of realm and culture therefore was guarded and acknowledged.

3.3.2 Ubuntu

The concept of Ubuntu which is a common African philosophy has been widely used in a number of disciplines such as social work, politics, management, theology etc (Mugumbate and Nyanguru, 2013). The concept emphasizes being human through other people and emphasizes the idea of human relations and creating bonds with others. According to the book buplished by (Shutte, 2001), Ubuntu can be summed as follows:

> Our deepest moral obligation is to become more fully human. And this means entering more and more deeply into community with others. So

although the goal is personal fulfilment, selfishness is excluded (Shutte 2001, page 30).

The concept of family in the African worldview is central to child rearing. The maxims ‘ it takes a village to raise a child’ is a reality in black African people of Southern African continent. The concepts promotes cennectedness in people and in communities. Applying Ubuntu to children with limitations such as those with ASD, children feel a sense of connectedness by enabling them to receive care at home and from other community groups (Marston, 2015). The article by (Marston, 2015) further states that Ubuntu formal health interventions are grounded in the values of the community and specifically designed to meet all the needs of the family and the child such as physical, social, emotional, spiritual, cultural and developmental.

3.4 Conclusion

The chapter discussed the two main theories underpinning this project. The theories have been briefly discussed to provide and indication of how they relate to this current project. These theories will be further revisited in the discussion chapter to emphasise the finding and the relevance and the ralations of the theory and the findings .

CHAPTER 4: RESEARCH METHODOLOGY

4.1 Introduction

Empirical research in bioethics may be characterised in a broader sense, firstly, as having 'encounters with experiences' of the participants (Dunn and Ives, 2009) Also, the aim of empirical research in bioethics is to engage the participant's moral worlds - to engage with these worlds, there needs to be a strategic intervention (s) that will enable researchers to tease out context-relevant moral reasoning of participants.

The previous two chapters were introductory chapters of this project which provided an overview of this project. The first chapter provided a discussion of the study aims as well as the underpinning theoretical framework of this project. In Chapter 1, the conceptual framework of the study was discussed. In Chapter 2 of this study, I provided an overview of the relevant literature which gives a picture of this research on ASD and provide relevant literature and information in the topic under research.

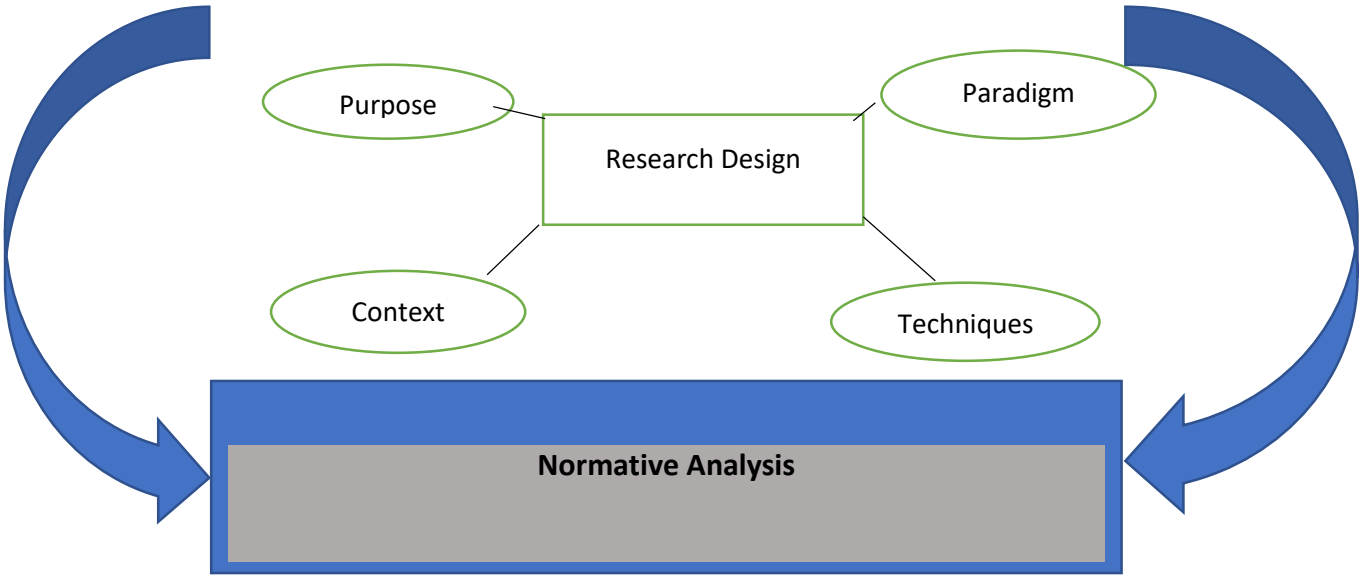
This current chapter explains the research methodology applied in addressing the above-mentioned objectives of the study. The purpose of this chapter is also to discuss the research design, the research questions and the research method of this study. Over and above this, the chapter provides a guide to the methodology and the process used to answer the research questions and objectives of this study.

4.2 Research design

In this study, a qualitative (Hamilton and Finley, 2020), exploratory (Jupp, 2006) and descriptive (Salkind, 2006) design which included a normative approach were followed. Several definitions in the literature define a research design but one that clearly outlines this concept and has been adopted in this research study is a definition stated in (Sileyew, 2019). Research design is not necessarily only the process that determines how relevant information will answer the research purpose and questions of the study but also one that provides an appropriate process or framework to be followed in conducting a study.

The decisions that were taken into consideration in the process of designing this research involved the four dimensions as stated by (Durrheim & Tredoux, 2004). The four dimensions by Durrheim include (1) the consideration of the main purpose of the research followed by (2) the theoretical format that underpins the research and (3) the context of the research which includes the situations where research is carried out and finally all (4) the relevant research techniques that were adopted in data collection and analysing (2004). These four dimensions as adopted in this study design are illustrated in the figure below from Durrheim (2004).

Figure 61:Four Dimensions of decision making in research design (Durrheim, 2004)



4.2.1 The purpose of the study

The first objective of this study was empirical objective which its aim was to identify and give an account of the nature of the cultural and religious practices and beliefs that children with ASD are exposed to and the beneficial or harmful effect of these on their well-being. The second objective of the study which was normative was focused on articulating and normatively defend the ethical responsibilities that arise from the described benefits and harms derived from the cultural and religious practices and beliefs that children with ASD are exposed to.In this chapter the study methods for the empirical component are described first (section 3.2 to 3.8). The methods employed for the normative component were the standard methods

for this kind of enquiry, and as such require less description. They are described in section 3.9.

4.2.2 The Study Context

The study was conducted at CHBH which is part of the group of 40 provincial hospitals managed by the Gauteng Provincial Health Authorities . CHBH is regarded as the 3rd largest hospital in the world and occupies approximately 173 acres of land (Chris Hani Baragwanath Hospital, 2013).

Image 1: Chris Hani Baragwanath Hospital



Source: Wits Website (https://www.wits.ac.za/clinicalmed/departments/paediatrics/contact-us/chris-hani-baragwanath-academic-hospital/)

The staff complement at CHBH is predominantly African, while some health practitioners who formed part of the study were of other racial groups. They all seem to be context-aware of the socio-cultural dynamics of their patients and participants of this research study. CHBH was chosen because it was one of the better-resourced hospitals in South Africa in terms of personnel, departments and other health resources. The hospital services all diverse groups in South Africa and people from other neighbouring countries like Zimbabwe, Mozambique and other documented asylum seekers. For these reasons, CHBH makes a valuable case for being the research site of this project.

Chris Hani Baragwanath Hospital is named after the political activist Chris Hani. The hospital has a significant history in South Africa. In contributing to the body of knowledge, the hospital is also a teaching hospital of the University of the Witwatersrand medical school along with

other hospitals. The hospital was also selected because of the location which is central in Johannesburg and the size of the hospital which suggested that the sample will be coming from a diverse population.

4.2.3 Techniques

In this study, semi-structured interviews and focus group discussions were conducted to gain information relevant to understand cultural and religious practices and beliefs that are known as one of the alternative treatments for children with ASD. Furthermore, the research sought to explore whether these practices that children were exposed to, posed any beneficial or harmful effect on the children's well-being.

4.3 Paradigm

The research follows a specific system and practices that assist researchers in understanding the nature of their enquiry (Terre Blanche, Durrheim & Kelly, 2006). These systems and practices are referred to as paradigms. There are differing views in the definition of the term paradigm. According to (Creswell, 2003) refers to a paradigm as an ontology, epistemology, or even research methodology. Paradigms are, thus, classified as a positivist, interpretive, constructionist, post-positivist, transformative, emancipatory, pragmatist, critical and decontructivist (Mackenzie & Knipe, 2006; Terre Blanche, Durrheim & Kelly, 2006).

A post-modern, interpretive paradigm was adopted for this research. According to Terre Blanche and Durrheim (2006), an interpretivist paradigm approach consists of a belief that "the reality to be studied consists of people's objective experiences of the external world". Thus, this research used interviews and reflective journal observations and focus groups to understand the external world. There is a body of literature which states that the interpretive paradigm seeks to understand a particular context and provides rich reports that are necessary to fully understand reality (Thanh & Thanh, 2015).Often, interpretive paradigm uses qualitative methods, therefore, a qualitative research method was employed to understand the social and psychological phenomenon of using traditional and religious interventions as treatment from the perspectives of the people involved in the well-being of children with ASD (Welman, J. C., & Kruger, 1999; Todd and Nind, 2011). Therefore, the role of the researcher was to interrogate

ideas and assumptions that are common and often are taken for granted in treating children with ASD. The researcher also interacted and engaged with the participants in a critical manner by addressing fundamental questions that were searching in their nature regarding the phenomenon under discussion (Pope and Mays, 2007). Based on the above justification, the method used in this study was relevant as stated by (Holstein & Gubrium, 2004), "If the interviewer asks questions properly and the interview situation is propitious, the respondent will automatically convey the desired information" (2004: 141).

Furthermore, interviews allowed flexibility and divergent perspectives which explored the issue in detail. The interviewer exercised skills of probing and also used follow up questions. Qualitative research was also a good fit for this research study because of its postmodern sensitivity and its verisimilitude (Denzin & Lincoln, 2000). Postmodern sensitivity, according to Denzin and Lincon (2000), is the ability that qualitative research has in getting closer to the real-life experiences of people in a way in-depth interviews get with the purpose to interact closely with people

4.3.1 Research Method

The type and the focus of the research questions that are under study inform the type of research methodology to be followed (Denzin, Lincoln and Giardina, 2006). Therefore, the format that is followed in this study aims to answer the main objectives of this study and could be seen as tools that are important in understanding and answering the main objective of this study. The focus was on exploring and understanding the meanings and understandings construed by the participants. The qualitative component of the study engaged with ethical issues relevant to cultural and religious practices and beliefs impacting children with ASD practically and directly. The research method are discussed under the following heading: study setting, population and sampling, data collection and data analysis.

4.3.2 Study Setting

This research study was conducted in the City of Johannesburg (JHB). This city has a rich history which includes the discovery of gold in the 1800s and the flocking of people with hopes to find riches and better life opportunities for themselves and their families. This historical picture which was painted back over two centuries ago is still a reality to many South Africans

today. The twenty-first-century picture of JHB is far different; it is marked by urbanisation, crowding, unemployment, poverty, overpopulation, the influx of migrants in search for a better life, increase in disease and high-income inequalities. In a recent article, it is mentioned that the daily picture of JHB is marked by buildings and other infrastructures that are dilapidated and neglected (Rees *et al.*, 2017). The authors further highlight the low focus of investment in human capital and the above normal rates of prevalence of HIV and TB (Rees et al, 2017).

According to a survey conducted at public JHB neurodevelopmental clinics, ASD in the city increased eight folds between 1996-2005 (Jacklin, 2006). There are over 18 public-funded schools in JHB for Children with ASD, which will allow for accessibility to the sample of the study (Evans, 2016).

Image 2: Map of Soweto



Source: SA Venues (https://www.sa-venues.com/maps/gauteng/soweto.php)

The study participants were parents of children diagnosed with ASD who attended therapy at CHBH and health practitioners at the hospital. Soweto is the location of the hospital and it is largely a black township, there are, however, a diverse number of patients at the hospital because of its size and resources. There is a fair amount of representation from other racial groups (White, Indian and Colored).

4.3.3 Population and Sampling

Sampling is a process of selecting cases or participants from a larger group and examines them in detail to learn the entire population (Neuman, 2014). Due to the nature of this study being qualitative, a nonprobability purposive sampling method was employed in this study. Purposive sampling is employed to select an information-rich group of able participants to provide greater insight into the research project under study (Devers and Frankel, 2000). This method allowed the researcher to select a specific sample of participants according to their relevance and association with children with autism spectrum disorders. Thereafter, the researcher followed a snowball principle sampling. This sampling method was applied to recruit parents by using a referral method system from the already located parents. Participants were identified at CHBH, from different wards servicing parents who were attending clinics for their children. Some parents were attending clinics to obtain a diagnosis of ASD and others were visiting for other follow up consultations such as to receive therapy from doctors, psychologists, social workers, speech or occupational therapy consultations. Access to participants was requested via the heads of departments at the wards where participants were highly likely to be located.

Prior commencing with the study, several departments at CHBH were visited in order to determine the number of children that were treated in each ward at a particular given period to determine the inclusion criteria of the study. After assessing all the necessary requirements in each ward,there were three departments identified as a good fit for this study (The Psychology Department, The Speech and occupational Health Department and the Neuro Department). Heads of departments were later approached in order to give a presentation of the study and to request access to their patients and staff. The following inclusion and exclusion criteria was a guide in this study in defining our sample universe.

Table 2: Inclusion and Exclusion Criteria For Selecting Participants

Inclusion Criteria	Exclusion Criteria
➢ Parents of children diagnosed with ASD will be selected in the study. The research will cross check the diagnosis information from the demographic form that will be completed prior to the interview.	➢ Parents of children with no diagnosis of autism spectrum disorders.
➢ Health Care Practitioners (Psychiatrists, Psychologists, Occupational Health Therapists, Speech Therapists, Social Workers) with experience in working with children with autism spectrum disorders will be selected to participate in the study. The experience will be measured by the understanding of whether the practitioner had previously treated a child with a diagnosis of ASD in the past or not. If the practitioner answers no, they will be excluded from participating in the study.	➢ Health Care Practitioners with no experience working with children with ASD.
➢ Religious leaders with an adequate understanding of children with autism spectrum disorders will be selected to participate in the research study. Religious leaders will be invited to a short discussion with the researcher that will explain ASD. After the discussion religious leaders who have helped a child with ASD or have an understanding of the disorder will be included in the study.	➢ Religious leaders with no adequate understanding of children with ASD.
➢ Cultural leaders with adequate understanding and knowledge will be selected to participate in the study. A short discussion of ASD will be conducted with all cultural leaders invited to explain the disorder. After the discussion, cultural leaders who have helped a child with ASD or have an understanding of the disorder will be included in the study.	➢ Cultural leaders with no adequate understanding of children diagnosed with ASD.

Table 3 below illustrates the different groups that were interviewed in this particular study with the purpose to answer the two main objectives of this study.To summarise the table below, semi-structured interviews were conducted with 25 parents of children diagnosed with ASD who attended CHBH. Patients were screened by health care practitioners to determine whether they were a good fit for this study as stated in the above inclusion criteria that guided the

selection of participants of this project, this included parents of a child with a confirmed diagnosis of ASD which was the main inclusion criteria of this study. Participants were further screened by the researcher on arrival to ascertain whether the participant met the requirements of this study.

A further 10 staff members of the hospital were interviewed and were all selected according to the inclusion criteria of this study. Hospital staff members stated above mean health practitioners who worked with children diagnosed with ASD. Health practitioners who participated were from different catergories which included nurses, medical doctors, psychologists and speech therapiests. In order to form and conduct focus group discussions, two organisations were approached 1) an organisation of traditional healers and 2) an organisation of religious leaders. Thereafter, two separate focus groups were conducted with each group respectively. Each focus group comprised of 6-12 members in each discussion group.

Table 3: Research Methods

Research Participants	Groups	Number of Participants
HEALTH PRACTITIONERS	PSYCHIATRISTS	1
	PSYCHOLOGISTS	3
	OCCUPATIONAL THERAPY	3
	SPEECH THERAPY	3
CAREGIVERS	BIOLOGICAL PARENTS	22
	CAREGIVERS	2
MEMBERS OF THE COMMUNITY	TRADITIONAL HEALERS	12 MEMBERS
	RELIGIOUS LEADERS	12 MEMEBRS

4.3.4 Data Collection

All interview guides were designed following the relevant literature and guided by the aims and objectives of the study. These were assessed by the supervisor as relevant and also assessed by the ethics committee before the commencement of the study. During data collection, the researcher exercised probing which resulted in more questions being posed to participants to cultivate a richer discussion and collection of relevant data. Relevant research sites that were ideal for accessing the sample under research were identified.

Permission to conduct the research study was obtained from all relevant points 1) CHBH, 2) focus group organisations, 3) relevant medical departments at the hospital. All study material was handed to all participants including a letter explaining the study and consenting letters for all participants.

Both organisations where focus groups were conducted requested that a brief explaination of ASD be conducted for all members who will be participating in focus groups before commencing with data collection process. The request was honoured and a concise indepth discussion explaining the disorder was rendered to both focus groups before commencing with the study.

Parents of children diagnosed with ASD were interviewed with the help of a research assistant who was fluent in all South African languages. While the interview process was completely in English there were momemnts where participants switched to IsiZulu or SeSotho. While this was not common occurance it was managed since the mother tounge of the research assistance was Sesotho and the mother language of principal researcher is IsiZulu. Emphasis was given to retaining the meaning of the participants as authentic as possible during transcription process. It is also worth noting that the research assistance was employed based on their relevant research experience and qualifications as a Psychology Masters graduate. CHBH services a diverse group of patients as mentioned earlier therefore the presence of a multilingual researcher allowed for participants to be able to converse freely in a language comfortable to them. The interviewer was sensitive not to pressure parents during discussion. At the end of the interviews and focus groups participants were allowed to pose questions to the researcher.

4.3.5 Data Collection Methods

This study followed different methods of data collection namely: semi-structured interviews and focus groups. A reflection journal was also used for reasons similar to those stated in (Boud, 2001). Boud states that a reflection journal is critical to capture interesting moments during the research process as a form of exploring the emotional journey of the research process and also as a therapeutic exercise (2001). The study was exploratory; it did not rely on existing data but new data was collected to contribute to new knowledge. The data was confirmatory in that it helped answer the research questions with empirical evidence.

4.3.6 Researcher Positionality

Intergrity in research comes from the ability to reflect on the relationship of the research itself, handling of the participants and the ethics of the researcher. It also comes out in the way a researcher analyses the data and present the information received from the participants of the study. The researcher does this in a respectful manner and without bias. As stated below :

> 'Bias comes not from having ethical and political positions – this is inevitable – but from not acknowledging them. Not only does such acknowledgment help to unmask any bias that is implicit in those views, but it helps to provide a way of responding critically and sensitively to the research.' (Griffiths, 1998)

As a single, African mother of a child with ASD and also being raised in KwaZulu Natal. Conducting a study that was close to my own personal experiences compelled me to write this section of positionality. It is important to state that, I am not new in conducting research that touches an issue close to mypersonal experiences. Therefore, I am well conscious about the issue of emotional attachment to the subject and I reflected intensely about it. I am confident that during this research study there was no point where I became uncomfortable because of my relationship with the topic that was under study. I say this because my son is now 13 years of age and he was diagnosed at age 4 with ASD. The process of acceptance has been enough for me to come to terms with his diagnosis and to understand it better as a parent. I have gone through all the stages of loss and I have found contentment with the subject over time, through several support structures which largely included my family. The involvement of the family about my sons conditions have taken different approaches in terms of dealing with his diagnoses some of which may be similar to what most parents in this study have mentioned

during data collection. As a researcher, Most of the discussion that were mentioned by participants was mostly similar to my own experience, the disctinction was just that most parents in the study were still grappling with acceptance of their children's condition. I was empathetic at most time because I understood genuinely their confusion, pain and their position of trying all they could to help their children.

The study design was qualitative and it emphasized on the authenthicity of data and its findings and this may only be achieved through a rigorous process and ethical reporting of the data. It was thus critical for the research to have clear self awareness and to remain reflexive throughout the research process. Being an African myself and a mother to a child with a diagnosis of ASD suggests that this research topic did not occur in a vaccum. I reflected on the way I as a researcher interacted with the participants and staying relevant to the research questions of this project. During data collection stage, I acquired a mountain of new knowledge and information about family, culture and how parents approach ASD. Some of this information was difficult to process, some was painful but some was enlightening and hopeful about the landscape of ASD in South Africa. The use of a reflective journal enabled me to stay neutral and ascertain that the participants' reality is reflected as is in the data analysis process without being influenced by my world and reality.

4.4 Interviews

4.4.1 Semi-structured interviews

The interview guide in this study was intended only to describe the basic direction of questioning in the semi-structured interviews. The exact wording of the interview questions was kept open-ended to go deep into the known experiences of the research participants to pull out maximum data from the process of interviews. The researcher exercised great sensitivity throughout the interview process, especially being aware of not making parents feel that their parenting behavior was being judged. All participants in the same grouping i.e. parents, health care practitioners and traditional healers were interviewed following the attached interviewing guide (Appendix 1, 2 and 3). Participants were asked one question at a time and allowed them some space to process the question being asked without being pressured by the interviewer.

Questions were designed using clear terms that are general to allow dive rsity, since scientific terms may sometimes be difficult for some participants. The researcher exercised sensitivity in probing more on to some follow-up questions, the ‘why’ question was avoided in most instances as it may have been understood to some participants as a lack of cultural sensitivity. The interview guide obtained questions informed by the literature on the development of children with autism spectrum disorders.

The second part of the schedule asked parents about the practices and traditions that inform their child-rearing practices. Table below (3) was used as a guide to interviewing parents selected according to the selection criteria for this study.

Table 4:Interview Guide-Semi Structured Interviews

SEMI-STRUCTURED INTERVIEW SCHEDULE: PARENTS
1. Tell me about 2. What cultural practices does the family believe concerning the child's condition? 3. Can you talk me through some of these practices? 4. Have you explored helping the child using this practice? 5. What were the benefits of this? (If 4 is yes) 6. Did it cause any harm? (If 4 is Yes) 7. What was the reason for not exploring the practice (If 4 is no)? 8. What religious practices does the family believe in that can help the child? 9. Please describe these practices. 10. Have you explored helping the child using this practice? 11. What were the benefits? (If 7 is yes) 12. What was the harm? (If 7 is yes) 13. What was the reason for not exploring the practice (If 7 is no)? 14. What can society do to protect children if some of these practices (cultural or religious) prove to be harmful to the child? 15. What can be done to strengthen the societal obligation to the protection of children with ASD from cultural and religious practices? 16. What measures exist out there to protect children exposed to harmful cultural and religious practices? 17. What can a society, in general, do to improve the wellbeing of children with ASD? 18. Can you think of interventions that can be implemented to improve the wellbeing of children with ASD? 19. If some of the practices are harmful, what can we do to protect children from harmful cultural practices and at the same time preserve our cultural beliefs? 20. In your opinion, what cultural practices are right to perform and which ones are not right? 21. How do you determine the rightness and the wrongness of a practice? 22. In those that are wrong or harmful, what can be done in that situation? 23. In the beneficial practices, what can be done to improve them?

The study used a similar technique in collecting data from parents and health practitioners. It used interviews to source information relevant to this study from participants. According to Dunn, there are three types of interviews: Structured, unstructured and semi-structured interviews. Semi-structured interviews are those that allow flexibility in how the informant

addresses issues (Dunn, 2005). This study employed the use of SSI's to source information necessary to answer the main research objectives of this study. SSI's are often conducted with one participant at a given period. In this study, SSI's were open-ended and followed with probing where more information was needed. Open-ended means that, the dialogue between the interviewer and the researcher was open to meandering around the research topic rather than a verbatim approach (table 4) illustrates a set of interview questions that were conducted to gather information from health care practitioners: -

Table 5 Interview Guide - Semi Structured Interviews

INTERVIEW GUIDE TO PRACTITIONERS
1. What is your involvement with children diagnosed with ASD?
2. Tell me about the process involved in diagnosing a child with ASD?
3. How much involvement there is between you and the parent/s?
4. In your experience, how do parents react when they are told about the child's condition?
5. In your experience and interaction with parents, have you come across parents who reject the child's diagnosis?
6. What would you say is the reason they reject the diagnosis?
7. What can you say about parents who seek alternative forms of treating their children with ASD?
8. Have you come across such parents who seek alternative forms of treatment?
9. Usually, what is the reason for them to seek other forms of medication?
10. Can you tell me what usually are these kinds of alternative medication?
11. Do you think it is right for parents to take their children to alternative forms of medication?
12. If 11 yes/ No, why? Tell me more.
13. What can you say about the issue of exposing children to other forms of medication, in terms of their well-being?
14. As a practitioner, can you share in your opinion who is obligated to protect children with ASD?

4.5 Focus groups

In addition to interviews, two formal focus discussions were conducted with traditional healers and religious leader's cohort. Focus groups were used with the two groups to generate information on their collective views. Pre-existing groups are easier to recruit and easier also to interact with in research studies (Gill *et al.*, 2008).

Focus groups are a special qualitative research technique method whereby a group of people are interviewed applying a group discussion setting. Focus groups, in this study,were added in order to complement individual interviews. It is also worth mentioning that focus groups are usually limited in terms of their generalisability to the general public. In this particular study the strength of focus groups were solely to gather insight and to find consensus from the group discussions about the impact of religion and culture on the wellbeing of children with ASD.

Focus groups were held at a venue identified by the gatekeeper which they mentioned as convenient to all the members of the focus group. In one group of traditional leaders, there were representatives of different kinds of traditional healers i.e. *Izangoma*[1] ,*Izinyanga*[2] and *Abathandazi*[3].

The group of religious leaders' comprised of eight to twelve representatives from different religious leaders. Most members in the religious focus group were from Christian-oriented churches and one representative from the Muslim faith. The participant from the Muslim faith was often occupied and was less interactional with the group.

The overrepresentation of Christian members was alarming, therefore, we asked the organisation "why there was an overrepresentation of Christian members?". The response was that other representatives of other faiths such as Hindus and Muslims, which are some of the common religions in South Africa, did not respond to their invite of the meeting.

Focus group discussion lasted between 2-3 hours each. Focus group discussions were tape recorded and permission to record was requested from all members. The services of a research assistant were used to translate and transcribe the recordings. The questions asked during the discussions were semi-structured. These questions were largely informed by the literature. Where necessary the services of a research assistance were used to direct and translate all questions in a language appropriate to participants. Complex discussions were approached using probing and follow up questions to better clarify the points under discussion.

[1] Izangoma- A plural of (Isangoma) which is a Southern African healer.
[2] Izinyanga- A plural of (Inyanga) – A Herbalist who is also a traditional healer
[3] Abathandazi- A plural of (Umthandazi)- A faith healer who heals through prayer. Mostly are Christians.

A research journal was kept with a view to capture apsects that the recording could not capture such as interesting moments during discussion. For instance, during focus group discussion, women were unable to freely take part in the discussion; they would either seek permission by using body language like giving the researcher eye contact or by show of hand.

The critical objective of conducting focus groups was to gather the views from people who shared common interests and to understand their views on the topic of ASD. These views came from people with a similar interest on a particular phenomenon but not familiar with one another in terms of the scope of their background. Participants, in this study, were not only seen as people who share similar truths about the field but rather they were viewed as typical social beings. Focus groups were conducted as a way of applying different sources of data to strengthen the validity of this research. It was anticipated that some participants may have difficulties sharing their views individually, therefore focus groups were identified as a good platform for information sharing and also to gain reliable information on the issue under discussion.

It is known that when people are approached on an individual basis they show skepticism and hold back from freely sharing information.Therefore, the researcher concluded that a group environment like a focus group was the best to yield information in an environment with like-minded people. Some members who were reluctant individually, in a focus group, seemed comfortable and willing to share information openly since there were familiar faces within the group. Majority of active participants in the discussion were males. Interestingly, most male participants wanted to be called as Baba[4]. The group leader refered to himself as Doctor. This observation could be explained in several ways by using the lens of culture. There are different levels of importance in the patterns culture use in addressing people (Anchimbe, 2011). In most African cultures, the age of the person (an older person could be called a mother or a father depending on the gender and a younger person could be called brother or sister) determines the degree of politeness or respect (Anchimbe, 2011) that needs to be afforded to a particular individual. Anchimbe (2011) further states that these appellations are not cast in stone; one person could be addressed in several different ways. The change could be overridden for instance in the case of *Baba*, referring to himself as a *Doctor* also could be seen as him bridging

[4] Baba- Father, is a direct meaning of the term. This term also is used by a healing apprentice to refer to his or her teacher.

the gap created by the title *Baba* and had to free the interaction or reduce the gap of interaction caused by the first appellations (Anchimbe, 2011).

At this point, the importance of putting the voices of the participants of this project and their epistemologies at the centre of the data collection process was the main objective. Also, it was important to follow the participants' protocols as it was already implied by these dynamics between the researchers and the participants. At no point did the researcher show the participants that their western epistemology approach was the only true science and the participants' understanding of the disorder of ASD was a myth. It was the intention of the reseacher, as a psychology graduate to understand these dynamics in order not to denigrate their indigenous knowledge. This research was an intersection of the western epistemology and the indigenous epistemology knowledge production which could at some point create tension in knowledge production. Knowledge productionmay have been hindered if certain protocols were overlooked and not adhered to. Table 5 below shows a list of questions that were followed for a focus group discussion with Community Members (Traditional Healers and Religious Leaders).

Table 5: Focus Group Interview Guide- Semi Structured Interviews

FOCUS GROUP INTERVIEW GUIDE	
Interviewers Instruction: Explain the Disorder Comprehensively	
1.	Based on my explanation of Autism Spectrum Disorders, have you treated a child with the condition I have explained?
2.	Tell me how often do you consult with these children?
3.	Who usually brings the child?
4.	What would you say is the cause of the Disorder?
5.	What do you usually tell parents is the cause of the disorder?
6.	What do you advise parents on how the disorder can be treated?
7.	Do you think the practice of cultural and religious rituals you perform can be beneficial to the wellbeing of the child?
8.	If yes – How?
9.	If No- why is then the practices of cultural and religious rituals performed?
10.	Do you think the ritual may cause any form of harm to the child?
11.	If yes – What form of harm?
i.	What can you do to prevent this from happening?
ii.	What can the parent do to protect the child?
12.	Do you think it is fair or right for anyone to prevent this ritual from being performed?
13.	If yes or no – Expand, please.

4.6 Challenges in data collection

The first challenge was that most parents who were interviewed in this study were largely female participants. This suggests that the discussion was told from the perspectives of female caregivers/parents. One couple who approached the study office agreed to take part in the study however the man soon asked to leave the discussion and left the female participant to continue with the discussion.Secondly, It was a mammoth task to find organisations of traditional healers that were properley registered and also active in their respective communities.

There were a number of organisations identified and had very good branding however, this was just the branding; when approached these organisations had no active structures and no

adequate personnel that existed. This was the case for both religious and traditional organisations.

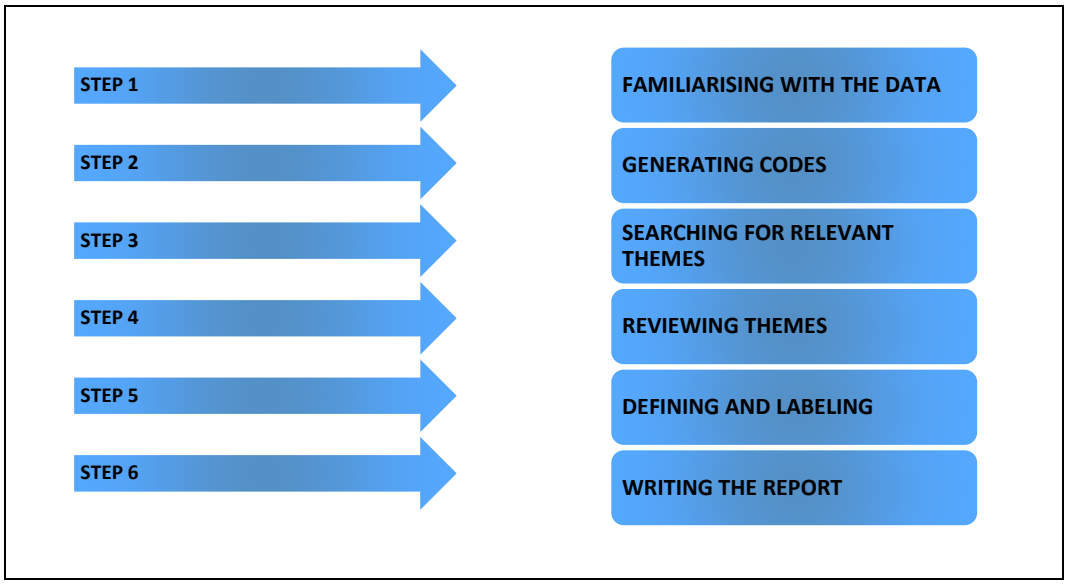
The idea was to get a well-represented organisation that encompassed religious leaders from all faiths and a traditional leader's organisation that encompassed healers who work from different types of traditional forms of healing. The two organisations that were finally approached were the only identified organisations with working structures and a fair amount of representation that were enough to conduct this study. Lastly, both religious leaders and traditional leaders were not familiar with the term "Autism" but only after a short discussion of explaining the academic definition and the characteristics of the child as it was taken from the DSM V they were able to understand the term . It turned out from the discussions that most participants were aware of the disorder but did not know what was the proper term for this particular disorder.

4.7 Data Analysis

Data analysis is central to qualitative research methodology (Maguire & Delahunt, 2017). Techniques, softwares and other programmess to analyse data are discussed in this section. All journal notes, transcriptions from individual interviews and focus groups are part of the qualitative data set.

Qualitative data was analysed using thematic analysis by (Braun and Clarke, 2006). Thematic analysis is a good fit for this study since it is a method, not a methodology. This means that it allows flexibility to epistemological and theoretical perspectives of analysis (Maguire & Delahunt, 2017). The thematic analysis allows for in-depth analysis of data. It also allows for latent and semantic analysis of data, meaning that the data is analysed at the surface as well as going deeper into the meaning of the data. The data analysis process followed Braun and Clarke's (2006) six phrase framework for doing thematic data analysis as illustrated below in Table 6:

Table 6: Braun and Clarkes (2006) Six Phrases Framework



- **Step 1**

  This process involved reading and re-reading the transcripts until the researcher was familiar with the interview transcripts. Transcripts were read more than once because the transcription responsibilities were outsourced and conducted by a a researcher who was qualified in the field of transcriptions. Through the process of reading, important phases and ideas were highlighted and written down. The highlighting and noting helped with the second phase of the analysis. I familiarised myself with the data and got to the depth of each transcript while writing down and highlighting and underlining the interesting and important parts of the transcript. It was important that I read through all the transcripts from the in-depth interviews with parents and health practitioners and later followed by the reading and familiarising with the focus group transcripts. The reading and familiarisation were thoroughly done to decide on how the analysis of data should be structured.

- **Step 2**

  The second phase involved coding a chunk of data into manageable codes. Interesting and important data sets were collected more systematically. Not all data was coded; only the ones relevant to answering the research question were coded, in this phase. First, meaningful data was coded into chunks but it is important to state that not all data was used or coded in this project, only the ones that were relevant in answering the main research question.

- **Step 3**

  Braun and Clarke (2006) state that there is no stringent guideline on what and how to identify a theme. A theme is anything significant or interesting that is related to the research project and contributes to answering the research question. At this phase, themes started to emerge and the data were categorised into themes that will later be discussed in Chapters 5 and 6.

- **Step 4**

  This phase involved a process of reviewing previously selected themes. Some themes were reviewed and others that were previously selected in step three were then modified. Some of the reasons that led to some themes being reviewed were the lack of coherence with other themes and some were important themes but irrelevant to the current study. Such themes that were left out were saved for future publications because they were genuine themes but outside of this research project.

- **Step 5**

  This phase identified the 'essence' of what each theme is about' (Braun & Clarke, 2006,). This was the process where the actual meaning of each theme was unleashed and interrogated. In this phase it was crucial to understand what each theme was 'saying' and its relevance on the main objectives of this research. In this phase, the definition of themes was applied; this meant that the themes were starting to shape into telling a story and this was closely observed and preserved while listening to the 'story told by themes'-the process of modifying and identifying irrelevant themes.

- **Step 6**

  This section was the final write up of the themes that emerged from the analysis of data. Most themes at this stage form part of this research thesis. Not all themes were used for this project since the data was enough to leave some for later projects.

The process of analysing and following the six phases as understood by Braun and Clark (2006) was revisited two weeks later after the first round of data analysis was completed. This was done to re-evaluate the interview transcripts and to alleviate some biases if there were any during the first round of analysis. The process may also eliminate and identify traces and potential of over-analysis of data if it occurred during the first round of analysis (Creswell et

al., 2007).

4.8 Trustworthiness

Without rigor, research becomes worthless, fictitious and loses its utility (Morse *et al.*, 2002). Whereas reliability and validity are pertinent to quantitative research, trustworthiness is what is important in qualitative research studies. The work of Guba and Lincon found a substitute for validity and reliability. They used the concept of "trustworthiness" which contains four aspects, credibility, transferability dependability and conformability (Morse *et al.*, 2002; Shenton, 2004). Before discussing the four concepts of trustworthiness, all data collected in this research will be the responsibility of the researcher.The data will be verified and stored collectively by the researcher, the assistant and the research supervisors. This will be done before and after the transcription process for confidentiality, safekeeping and authentication of data.

- **Credibility**

It is defined as a criterion for understanding the quality of qualitative data, that is, confidence in the truth of data (Polit, & Hungler, 1995). Participants were allowed to withdraw from the study at any point they felt the need to do so. This process strengthened the honesty and truthfulness of participants. Different forms of data collection were used such as semi-structured interviews, focus groups and observations. Nonetheless, no participants withdrew from this particular study.

Different forms of data collection were used in order to strengthen the credibility of the data. This process may be similar to the process of triangulation which is defined as the use of multiple methods in qualitative research to get to a deeper and comprehensive understanding of the phenomenon under research (Patton, 1990). It allows for a deeper understanding of the phenomenon of interest and may provide more valid findings to the study. Patton (1999) mentions different types of triangulation which are data, theory investigator and method triangulation. The current study employed what (Carter *et al.*, 2014) called data source triangulation by combining different methods of data such as focus groups, in-depth interviews and reflection journals. The study explored triangulation because the nature of data yielded by these different methods differs and it is a method that explores and enhances the understanding

of the phenomenon, its context, data convergence and trustworthiness of the findings (Carter, 2014).

As mentioned by (Morrow and Smith, 2000), the use of a reflective journal in qualitative research adds rigour as the researcher can write about his/her assumptions, expectations and biases about the process of research.

- **Transferability**

The process of adding rigor in this research was the core component driving the objectives of the study, thus, triangulation was used to allow the findings of this research to be replicated to a wider population (ASD).

- **Conformability**

The data collected in this research was the sole experiences of the participants and not influenced by the researcher's bias. The researcher employed the use of a reflection journal to control for emotional attachment and bias.

- **Dependability**

The study was essentially normative but included an empirical component to ensure rigor in findings and the research process. From time to time, the supervisors will review the data collected to ascertain the quality and the process of data collection.

- **Reflexivity**

The researcher of the project has completed a Master's dissertation on the topic of children with ASD and has a personal attachment with the topic under discussion since she is a mother to a boy with ASD. The purpose of journaling also was to achieve the objective of separating between the research-researcher standpoint. As a mother of a child with ASD it was crucial to stay completely objective on the research process, I needed to journal the process and stay completely detached from the process. My connection to the topic of ASD and my African background compelled me to keep a reflexive journal throughout all the stages of data collection. My positionality statement is detailed in researcher positionality paragraph.

4.9 Normative Methodology

The normative part of this study was based on desktop and library-based research. It was an ethical critique drawing from the literature, relevant to the topic under research. The study employed the typical research methods and standards applicable to philosophical research. Primarily, this involved the interpretation and critical analysis of salient texts. The critical analysis of relevant texts involved the definition and clarification of concepts, the identification and criticism of assumptions, the analysis and evaluation of theoretical frameworks, the development and defense of arguments, the establishment of consistency between general principle and particular judgment and the articulation of the most plausible interpretation of significant concepts found in the sources. Sources of literature included but were not limited to articles at the Wits University Library, online library sources, Biomed Central, Wiley Online and Google Scholar.

The normative component in this study, complemented the facts gathered from qualitative data while the normative comment was responsible for the norms and values in using traditional and religious forms of treating children with ASD. It is, therefore, important and critical to note that this study is solely not normative as already mentioned but will apply what (Molewijk *et al.*, 2003) called the empirical ethics research. Empirical work in bioethics is a wide field and may be very difficult to go in-depth and to attempt to give a specific definition onto the field (Smajdor *et al.*, 2008).That said, not much empirical research has been conducted to determine the impact of traditional and religious interventions on children diagnosed with ASD. Most work, in this field, has been pure anthropological, sociological and psychological. Therefore, applying this approach in this project is somehow in agreement with a critique by (Hedgecoe, 2004) which argues that often traditional bioethics fail to and should align with the contextual living experiences that are more grounded in people's realities.

4.10 Research Ethics

There were several research ethical issues to be considered for this research because it dealt with human participation and sensitive emotional issues. This study commenced after a clearance had been granted by the Human Research Ethics Committee (Non-Medical H17/11/52) of the University of the Witwatersrand. The following information was also

approved to be used in the study by the committe : participants' information sheet, consent form and interview guides for all participants involved in the study (parents, practitioners and focus group interview guides). Thus, all participants who took part in the study were provided with detailed approved information about the study. Those who voluntarily agreed to participate were asked to sign and complete a consent form.

Participants were allowed to withdraw from the study at any given moment of the study process without any form of prejudice. Focus group participation may not guarantee participants anonymity or confidentiality since participating members of the focus group will be known to each other. Participants of focus groups were asked to sign a separate consent form to indicate that they were willing to keep all discussions made during the discussions confidential and not discuss the content of the meeting outside of the discussions. All information capable of identifying participants such as participants' name as well as their children's information was kept confidential. All data would, therefore, be kept for five years and might be used for further journal articles after this project is completed. The services of research assistance were used at times for language purposes; participants were informed of the assistant's commitment to the study and that the research assistant was also advised to keep all the identifying information of the participant confidential.

Traditional healers and religious healers had standard protocol when dealing with researchers. Travel reimbursements were a rule that they often expect from all researchers that required their knowledge.. Also, part of the standard requirements was to provide the participants with refreshments such as water and light meals. Because this was anticipated and included in the approved research proposal, the researcher self-funded the reimbursement and refreshments.

Previous researchers have mentioned that parents of children with ASD face more than usual parenting hassles and may lead to anxiety.Thus, for those parents who might have required emotional and therapeutic support during the process of the study, the researcher was prepared to make necessary arrangements for psychological services at Wits Emthonjeni Centre . Emthonjeni Centre offers psychology services to the general public at nominal fees.

CHAPTER 5: DESCRIPTION OF FINDINGS

5.1 Introduction

In this chapter, I present the empirical findings of this study which are discussed in the rest of this thesis. All empirical findings collected from all participants that were selected to form part of this study were analysed using thematic analysis and later presented below.

In the previous three chapters, I have laid a foundation of the current landscape of ASD, locally, regionally and globally. The first chapter introduced the study and its components. Also, I discussed the two main theoretical frameworks underpinning this study, which are: the ecological system by Uri Bronfenbrenner and the philosophical framework of moral theoretical pluralism (Ubuntu and Cultural Relativism). The first chapter also provided the objectives and tabulated the expected outcomes of the study.

Chapter two discussed the landscape and overview of the literature in ASD and gives a detailed account of the current status quo mainly of already known and existing treatments of the disorder. Chapter three provides a detailed discussion of the methodology followed when this study was conducted. The results of this study were organised following the 4 cohorts that make up the data. These cohort are made out of the themes from (Parents, Health Practitioners, Religious leaders and Traditional Healers) and are presented separately and discussed in this chapter.

5.2 Overview of the findings

The graph below labeled graph 1, presents the demographics of parents who were interviewed in the study as well as the gender of children as given by parents. There were 17 parents of boys and 5 parents of the girl children diagnosed with ASD. Because the hospital is situates in an area that has majority of black South Africans residing around it, there is therefore notable skewness in the sample of the study in terms of race and gender. The study interviewed only black African participants in terms of race and there were no other racial groups. The skewness was not intentional but by default, however, it did not affect the objectives of the study since the data received was rich enough to answer the research question.

Parents and caregivers are the ones closest to the child; they are a part of the child's most immediate relationships and interactions. Immediate relationships include teachers, siblings and all the people who are sharing the immediate space with the child, and they will be grouped in this cluster. In this changing society, the family is no longer the conventional set up of a nuclear one with a father as the head and a primary supporter of the family, a mother who assumes the role of a caregiver and children. Families have evolved and become more diverse than what was previously the norm. Some families have same-sex parents; others are child-headed while some are led by grandparents. Even some have extended family members as 'coresident members' under one roof, assuming and interchanging roles of caregiving. For the benefit of this research, we consider family as given by each participant and considering the changing times we adopt the diversity that the 21st-century family embraces.

In this study, most of the participants were single parents where a father does not support nor interacts with the child. Some caregivers were grandparents where biological parents were unmarried and/or no longer together and the grandparents were left to assume the role of the primary caregiver for the child. In some cases, grandparents had to take over the caregiving role due to reasons such as: the parents have abandoned the child because of the disorder. Only one couple was interviewed, meaning a man and a woman married and raising a child as a family unit. (Mandell and Novak, 2005) mentioned that the families' belief system will affect the treatment decision of the type of treatment that the child will receive. Therefore, families that believe autism is a culturally related disorder will seek cultural treatments to treat the disorder. Similarly, families that believe in other beliefs such as religion or western forms of medication will follow the model mentioned in Mandel and Novak (2005). In cases where families were asked which type of belief system that they followed, in many cases participants consulted either elders or the entire family to deliberate the treatment process of the child. Some participants, when asked if they used traditional forms of medication, answers were mostly informed by the holistic belief system of the family and not that of the parent of what was best for the child.

While some families rejected the traditional route of treatment such as in the above case, some pursued more than one form of alternative treatment for the child. Still, those who rejected the traditional path were guided by the family belief system and not the children. However, most families who rejected the traditional form of treating their children would still pursue the

religious path of seeking help. These decisions, mostly, were guided by what the larger family structure believed in.

According to Bronfenbrenner,(1979), a child's development should not be viewed in social isolation. The presence of third parties in the child's life has a great influence on the child's setting. These involve the child's neighbourhood, school, extended family and other social relationships. These parties have a greater influence on the timing, type and process of treatment that the child will receive. Most decisions that parents took for the child were a collective from other members of the family. The reasons vary but the interconnectedness is but one finding of the study. This, then, creates some overlap in understanding the responsibility of protecting the child. In most cases, biological parents will refer to either in-laws, grandparents, the societal norms or other known organisational structures close to the child's family. The referral process is part of the African way of raising children which is grounded in the African philosophy of Ubuntu. Africans believe in relations and connectedness and concepts such as *umuntu ngumuntu ngabantu* (you are because I am) are largely considered in issues pertaining to help seeking and raising children.

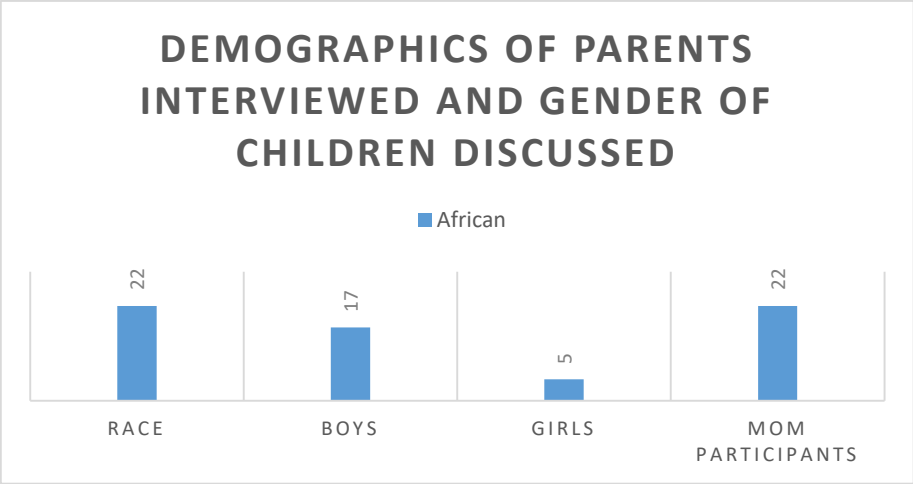
The decision of whether a child attends one particular form of treatment does not necessarily end on the parent but the entire system as stated by the ecological system by Uri (Bronfenbrenner, 1979). He further states that third parties can either play a supportive role or a disruptive role. Some parents when exploring an alternative treatment for the child would abandon the western approach. This may leave the child vulnerable or even causing a regression in the child's development.

Several overarching factors were a critical part in deciding the right process to follow as a treatment choice for the child. Some parents mentioned that economic factors were amongst some of the factors that were central to parents choosing a particular form of treatment. Most parents could not afford the private care system and were attending the public care system. Alternative treatments came in cheaper and parents felt they were going an extra mile in caring for the child. Accessing health care in other underdeveloped parts of the country is difficult which leaves the parent with a choice of public health care. To most parents, the private health care system was expensive, thus, they were forced to move to the city in order to access the public health care system. Other parents'resources were limited where they stayed and there were poor health systems, as a result, they were forced to move to locations that were better resourced in helping their child with ASD.

The poor schooling system was among the things that parents mentioned in the interviews. There are limited schools that look after children with ASD in Johannesburg and some have waiting lists that go up to five years. This creates anxiety for parents and leaves them in a state of helplessness when it comes to the child's development and wellbeing. Schools that are well equipped for children with ASD are managed privately and usually cost very high for parents to afford access for their children.

Participants, in the study, were mostly female and single. Most of them mentioned that the biological father abandoned the child and the relationship ended soon after the realisation that the child was diagnosed with ASD. The impact of absent fathers in the child's life affects the child's well-being as well as the mother's emotional state. The birth of a child is a time of joy foralmost all parents. Many parents do not anticipate or plan to have a child with a disorder. It is even worse if the disorder is ASD. This means that the parent has to understand the nuances that come with the background of ASD. The realisation that the cause and the cure are not yet known is catastrophic to most parents and their families. The family undergoes a series of negative feelings such as stereotyping, isolation from the community and friends. But most importantly, there is a huge influx of advice and knowledge that the family may receive from those who show support towards the situation. From this advice, the family may end up getting into a desperate state of exploring damaging endeavours in treating the child.

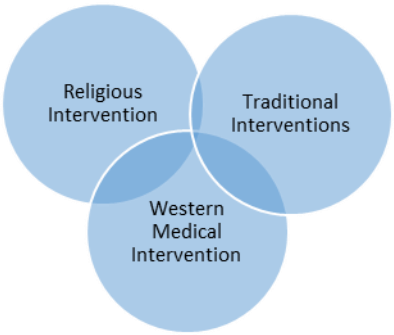
Graph 1:Demographics of Parents Interviewed and gender of children



5.2.1 Unpacking the child's background

There are several pertinent aspects and information that connect people in their environment and it is important to make sense of the connectedness of people and their environment. Social issues such as the family's income, emotional wellbeing, health care system, legal issues and schooling matters are all incorporated under the ecological model which underpins this study and can assist all stakeholders in improving children's wellbeing. Therefore, discussing the background of children and their surrounding is a critical component of this study. Utilising Bronfenbrenner's (1977; 1979) ecological framework in this study, I explored the family, environment and parenting dynamics at the micro-level and at the macro level the caregivers' religious support and cultural variations are discussed. At a macro level, which is the largest layer of the ecological system, the cultural values, laws and customs are critical to consider in a study like this one. This layer also subsumes the health care delivery system, racial and ethnic disparities which are relevant to the wellbeing of children with disabilities in this case disability being ASD (Algood, Harris and Hong, 2013). At the meso level, the interaction that happens between two different micro levels and how it plays out in the child's well-being are important in understanding the wellbeing of the child. The exo level discusses the influences affecting the child where the child does not form part of the environmental factors such as the parents' workplace. Lastly, the chrono system looks at the changes affecting the child over the life span such as family dynamics like divorce or other changes in family structure (Hong and Espelage, 2012). It is also important to understand parental explanations of the obligations that surround their children's well-being. The chapter will unpack parental responses on their understanding of treatment, particularly their obligations and also the results from the interviews with parents are discussed below.

Figure 7: Types of Interventions mentioned by parents to treat children



The figure above provides a view of the types of interventions that were used by parents in this

study to care for their children diagnosed with ASD. In this study, parents used more than one intervention or all three interventions. Medical intervention was used by all parents since participants were accessed in the hospital. The overlap in the figure above confirms evidence in the literature and in this study that states that in Africa, the use of traditional medicine is very rampant. The World Health Organization (WHO) estimates that about 80% of the African population makes use of traditional medicine. It is, thus, impossible to understand healing in a study conducted in Africa without exploring the traditional part of it.

5.3 FINDINGS FROM PARENTS

The results of this research illustrate that parents of children with ASD continue to use alternative forms of treating ASD. The purpose of this study was to understand the ethical obligations of using religious alternative treatments and traditional medicine in children with ASD. While the medical approach is still a large component in the treatment of ASD, parents often try the two mentioned methods as other available options for treatment. This discussion will focus on four major themes as tabulated in table 8 below.These themes emerged from the analysis of data. There were several alternatives taken by parents for their children with ASD. Some of these interventions involved traditional forms of treatement and others were faith based. Below are some of the alternatives mentioned by parents. The rituals listed below in Table 7 will be discussed further in detail in Chapter 8, in the normative chapter of this thesis.

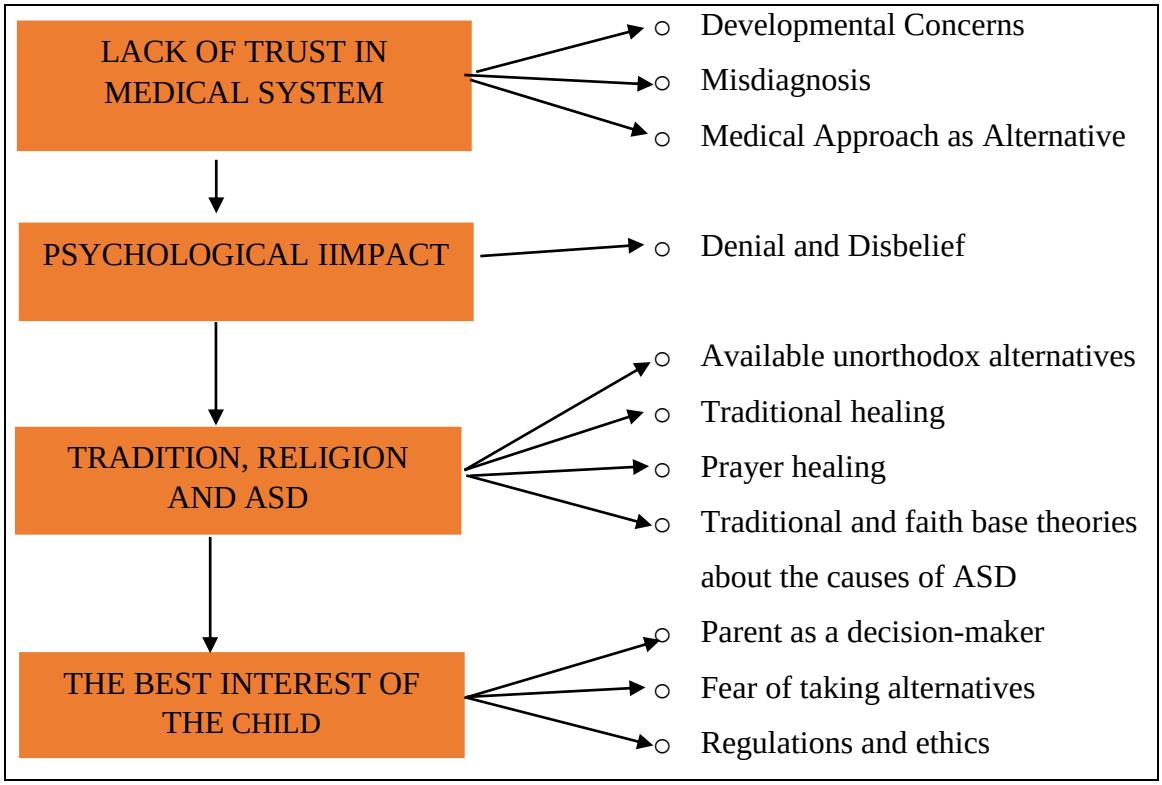
Table 7: Common Rituals Mentioned by Parents

COMMON RITUALS MENTIONED BY PARENTS

'I took him to born again church (for the holy spirit prayer)'	'I took him to traditional healers (they said I should boil a lizard alive until it dies once dead cool the water and give the child to drink)'	'I took him to ZCC (for their tea)'	'I took the child to a prophet (they said it is people's doing, they gave me a string to put around his waist to protect my child from evil spirits)'	'I took him to traditional healers (they said I should put the child on a pond with green algae)'
'I took him to traditional healers (they said I should take him to the graveyard)'	'I listen to Emanuel church on TV (touched the TV and they prayed with us)'	I took him to traditional healers (they said I should burn incense, and they gave me Imbiza)	'I took him to traditional healers (they said I should pull the child's tongue tongue every morning)'	'I took him to traditional healers (they gave him water to drink)'

Some of the above mentioned were rituals that were mentioned by parents as some of the interventions that were opted for by either the parents themselves or from the main family members such as grandparents of the child to be opted for as some of the remedies to 'cure' the child's condition.

Table 8: Parents' Themes



5.3.1 THEME 1: LACK OF TRUST IN MEDICAL SYSTEM

The study findings illustrate that majority of parents mentioned a delay in seeking help associated with early symptoms of ASD. While there were various reasons given by parents of why this was the case, fistly it is important to acknowledge the common characteristics that were notable in this study participants. Most of the participants were from the same race group, 'Black African,' from humble backgrounds. The demographics are often a critical determining factor in the help-seeking behavior of patients. (Boulware *et al.*, 2003) explain low levels of trust in Black Americans in the health care system, clinical research and clinicians in general. The authors understand this lack of trust as emanating from different sources and one being the Tuskegee Syphilis study which left many black participants in that study in worse off conditions. The authors explain trust as an important factor in the formation of a therapeutic alliance. They further state that trust is closely associated with the way patients seek medical care, adherence to treatment and also the maintenance of the long-term relationship between patient and health practitioner (Boulware *et al.*, 2003).

Some researchers state that the socio-economic status of the patient is often associated with delays in help-seeking (Dubayova *et al.*, 2010). The group of participants who consulted the medical system experienced some difficulties in navigating the health system. Some mentioned that they were either referred from one doctor to the other or told of several theories regarding the condition of the child before a final diagnosis of ASD was obtained. While other forms of treatment like traditional medicine and religious interventions are often referred to as alternatives in treatments, in this study, there were participants who approached the medical system as an alternative.

Most parents, in this study, consulted either traditional or religious interventions before approaching the mainstream medical system. This may be due to several factors such as lower levels of trust in the medical system for certain conditions like ASD.

The daunting process that parents explained that is associated with being referred from hospital to hospital without a diagnosis is concurrent with (Burns and Tomita, 2015) where they state people in lower-middle-class countries rely on alternative treatments because of inadequacies in infrastructure, human resources and treatment options. Parents end up being demotivated and the trust in the medical system end up being compromised because of the unclear pathway

to care in the health care system for conditions such as ASD. Thus, the findings in this study are in line with the common literature which states that patients in Africa often consult the services of alternatives before consulting the medical system especially when it comes to mental health issues (Burna & Tomita, 2015).

5.3.1.1 Developmental Concerns

The common trigger for seeking help that made many parents in this study suspicious was the realisation that the child was not meeting certain milestones such as the development of language at an appropriate age; potty training became a concern to most parents and other parents saw peculiar behaviors that were not age-appropriate:

> *…...we saw that maybe there's something wrong with him because the kids at that age are walking or they are crawling but then after some year and six months he started crawling but he was forever drooling, then, I saw that, maybe, he has a problem but the elders just kept saying, no he will be fine* (P2)

> *He took her at night and brought her here at the hospital, they checked her. She had a problem of messing herself up, urinating on herself and we didn't know what was happening, we saw her becoming worse at night and brought her (P1)*

The above cases, the caregivers realised that children were not developing as normal. They were finding it difficult to potty train the child other parents mentioned that the child was not walking at the age that most children are already or have started walking, the parent mention that the child was drooling at the age of almost 18 months. These parents were only prompted to see the practitioners by noticing that the kids had delayes in most of the mile stones but not based on the suspicion of ASD. Some parents were triggered by other co-mobidities in the child then they seeked professional help:

> *……At five months he had seizures, the whole body (P8)*

> *So when it was after three years, he was talking well, calling me, saying mama, after three years she was quiet and not talking anymore, When I brought him here they said he had autism (P4)*

In the case above, seizures were a reason why the caregiver was able to go and seek medical treatment or get a professional opinion of the child's delay in development. The illness of seizures led to doctors eventually noticing some developmental delays in the child and later the child was given a diagnosis of ASD. Another parent mentioned that the child started regressing in their development, the child was once talking and later the child regressed and could not speak anymore.

> *I decided to tell them about the milestones where he delayed to walk, to sit, everything that children at his age do, and my child didn't do (P8)*

Delays to most parents were a very confusing period. Most parents in this study mentioned that they were often taken aback by the child's delayed milestone to a point most of them did not know where to begin helping the child overcome some of these delays and the hospital was their first point of contact:

> *when I came to Bara[5], then, I complained about this thing of speech and the fact that she can't talk properly. When she talks, she can't put together a sentence; she says one by one words only (P9)*

> *And a couple of months, then, I said he can't talk, then, they said like how come he can't talk and I said, no, he doesn't; that time he could only say 'mama'. I said he only says mama and they said why didn't I bring him earlier and I said it's because I don't have enough information, you see; so, they transferred me here at Bara for speech (P3)*

Most parents started reporting the problem of delays very late after the child had missed their milestone. The reporting was also often defaulted by either another existing illness or because the delay was long overdue. Consulting medical practitionets was in most cases not based on the parents detecting that a child may have ASD. Some of the reasons that parents mentioned for not taking the developmental delays very seriously was because of the family and friends' involvement in the child's development. Family members had a lot of theories regarding the child's delayed milestones which ranged from boys are not the same as girls; they are often delayed.When it was a girl, there were theories of a child being the same as one of the family members who took longer to develop speech or other milestones. There was also a notion of a 'slow' child which was often mentioned by parents as a reason why parents would delay taking a child for treatment.

[5] Bara: Is the common name used by locals to refer to CHBH

So I was surprised as to why he was like that; his father said maybe he's a slow child….He's, slow because even himself when he was young he was like that, he was a slow child, he couldn't talk; he started talking when he was old (P24)

People don't know about autism … like myself; I've never seen a child with autism before until I had him; so, that's why I delayed going to the hospital cos I always thought he's just a slow child, he's going to be fine …. and people don't know these things (P6)

The concept of a slow child was part of the reasons why parents would normalise the delayed milestone and not seek further advice or professional opinion. Parents tried to have their own explaination of the reasons why the child was not typical or reaching critical milestones like language and potty traning. Some children at eighteen months were still drooling but still parents would form their own theories and reasons why the child was experiencing delays.

5.3.1.2 Misdiagnosis

Most parents stated that before a diagnosis of ASD was given to them, they had to endure several other misdiagnoses that were not fitting with the child's symptoms. The public system process seemed to take very long for many parents before getting a diagnosis of autism. Parents went to several different hospitals before reaching the main hospital that was able to provide them with a final diagnosis. They stated, however, that some examinations like speech therapy and audio examination were done. However, smaller hospitals did not seem to know or do not have the capacity to continue with the necessary screenings and examination for autism beyond speech therapy:

They referred me from hospital to hospital and then they sent me to Leratong for a speech therapist, then, they referred me to CHBH and then, at CHBH, they sent me to the developmental unit where they diagnosed him with autism (P11)

Then first step they said I should go to Straighfort Clinic In extension two then I went there, she attended speech there, then she attended speech there from

speech then they gave me a letter so that she can be assessed, that's when I came for a booking. It was twenty twelve, I came and made a booking, they told me that they will call me and then I stayed until twenty fifteen. Twenty fifteen was when they assessed and found that it's ADHD and autism (P7)

Parents from district clinics and other smaller hospitals had to navigate a system that was not fully resourced with very limited capacity to attend to a child with ASD. Smaller clinics lacked resources such as professionals with knowledge of autism. Those that had the resources, it turned out that the resources were not enough to service children with symptoms that fit a diagnosis of ASD to an extent that some parents had to wait for up to 3 years for a doctors appointment. Most parents who mentioned speech and occupational delays in children who attended smaller clinics were often referred to CHBH for attendance and therapy:

And he didn't have speech, so, I took him to the doctor. When we got to the doctor, I then told the doctor that the child is like this; he's not talking and when he got to the doctor he was crying…So, I explained to them that the child is like this and that, so, they gave him a referral letter to Bara, then, I brought him (P19)

Most parents mention their struggle to find a diagnosis and the lack of knowledge from their community clinics. Some parents mentioned that they were sometimes suspecting that the child may have ASD after having read an article or seen a documentary on television, but then, community clinics took too long to give a definite diagnosis and/or to even start the child on therapy.

5.3.1.3 Medical Approach

All participants were accessed from CHBH, therefore, a medical treatment method was part of the options plan for all our participants. However, using a medical approach to some was unintentional but a result of an ineffective first option which failed to deliver expected outcomes. Some parents opted for the medical option due to fear of trying other available alternative methods. Some rejected other alternatives because of their belief system which

forbids them from the use of such, as a result of this, the medical option remained the only acceptable option for some. There were those also who received and adhered to family advices which instructed them not to see medical doctors because of the hope that the child may soon become well:

> *Okay, we saw that, maybe, there's something wrong with him because the kids at that age are walking or they are crawling, but then, after some year and six months he started crawling but he was forever drooling, then I saw that maybe he has a problem but the elders just kept saying no he will be fine. After two years when he was still not walking, I became worried that the child is two years and he's not walking; he doesn't talk. Okay, my mother said, maybe, he will be fine. He started walking maybe when he was two years four months; he started walking. We thought, maybe, he will be alright with speech. He became three years, four years; last year when he was five years, that's when I became more worried and I started to take him to the doctors (P2)*

> *I was concerned and talked to my relatives, my sisters, my brothers but they said children are not the same. So, I took it easy but it was concerning.And then, I think he was two and a half, then, I decided to go to the hospital to find out and then, we went through a series of speech therapists (P11)*

The above participant had previously sought alternative traditional treatment before going to the doctors. Other participants mention waiting for as long as five years before seeking for medical assistance. To the participant the child looked normal and that was what confused them about the childs delays. They were also advised that because the child looked typical or 'normal', then, it was 'people's things,' hence, the delays in seeking medical treatment.

5.3.2 THEME 2: PSYCHOLOGICAL IMPACT

Obtaining a child's final diagnosis of ASD can be an emotional and life-changing moment for parents and the family at large. The literature states that many parents after getting a diagnosis of ASD reported emotions of loss, shock, self-blame, guilt, anger, surprise and some felt a sense of relief (Banach *et al.*, 2010). The findings, in this study, are similar to the literature as most parents in the study were confused, angry and some were sad after receiving a diagnosis.

While most of them were attending a support group at the psychology unit, others were still not fully accepting of the child's condition. The emotional wellbeing of parents is critical in the development of children in general. It becomes even more pertinent when the child has ASD. There is a body of literature stating that depression is prevalent in women raising children (Jeans *et al.*, 2013). Children who are raised by mothers who are depressed show deficit in most aspects of their lives such as psychological, cognitive and they are at a very high rate of exposure to abuse (Burke, 2009). While this research did not fully measure depression in mothers and caregivers of children diagnosed with ASD, the literature on depression and parenting shows that mothers who are depressed show a high risk of maltreating their children than mothers who were not depressed (Slomian *et al.,* 2019).There are several emotions that parents present after a diagnosis and these often do not conclude that parents are depressed. However, care and more research need to be done in understanding the depression status of parents with a child diagnosed with ASD and the consequences thereof. One parent, in this study, mentioned emotions of resenting her child and she also mentioned that she would cry on most days because she could not deal with her child's condition. The well-being of the child may be compromised and the mother-child bond could not be formed or develop fully.

5.3.2.1 Denial and Disbelief

Soon after a diagnosis is obtained, a period of denial and disbelief is often seen and it commences to almost majority of parents. To a large extent, parents hear about autism for the first time on the day they are given a diagnosis by the hospital or a trained health practitioner. Some reject it; some blame themselves some blame others and others begin an expedition of finding corrective measures for the condition:

> *I didn't know what is autism; I think when he was four years old, then, my friend said no this child it's like he has autism, so, I didn't know autism, what is autism; I thought autism was a condition for white people (P8)*

Some parents mentioned that even after a diagnosis was given, they were unable to wrap themselves around accepting a condition that they were hearing for the first time and had no known cause and no cure:

> *So, my friend brought some papers which explained that when the child repeats a behavior, it meant that its autism but even with that, still, I did not believe that my child had such a condition in my mind (P8)*

Because children with ASD do not show any physical features that may indicate that there may be a form of a difference in the child, parents find it difficult to accept the child's diagnosis based on such.

5.3.3 THEME 3: TRADITION, RELIGION AND ASD

African Traditional Medicine (TRM) and religious healing in a country like South Africa is still largely interwoven. This may be understood by looking holistically at the history of the country and its recently found independence which suppressed all African philosophies to the extent that some practices were deemed criminal and banned. The then government imposed on people the western approach of healing without understanding the validity of the African worldview and the rest of the African forms of healing (Mokgobi, 2014). TRM remains the first choice of treatment in most people in Africa. This study also replicates the findings in the literature stating that about 27 million South Africans rely on the services of TRM for primary health care (Mander, Ntuli, Diederichs & Mavundla, 2007). Black African people are known for worrying about the invisible forces and the ideation of people doing evil things to them such as witchcraft, says (Ashforth, 2005). The evil forces that they worry about do not necessarily need to be in contact with the victim; they can be miles away, in long distances and even can be administered via dreams (Ashforth, 2005). The paper by Ashforth echoes the words of some of the participants interviewed in this study. Most believed that the child's condition of ASD may have been caused by witchcraft or some supernatural power from someone with malicious intentions. In light of the obvious fact, which I will repeat, millions of South Africans rely on TRM for most of their primary needs. These numbers which were earlier presented in the literature are enough evidence to support pharmacological research that will provide users of this stream with enough information about the safety and toxicity of some of these medications. There are indeed efforts that have been made, thus far, soon after the country found its independence in 1994 around TRM. However, the efforts are too clouded by politics, issues of intellectual property and big words (African Renaissance, Indigenous Knowledge System and decolonisation) that change now and again.

As stated earlier, traditional healing and religion in South Africa are interwoven because of the historical baggage of the country. Most Black South Africans (Which made out the majority of participants in this study) entered the Christian religion out of force or unwillingly. During the old Apartheid regime, children could not enter the primary school system without having been

given a Christian name (Mokgobi, 2014). Such conditions of pressure left many African people converting to the Christian religion; this is the reason why Africans still use pluralistic treatment methods which often include religion (western) and traditional medicine because most of them did not abandon their original beliefs and value system. Most parents, in this study, confirmed that both systems were consulted as a treatment option for their child with ASD. The sub-themes available, unorthodox alternatives, traditional healing, prayer healing, traditional and faith-based theories about the causes of ASD are discussed below.

5.3.3.1 Available Unorthodox Alternatives

In search of a solution and treatment for the child's condition, parents mentioned a variety of unorthodox alternative treatments that they tried in pursuit of a solution to the child's condition. Almost all parents tried religion as a source of treatment. One evident aspect was that under the umbrella of religion, some different categories and approaches were available. Some churches did not only use prayer as a means of healing but they had other holy substances that they offered to people in order to enhance or to speed up the healing process. Some religious organisations offered prophecy to determine the root cause of the problem and clarity to parents of the child's condition:

> *……his father said why don't we take him to church. Then, we went to church with the pastor;, I think we stayed for a week trying to see how is the child. He also said he doesn't see anything (P22)*

> *We went through a lot; the first person I remember that we went to see, told us to go to a deserted place in the bushes and they said when we get there, we must shout the child's father's clan names and then, when we are finished with their clan name and then shout mine… to tell you the truth, in search of help there is no province I didn't go to here in South Africa, all nine of them, there isn't one I didn't go to looking for help for my son (P8)*

> *I took him to ZCC*[6] *and they gave us the tea but after drinking the tea, there were no changes in the child's condition (P12)*

[6] ZCC – Zion Christian Church is one of the largest African initiated churches with head quarters in Limpompo Province SA called the Zion City.

The duration of prayers differed; some prayers took longer while others were shorter. Some prayers included prophecy and others were based on miracles. Some prayers were focused on deliverance, others were on casting out spells. Others were to beg for God to heal the child. Some prayer consultations were personal and face to face and some got their prayers via television:

> *There's a church that I watch on television called Emanuel TV.Emmanuel TV helped me a lot because I didn't have a break. So, normally when I switch on Emmanuel TV and pray with her, she puts her hand; she actually sleeps you know (P9)*

> *She said, granny, I want to take her to the man that I attend church with, the born again one; he's also seen on the TV (P5)*

Some parents mention seeing some change after attending church or some positive shift or improvement in the child's condition after the religious intervention had been performed on the child or for the family.

> *His behaviour before prayer wasn't satisfactory; he would cry for no reason and there was no way to stop him; he would stop crying maybe after five to six hours crying but now he's calm; he's alright; he's sharp (P10)*

While some parents expressed that the intervention yielded positive outcomes for their child's condition, others did not see any changes after the religious interventions, the condition remained the same and the child showed no improvements:

> *…….. I just see them giving the child some oil; they rub the child with that oil. I don't see any difference. I just see her the same (P1)*

> *We took her to some lady who is a prophet there, she said there was nothing she could do because when she looks at the child's condition; there is nothing she sees; she said she did not even believe that the child was bewitched (P13)*

Other parents mentioned that the church they attended had prophets who give some form of advice regarding the condition of the child and how the condition could be improved based on the prophecy reading:

> *…at church they would say they must do amasiko (a traditional related ritual) from his father's home, you see things like that. They say the ancestors are fighting over him;*

it's a struggle, things like that.My church, I can say it has prophets, I didn't decide that I'm taking him to church; I was at church and they prophesied on the child (P3)

My mother suggested that it was best for him (the child) to go to a Zionist person.So, she did take him; I didn't go because I was against the idea of Zionist and the Zionist prophet said the child's condition was caused or were things done to him by people. So, they put ropes around his waist to protect him from whoever that's against (bad spirits) the child which I don't believe- the Zionist guy told us also during his visit at our house that he was going to find a guy that will cut something below the child's tongue so that he can talk (P17)

The availability of alternatives as a treatment for ASD was consistently mentioned by parents. There is an array of church beliefs and rituals that were also mentioned by parents which formed part of the healing process for the child a ASD.

5.3.3.2 Traditional Healing

Out of many alternatives that are out there and are available to parents, TRM was the most sort after and commonly used form of treatment by parents. The use of TRM was also a known alternative so much that parents did not have to be referred or told about it as an option. All parents who were asked whether they used traditional medicine as an alternative answered either yes, not yet or no but surprisingly none asked what TRM was. The reasons for not using traditional medicine varied from the family that was against it or the church (born again Christian) was not allowing them to use the alternative. Some mentioned they did not believe that traditional medicine would help the child:

It's because he wasn't talking, so, at his father's family, they thought that maybe he's not talking because …they thought that they didn't do things right with the ancestors. (P19)

At her father's side and even her father also believes and the entire family, they told me to take the child to church to be prayed for, maybe, she will be alright (P14)

Doing rituals for ancestors were the common reasons why parents would consider the traditional way of treating the child. Most rituals were often suggested by either a prophet or a diviner or a spiritual person that was consulted by family members. There are cases where the

primary parent is against taking the child for TRM but the involvement of other family members exerts pressure on parents so much that they evently succumb to the idea of consulting TRM:

> *Well, I was against it and his father said that we should go, so, I went because his father said we should go to the prophets (P19)*

> *The child would cry for hours; we don't believe in Imbiza[7] and all those things. …. But my mom took him to church so that they could pray for him.They just prayed for him; they are people like those Christian like the born again church… They believe that prayer is the only way …They said at a certain time, we must pray. There weren't a lot of changes; the crying would stop a little after prayer, then, again it will start (P20)*

The need for a cure or a reason behind the child's condition is often one of the reasons why parents seek alternatives to medical treatments. Also, the lack of practical cause for ASD pushes parents to opt for a number of remedies available in the market that claim to cure the child's condition. Most parents mentioned that they received herbal medicine of some form after consulting traditional practitioners:

> *Yes, they gave him muthi[8] that I bath him with and also give him to drink (P4)*

> *..that man said we must go and find a big lizard. Then, we found that lizard; he said we must boil it; I don't know what he did but he boiled it until it died; the child drank that water; he said I should go throw away the lizard in a place a little far like deep Soweto and never look back after throwing it away (P8)*

There were very few parents who mentioned the effectiveness of the medication that was received from traditional healers. Most parents ended up looking for other alternatives such as church or even going to the hospital because of the ineffectiveness of traditional medicine.

5.3.3.3 Prayer Healing

Of the many alternatives that were available to parents, prayer was one of the commonly used alternatives as a treatment for ASD. Many denominations offered a prayer to participants. Some

[7] Imbiza-A herbal solution for drinking.
[8] Muthi- Traditional mixture (medicine)

parents referred to prayer in the Christianity format and others referred to Zionist and some prayers were sought from spiritual healers who also practice healing using prayers:

> *At churches, they just prayed and gave him water, said we must give him to drink, sharp; they gave him soil, that we must put it on him on the head like that…you will just be at the church and then they say this, this soil you use it, when you bathe him you must put it in the water and bathe him in it, also, pour this water for him when he wants to drink, give him that water and sprinkle the yard with it (P2)*

> *you know at church, they would say we must do Amasiko[9] fom him from his father's home; you see things like that.Cos they say the ancestors are fighting over him; it's a struggle; things like that?No, I mean my church like I can say it has prophets.I didn't decide that I'm taking him to church, I was at church and they prophesied (P3)*

Over and above receiving prayer, parents were instructed to perform other rituals and perform other tasks to children. Some were given liquids (solutions, water); others were given substances (oil, soil, etc.). When asked whether these practices were working or yielding some results, most parents explained they saw no changes in their children's condition:

5.3.3.4 Traditional and faith-based theories about the causes of ASD

People understand illness beyond the biomedical model. The concept of neurodevelopmental disorder is not enough for some people. Because of this context-based understanding of illness, parents make their contextual understanding of the causes of ASD. To most people, a 'difference' that does not fit into the known social standard has to be explained and to some a cause ought to be found. Parents resorted to other theories that may be linked to their beliefs and socialisation in order to get to the core of the cause of ASD for their child. Some parents stated the idea of witchcraft to be the reason why the child had ASD. Witchcraft, bad spirits, people's deeds and evil spirits were also other causes that were mentioned by some parents. Also, ancestors were another reason that was given as a cause of ASD. Rituals that needed to be done by the family either the mother's side or the father's side was amongst the reasons that parents mentioned for the child that has ASD:

[9] Amasiko – A culture bound ritual specific to each family belief value system

At the traditional healers, they give him medication; they give us things to put of his waist like strings (P2)

So, she did take him; I didn't go because I was against it and he said it was caused by people (P17)

Theories of supernatural causes of ASD start from the time the child is conceived until the child is born and continue to be present during the child's development. So, parents who believed in witchcraft or the 'things of people' will continue to protect the child as the child grows and for as long as they have the means and the strength to continue with traditional related processes of protecting their child against bad forces:

So, they put ropes around his waist to protect him from whomever that's against the child which I don't believe him (P17)

You know at churches they would say no he has; they must do Amasiko from his father's home, you see things like that (P4)

The option of church and traditional healers was quoted by many parents during the interviews. It seemed that the church path was socially acceptable and the traditional healer was the family's preference.

5.3.4 THEME 4: THE BEST INTEREST OF THE CHILD

The main objectives of the study were to understand whether using alternatives such as traditional medicine and religious intervention impacts the child's wellbeing. The study further explored whether these alternatives mentioned above have benefits or were harmful to the development of the child with ASD. Section 9 of the Children's Act 38, 2005, clearly states that the child's best interest is of paramount importance, with a clear focus on the child's protection, care and wellbeing of the child. Caring for and treating children is not the same as treating an adult; children have special pharmacokinetics and their inability to consent leaves them vulnerable. It is even worse for children with ASD because some of them are non-verbal and lack social skills; their vulnerability is sensitive. For this reason, children with ASD lack decisional capacity and parents, caregivers or legal guardians have been entrusted the responsibility of taking over matters of informed consent for all healthcare-related interventions of the child with ASD. Practitioners, usually, will have offered the opportunity

to the minor to accent for treatment after providing them with enough information about the treatment method. Also, the accenting option may not be necessary since most children with ASD lack theory of mind. Besides, in this study, most children were low functioning.According to the DSM 5, they were level 1 (Requiring support). Therefore, the issue of informed consent becomes complicated in the case of traditional medicine and differs to the western approach of informed consent. According to (Osuji, 2012), consent in African traditional medicine takes into account that the individual is part of a larger community and this community is largely involved in the wellbeing of another, hence the use of the African philosophy *umuntu, ngumuntu ngabantu* which means a person is a person because of other people. That said, the issue of informed consent is but one of the concerns in the treatment of children with ASD. The larger issue is the safety of using traditional medicine on children with ASD. Do parents take this into account when choosing treatment options for their children? One parent, in this study, mentioned that a traditional healer advised that they find a lizard, put it in boiling water and leave it to boil until it dies and then, give this solution to the child to drink. The reason for this solution was to improve some of the symptoms of ASD. Parents become the decision-makers of what treatment the child should take and what should be administered first before the other and so on. Another question would be, do all parents have the best interest of the child when making these decisions? The fundamental question would be to unpack the question which asks,what is the best interest of the child with ASD?

5.3.4.1 Parent as a Decision Maker

Parents remain the primary caregivers of their children. In the case of ASD, the emotional state of the parent and their ability to make decisions that are serving the best interest of the child should be at the centre. Families have a bigger role in child-rearing and also, this role should be centred around the interest of the child. Most parents, after receiving a diagnosis, continue to seek more information about ASD. It is critical that when parents are given a diagnosis, they are also given enough information about ASD, its treatment methods, the available alternatives and its effectiveness to make a sound decision about the child's condition:

> *After one year and six months, I saw that the child was not like other children, the child was behind with several things that children his age would do. I had to see where I could go, I didn't start by going to the clinic; I didn't go anywhere to ask what is happening with the child. I thought that since he is my child, I will stay with him to see what happens. After the child was two years and was still behind, I had to tell the father*

that we should see someone so that we can know what is happening with the child. The child was two but he didn't do anything; he couldn't talk; he doesn't want a lot of things, can't see the world, he doesn't know other people, he only knows his mother, not his sister, his brother, he only knows that he has a mother, only where he stays.Then his father said why don't we take him to church (P22)

Parents made different decisions about taking steps to help their child's condition of ASD. Some preferred to tell the family and let them make the decision. Others wanted a solution outside of allopathic remedies such as church and other alternatives. Parents remain the main decision-makers when taking up the treatment of the child.

5.3.4.2 Fear of taking alternatives

Some parents mentioned some level of fear around using alternative treatments such as traditional medicine to their children. Their reasons ranged from the fact that the family belief system was against the use of traditional medicine. To some, the use of traditional medicine was seen as against Christianity. Most traditional African healers base their practices on ancestors and this can be against some denominations like Evangelicals who believe in spiritual renewal. Some feared the efficacy of using alternatives. Some mentioned that they did not trust the process, hence they rather take their children to hospitals or doctors:

Traditional things no, I haven't tried them, I haven't tried them at all because I trusted that since I brought him to the hospital, the hospital will be the one that helps him, I tried things like that but I didn't find help, before, I haven't done that, So, when it came to him, I thought of taking him but I saw that no maybe it's a waste of time (P24)

No, eish, according to me, I believe that she's is the way she is like really it's a disability, I don't believe that there is something that she needs, (P7)

Beyond fear, some parents did not believe in using alternatives. They understood the concept of a disorder and disability. They accepted that the child had a condition and there is no alternativethat could be done by the church or by any traditional medicine that could reverse the child's condition.

5.3.4.3 Regulations and ethics

Most parents mentioned concerns in the use of traditional medicine and some raised their personal fears about the safety of the treatments that some of the alternatives may pose to children. They also mentioned the rising numbers of traditional healers who are openly operating in their communities for financial gains. Others mentioned a need that was of paramount importance which includes the regulation and standardisation of alternative treatments. They also expressed that practitioners who practice without training expose children to portions that are not safe. Such negligence is bound to lead to toxicity and health hazards and those found to do such should be held accountable for their unethical and unregulated practices. Some participants were concerned about the lack of hygiene in some of the consulting rooms of traditional practitioners which may also put children at the risk of being exposed to other hygiene-related risks.

> *I think they will put a child in danger, you know why sister?So now you will take this child to that person and put the child in the steamer (ukufutha[10]) cover the child with a blanket, and other kids may have seizures and all that, and the child will develop other illnesses, better I just follow this one at the hospital because the doctors go out to other countries and learn about these things you see (P5)*

> *I think they will harm the child worse, these people train in different ways, Others are trained with animals, others with trees, others they pray, you see?So my belief, is that I don't think they can help the child (P9)*

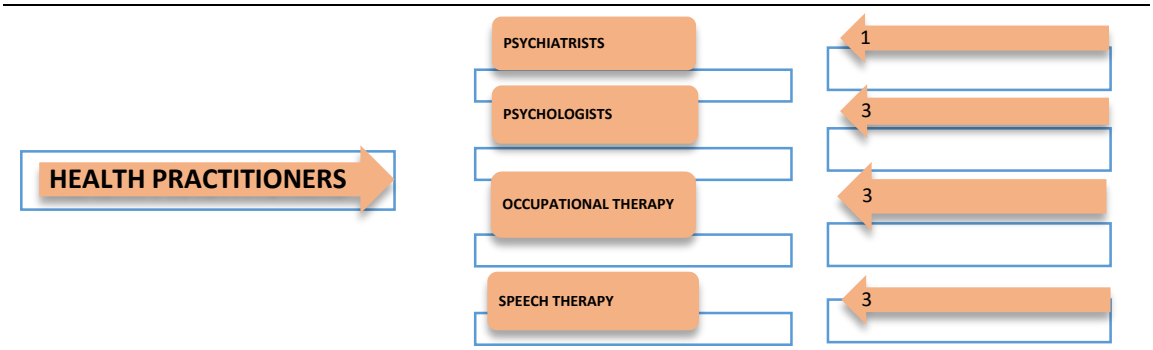
Parents were concerned with the safety of some of the traditional related processes and medication expressing that some of the alternatives substances may have a potential of harming their children. Some parents were concerned about the regulation of the traditional healing industry because of the possibility that some may exploit the situation to a point that harmful risks to children may be possible.

[10] Ukufutha- steaming with herbal medicine prescribed bt TRH

5.4 HEALTH CARE PRACTITIONERS- THEMES

This section presents the results of semi-structured interviews conducted with health practitioners who participated in this particular study and who met the required study criterion. All practitioners interviewed were involved in treating children with ASD. This section unpacks all the themes analysed. Major themes and subthemes are presented in table 9 below in the presentation of results.

Table 9: Characteristics of Health Professionals Interviewed



Each health care professional interviewed in this study met the main inclusion criterion of the study, each gave accounts of their work with children diagnosed with ASD according to the scope of their practice and based on their responsibilities in the hospital .

Based on the data and the interviews from the participants which included a psychiatrist doctor who was the only professional in this group of participants that gave a formal diagnosis of ASD. All other practitioners such as psychologists, nurses, speech therapists were restricted to give a diagnosis based on the scope of their practice which prohibited such responsibility. The diagnosis was, often done, after several medical processes had been followed. It was worth mentioning that at the psychology unit, there was only one psychiatrist designated for the entire department. The process of issuing a final diagnosis usually took up to a maximum of six months because of limited staff and also the doctor did not rush to give a label but was more into thoroughly examining the problem.

Psychologists mentioned that they were more involved with both the child and the mother. They took part in handling behavioural problems of the child such as physical aggression, tantrums and in some instances self-injury. They also were involved in the process of helping

in regards to the psychological impact experienced by caregivers and mothers of children attending the clinic.Their involvement included psychoeducation and psychological support of how parents ought to handle a child with ASD. However, not all parents who took part in this study were part of the psychoeducation support groups. Some did not even know of the existence of the psychosupport groups for parents due to different reasons.. This was because some parents started their childs treatement journey at other nearby clinics and then later refered to CHBH for language and speech therapy only therefore their interaction with the hospital was only limited to the speech department only.. Some may have been preoccupied in dealing with challenges experienced by the child to an extent that they may have neglected their self-care needs.

A child with speech challenges was assisted in the speech therapy departments by a trained speech and language therapist. Staff and parents from this unit also formed a critical component of this research study.

The occupational therapy team supports the mother and the child. They are mostly involved in assisting children with behavioural problems and also to teach mothers how to cope with children with developmental issues and help those who were unable to take care of themselves. This group of professionals also formed a critical part of this study.

5.4.1 Description of results

The analysis of the data followed the main objectives of this project. Health practitioner's opinions and answers formed part of the integral area of the study. The study sought to understand if practitioners encounter parents who opt out of the medical approach system because of the strong belief in other alternatives. Also, the analysis looked at some types of alternatives that the practitioners know to exist that are normaly an alternative for parents who attended the hospital. The following main themes became relevant and were followed in the analysis of the data.

i. *The role of the practitioner in the process of diagnosing the child* – This part of the data gave an understanding of the reaction of the parent after a diagnosis is obtained. It was important to understand whether parents rejected a diagnosis or accepted it. Most

parents who rejected the diagnosis were likely to withdraw from attending medical consultations for the child and opt for other alternatives.

ii. *The practitioner's involvement focuses on the child or the parent* – this information was important because it may help to understand the relationship of the practitioner and the patient and how the practitioner dealt with both the parent and the .

iii. *The practitioner's understanding of alternative treatments used by parents* – This was relevant because it provided an understanding of whether practitioners dismissed alternative forms of treatment as quackery or they allowed the patient to fully disclose all treatment methods used in treating the child.

iv. *The obligation to protect children with ASD* – in the context of SA where the majority of people are exposed to a pluralistic approach of treatment. It is important to understand the practitioner's obligation to treat patients. .

See table (10) below for the main themes.This chapter presents and discusses these themes presented in Table 10 below and highlights the relevant contradictions and relationships between these themes.

5.4.2 FINDINGS (THEMES FROM HEALTH PRACTITIONERS)

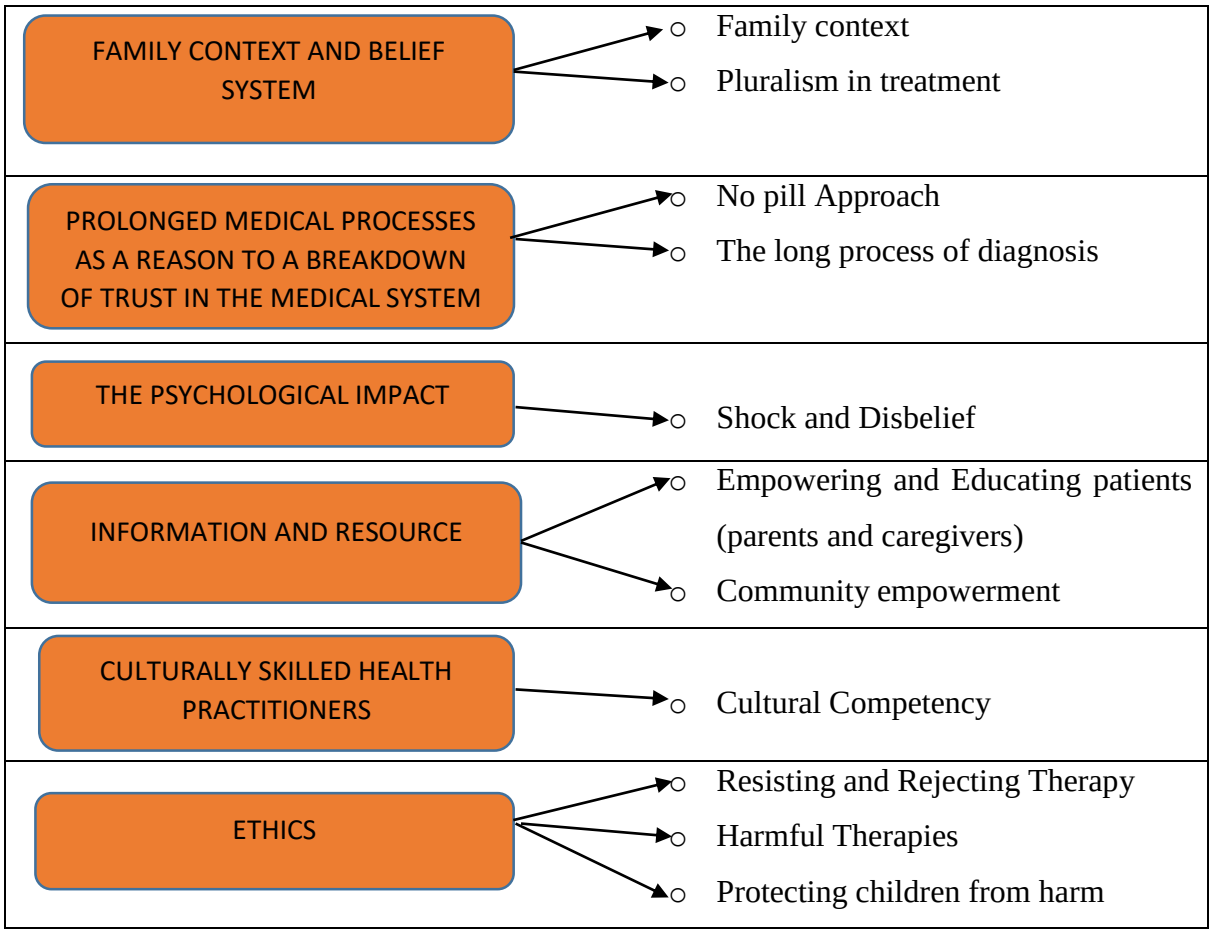
It was evident throughout most themes that there is indeed exposure to harm that is attached around the use of traditional forms of healing/ medicine. Based on the practitioner's discussion during this study, there have been cases of children brought into hospital after they had been given solutions or other forms of medicine from traditional based healers. The findings of this section are in line with other studies that found that some types of traditional medicine may contain toxic and potentially dangerous constituents (Adewunmi & Ojewole, 2004).

Traditional medicine, as an alternative, was not the main and the known alternative form of treatment that practitioners mentioned.there were several other forms of healing which were known by practitioners that parents used as alternatives for children with ASD. They mentioned religion, rituals, special diets and other calming machines formed a collective for a collection of the many chosen alternatives by parents. During the discussion, there were other forms of treatments, which may also be categorised as complementary treatment methods according to the discussion with practitioners which they regarded as carrying less harm to children. The literature on the use of CAM suggests that the results on CAM treatments and

their safety are still not yet conclusive (Brondino *et al.*, 2015). Also, the scope of this study was limited to religious and traditional interventions only as alternative methods.

The decision of a parent to consult alternative sources of treatment needs to be looked at with a deeper level of explanation since they involve not only the parent by usually in the African context the entire family is often involved. The process of caring for a child with ASD is difficult, depressing, shocking and to some can be regarded as a period of grief. Therefore, the child's diagnosis of ASD can be sensitive to both the health practitioner and the caregiver.

Table 10: Health Practitioners Themes



5.4.2.1 FAMILY CONTEXT AND BELIEF SYSTEM

Practitioners mentioned a bewildering number of alternative treatments that were often considered by parents as a form of treatment for ASD. The options ranged from diets, detoxing machines to a range of traditional and religious treatments. It is no secret that most of these options mentioned by parents lack scientific testing to determine the effectiveness and efficacy. The family's beliefs and context played an integral role in the treatment journey of

children in this study. A very large component such as decisions for the child's choice of treatment was informed by the context of each patient. Often doctors reported a very large interference and influence caused by the family and the context of the patient which includes community members who bombard parents with theories and an avalanche of information regarding the treatment of ASD. This influx of information is likely to create confusion to parents when deciding the child's life. The context that most parents came from is embedded in in the philosophy which is deeply rooted in the following saying:it *takes a village to raise a child.* Mandell and Novak (2005) says that the meaning parents place on the comprehension of the child's condition is likely to be predisposed by culture and family's belief system. Also, they discuss the impact of culture in a person's thoughts and understanding of the worldview which is possible that these dynamics play a pertinent role in child development and the understanding of any deviations in the child's health.

5.4.2.1.1 Sub-Theme 1: Family Context

Family context is one of the critical roles involved in the process of acceptance and in the treatment choice to be taken for the child. Some health professionals who took part in this study have years of experience working with children with ASD in different social context (public and private). The acceptance of a diagnosis by parents from these two contexts differ significantly. The context in Baragwanath is predominantly African, mainly, because of the location of the hospital and and also by virtue of it being a public hospital. Most parents who attend CHBH were unable to afford the private health care system. This, then, makes it difficult for parents to seek alternatives or secondary opinions about the child's condition:

> *I work in two different settings, government and private. In private practice, most parents struggle to accept the child's condition but here in a public setting, I find that parents find it less difficult to accepts the child's diagnosis (HP3)*

Parents in the initial stages of the process have trust in health practitioners and the health system in general mainly for things like expert advices and care, hence they easily accept a diagnosis when given to them by the practitioner. However, this acceptance often changes down the line when parents learn to understand that there is no cure for the disorder. After the news are passed to the larger family structure it becomes even harder to accept the condition of the child;

> *But a lot of the times, it's exactly like I said, it's often when the bigger family becomes involved and the granny from this province and grandpa from this place is coming in,*

everyone is giving the parents a sort of their view and their opinion that's often where we find the patient sort of default and don't come back to the service.I can't tell you hundred percent what these alternative methods are, ...but we have definitely had parents come to say that you know I don't feel that this is what my child needs, I'm going to deal with it the way granny says, they would say she said we must go here, this is what we are going to try (HP4)

One health practitioner acknowledges the power that comes with family dynamics. Parents are usually not the last voice to decide for the child's treatment process and how it should be undertaken. It is often a collective decision which includes elders such as great grandparents, aunts and other important family relatives who are often consulted after the doctor has either issued a diagnosis or a treatment method for the child:

The older generation has a big role in this community in raising the children (HP10)

About the involvement of the patient, practitioners understood the dynamics that are at play in the type of community that they serve. However, the duty to provide information to the patient or those who make decisions on behalf of the patient still prevails. Almost all practitioners were aware that the bigger family structure gets involved once the process of treating the child is in motion. In most cases, once the parent learns the news that there is "no pill" that can cure autism, the family consultation begins to interfere with the treatment process;

There's a perception that sickness is something you go to the doctor; you get medication and you get better(HP3)

The absence of a cure/pill and clear explanation was usually the reason why alternative treatments come into the picture.

5.4.2.1.2 Sub Theme 2: Pluralism in Treatment

Most health practitioners during interviews were aware that the community that they are serving practised a pluralistic approach to treatment. This pluralistic approach to treatment seemed to be an issue that was very sensitive to handle. Some practitioners understood the sensitivity of respecting others' beliefs and understanding the beliefs of their patients:

family dynamics sort of start showing themselves a lot when maybe the parents now have to go and talk to the grandparents about the diagnosis, then, getting the whole family involved and there's a lot of sort of stigma and cultural beliefs around autism

that we've picked up and noticed throughout the years and people come and say, you know this is how we want to approach this- as a speech therapist you feel that you need to do your part but I just feel like I can't tell a caregiver or parent that you know your belief system or this thing that you feel is going to, maybe, make the difference may not… you cannot do that (HP4)

Yeah, we have a lot of caregivers giving children things to, eat or to drink or animals that have maybe been prescribed or suggestions, suggested by traditional healers, I think what's important is - the doctors are very aware of the environment and community in which we working in and that people may have views and beliefs in terms of traditional medicine (HP1)

Practitioners also stated that some parents do not disclose their use of both traditional and allopathic medicine. This is mostly because they are scared to mention this for several reasons known to them:

They wouldn't tell us; they don't go into details as to, you know what happens or what they get given or what they get told but what we or what they feel comfortable sharing with us,is that they consulted a healer and they were told they need to perform you know a ceremony so if the child is admitted that's when they would ask for permission that can you please release you know the patient we need to perform a certain ritual (HP5)

There was a common understanding among practitioners that the patient's beliefs are to be respected. Also, some mention that it was not the intention of any health practitioner to discourage patients from stopping alternatives.

We sit down with the parent and let them know at the end of the day we can't force them to do something but we let them know that you know this is what we know, this is how it works not only research but also experience you know, the results of other children you know who presented with the same condition and behaviour and were given the medication and what the results are, so we sort of share that knowledge with them but at the end of the day, it's the parent's decision and choice but you'll find those parents that after explaining they feel relieved that they need to do that, it is difficult but we tell them that we cannot be treating the child with this medication and then the next thing they'll be giving the traditional, you know so bombarding the child with all

this medication it's quite harmful so they need to decide what is it that they want to do, should we stop our medication while they you know seek uh treatment traditional, yeah we, we sit down and we give them a choice (HP5)

Some health practitioners stated concerns about the lack of collaboration between traditional and western forms of treatments. They also mentioned limited interventions available to help parents and their children in the event the alternatives proved to be harmful.

It is difficult for us doctors to evaluate because we don't know what the child is going to be given (HP3)

There were concerns from health practitioners that they are unable to access the ingredients or to understand what ingredients are used in some of the traditional medications that are offered by alternative healers for the children. Some practitioners mentioned that in the work they do in the hospital, they have witnessed some elements of harm that some alternatives have to a large extent impacted the health of children.

*Exposing children to alternatives, I think has a potential direct harm, where children are given certain substances (*HP3)

Some practitioners explained harm that comes with alternative treatments as a concern since they could be dangerous to children. In most cases, parents do not know what is usually given to the child by the healers they consult. Health practitioners also explained that when parents happen to discuss alternative treatments, they often have very limited knowledge of what is administered to the child:

We would explain that to the caregiver and say please, by all means, go to the traditional healer but should they suggest that there is something that you give your child, maybe, before you give that to your child, discuss that with your medical professional, in terms of the safety of giving it to a child when I asked mom about what was in the water she said she didn't know what was in the water (HP1)

Some practitioners did not know where to draw the line when it came to the involvement of alternative forms of treatments. In most cases, there was a lack of understanding of the context of the patient and also the role that most of these forms of alternatives play in the holistic health life of the people that they served:

I have to respect their religion, their cultural beliefs so it's hard to say yes or no but like I said in my answer earlier, if I'm reluctant to say be open to anything that is not proven to be successful but I don't know if you have the right to judge a parent if they feel that they need to try an alternative (HP4)

Most health practitioners found the issue of alternative use of medication a sensitive issue to discuss and in most cases, they seemed to lack the experienced in dealing with such issues even though it was evident that it carried a high potential exposure to harm for children.

Here, in hospital general and not speaking about ASD just general we see children coming back intoxicated coming back who've been to traditional healers and have been exposed to traditional random things very ill (HP8)

Traditional medicine was not the only form of an alternative that health practitioners discussed but they mentioned also that caregivers sometimes perform certain rituals to speed up the process of healing. Other practitioners stated that parents have mentioned unorthodox reasons for the child's illness. The rituals and all the other unusual explanations also have elements of exposing the child to some form of harm:

In my experience in this unit, I have come across parents who will say, please, check the child's tongue; maybe, it is stuck (HP4)

Practitioners also mentioned that there have also been incidents where parents tell them that they will deal with the child's diagnosis of ASD their way. In most instances, such parents may withdraw the child from the treatment therapy and abandon the medical system completely:

We have had parents that do not come back after a diagnosis and a planned program. They say I will deal with this my own way (HP4)

Attending church and getting healing from church and prayers was also another intervention that was identified by health practitioners.

Yes, there's quite a few who will either go to church like a Christian church getting a pastor to pray for their child to be healed and that kind of stuff; I think that's more common than like a traditional healer (HP10)

While attending church did not come up as an alternative that had the potential to expose the child to harm, however, it was a concern to some health practitioners if they replaced the medical treatment plan of the child:

look the earlier we get, we start intervention with the child I believe is the best. You know the younger the brain, the more plastic it is (HP2)

The importance of resuming treatment early for children with ASD was highlighted by most health practitioners. So, if clinics are abandoned by parents and take the option of traditional alternatives, children could be put in a compromising position that has potential to damage their development.

5.4.2.2 PROLONGED MEDICAL PROCESSES AS A REASON OF BREAKDOWN OF TRUST IN THE MEDICAL SYSTEM

Lack of trust in the medical system is a problem not only that affects the wellbeing of people but a pertinent factor that can be viewed as an ethical, political and epistemological component in health care (Camporesi, Vaccarella and Davis, 2017). The definition adopted for the term 'trust' is one that specifies this concept as strongly embedded in expectations (Calnan and Sanford, 2004). The fundamental relationship between a patient and a health care professional is in essence based upon mutual trust between the two parties. Thus, it is an expectation crated by the public that health professionals have enough knowledge, skills and competencies and they have their (the public) best interest when providing health care. Often, this is not the case. Some health professionals are not adequately trained in the field of ASD.Thus, if not enough expertise is evident, the trust may be broken leading some patients to look for better alternatives. Those who received enough training may not have enough competencies to understand the context of patients, thus, leading the public to other approaches available and ready to treat their children. Only a few professionals are well rounded in the space of ASD and often, these professionals are serving the higher end of the population. A comprehensive review by (Franz, Carolina and Chambers, 2018) in Sub- Saharan Africa found that there was a shortage and low knowledge of ASD in professionals working in this space.They claimed that there was a need for improved development and training of professionals in ASD.

The concept of 'trust' in the bioethics community is one of the core pillars in many health-related topics but more importantly, in the clinical research space (Camporesi, Vaccarella and Davis, 2017). One of the determinants of trust in the health care sector is the interplay of power between health care professionals and patients (Østergaard, 2015). The author states that, firstly, health care professionals are at the forefront as producers of knowledge of health-related matters. This is the critical point where trust could be built or lost. The fact that ASD has no known aetiology creates a quest for parents to seek knowledge from medical experts. It is, thus,

important that trust is present during this stage of information-seeking because as Ostergaard says, trust also has the potential to forge or improve relations and collaborations between health care practitioners and patients. Furthermore, the presence of trust promotes patients to have easy disclosure of symptoms to their health care practitioners. Also, patients could relate better when trust is forged successfully. Patients may also be able to open up to medical staff about other alternatives that they know or that they have been informed about. Patients often expect that any anomaly, disease and other health-related issues can be resolved with a pill or some medication. Once their expectations are not met by either not receiving the form of treatment that they expected or being referred from one specialist to the other, this prolonged process weakens the trust and may lead patients to seek for other alternatived that will be more helpful towards their childs condition.

5.4.2.2.1 Sub-Theme: No Pill Approach

Most practitioners mentioned that mothers/caregivers come with expectations that the hospital or doctors will give an injection or a pill to the child and afterthis medication has been taken by the child all the symptoms will go away. Thus, one doctor mentioned that in her experience, treating symptoms of ASD using medication is, usually, the last resort in handling the child's condition. In her twenty-years of experience, medicating, a child comes with false hopes for parents. Parents end up thinking that the medication that is prescribed for behavioural related symptoms such as fidgetiness and hyperactivity for children who have more than one diagnoses is the solution to the child. While medication is given, a procedure of the medication is handed to the patient together with high level of information clearly stating how the medication is to be administered to help the child become calm. So, parents need some form of solution or explanation of the child's condition. Giving a pill to some parents may mean that the 'pill' will 'cure'

> *There's a perception that sickness is something you go to the doctor, you get medication and you get better. They just don't understand,Uhm, I think many of our parents just come to the doctor thinking the doctor will give a pill (HP3)*
>
> *Okay, because I don't want parents to think that I'm going to give you a pill and your child is going to stop doing stereotypic movements (HP3)*

Health practitioners were cautious of giving parents hopes that the child will become better after a pill has been given. This was a practice that they did and tried to make parents aware that the pill only will not provide them with complete care for the child.

5.4.2.2.2 Sub-Theme 2: The Long Process of Finding a Diagnosis

The stigma that is often attached with a diagnosis of ASD leaves lifelong negative labelling to patients. A number of mental health realated illness and diagnosis are known to carry a negative stigma. The practitioner, therefore, is bound to conduct thorough assessments mainly due to this fact. Also, ASD is a qualitative disorder meaning there is no scientific biomedical analysis involved in the diagnosis therefore the process of diagnosing may take longer than just a blood test:

> *The process of diagnosing the child takes about six months. It involves a process of getting the general history of the child. I also observe how the child intervenes with toys; is he interested in the toys, does he show mommy the toys? (HP3)*
>
> *we also struggle with a diagnosis so if we just work purely on diagnosis, we'll have very few kids in our clinic.because they will go and get an appointment but they wait six months if they lucky it's usually a year to see the doctor (HP10)*
>
> *Other children come just from the child psychologist or child psychiatrist already with a diagnosis sometimes from the neurodevelopmental doctors with a diagnosis to start their treatment, so it's a case by case basis,sometimes we wait a long time to get a diagnosis (HP8)*

Sometimes the western approach becomes the alternative for some parents. Usually, most parents are able to endure this long process of assessments because they have consulted other alternative forms of treatment. These have proved to yield no immediate cure or yielded any changes to the condition of the child.

5.4.2.3 THE PSYCHOLOGICAL IMPACT

Health practitioners mentioned the element of shock after parents have been told of the child's diagnosis of ASD. While the hospital had a psychology unit, some parents were not referred or had no information about the the unit that provided psychologicalsupport groups. Health care practitioners shared differing views in regards to the impact endured by parents after obtaining

a diagnosis. Arriving at the point of diagnosis for parents meant that they had to go through several psychological stages which included a denial stage about the condition of the child.

Other parents mentioned struggles and challenges with the family and other community members who did not understand about ASD. Some parents went through periods where their child wascalled names like 'naughty' or them being labelled 'bad parents' who lacked discipline.Therefore, giving a diagnosis of ASD ought to be a very sensitive process. Often, after obtaining a diagnosis, a parents' perfect world seemed to collapse, their picture of 'bundle of joy' soon seemed blur and replaced by a picture of an unmanageable, disabled child with ASD. This picture to some parents was a completely new word all together (Trigonaki, 2002). In this project, health practitioners may have watered down the magnitude of giving parents a diagnosis of ASD and gave attention to a point of parental denial of ASD. practitioners may have overlooked or gave less focus to the parental psychological wellbeing in this study. This oversight from practitioners, in this study, was also seen as a huge gap that drives parents to seek alternative treatments for their children.

5.4.2.3.1 Sub- Theme 5: Shock and Disbelief

After a diagnosis is given to a parent or a caregiver, health practitioners stated that parents often reacted with feelings of shock and disbelief towards the condition of the child. The fact that the illness is a lifelong condition, usually, is the central reason why parents react in shock. In most instances, parents lack understanding of autism. Nearly most parents in the community setting of this study had little or no knowledge of autism which lead most of them to default to a culturally related rational way of dealing with ASD. Most often it was seen in this study that when parents bring about the topic of traditional explanations of the disorder often the topic is extended further to other topics such as:witchcraft, ancestors and other tradition related ways to understand illnesses that do not have a cause or origin:

· *They believe that the child is bewitched or a certain ritual should be done (HP 01)*

It's not often, in our unit, we mostly see moms and not dads and the parents who outright reject the diagnosis, are the dads who are parents who don't bring the child (HP5)

Majority of health practitioners who were interviewed in this study mentioned that they have heard a number of parents mentioning tradition and culture as the reason why the child had ASD. Most practitioners also mentioned that a parents' background informs their exposure to knowledge of autism:

> *depending then again whether the child's parent are still together or they separated, uh if they are separated there'll also be a belief that, you know maybe there are some certain family rituals you know that needed to be performed you know for the child or to introduce the child to the dad's family you know (HP5)*

Health practitioners explained an interesting point about parental shock and denial, that those who normally are shocked or in denial do not take part in the child's therapy . This is because they are not receiving the news direct from the doctor or health care practitioner.

5.4.2.4 INFORMATION AND RESOURCES

It is a fact that patients, in this case, parents of children with ASD hold the right to information about their children's health and treatments and other available health care services for children with ASD. Not only this right ends just there, they also have the right to receive this information in a medium that is easy to understand and easy to follow. In this study, it became clear that parents of children have limited information about ASD even after having attended hospital consultations for several months.

There was a lack of emphasis from health practitioners about the importance of information that should be given to parents about ASD and its treatment method. Many alternative treatments are available to children with ASD; some parents often ask health practitioners about them. While health professionals need to respect the rights of patients who choose not to receive information about the available treatments and alternatives, it is of paramount importance that patients are empowered with enough information so that they make meaningful choices about their children's future. There should also be enough emphasis made on the importance of giving patients information in a right and respectable way because the opposite could be harmful to some patients (Osuna *et al.*, 1998).

5.4.2.4.1 Sub-Theme Empowering and Educating

It was evident based on the practitioner's responses that parents and caregivers needed more knowledge about ASD. While some practitioners advise parents/caregivers to read literature, some have mentioned that there is an important role that doctors can play in educating and empowering parents about autism. One practitioner also mentioned that doctors, sometimes, ask mothers to bring their extended family members who need more knowledge of autism to the clinics to get more information. Some also stated that when mothers disclose or suggest that they take the child to any forms of traditional medicine, they often ask the parent to come or invite the relevant healer to the hospital so that a treatment relationship is formed:

> *I think it's important that we respect everybody's decision, I think as a professional it's our job to educate caregivers and provide enough information (HP1)*

Most practitioners stated that there is very little that they can do when it comes to influencing patient's choices. The involvement of extended family and the type of background of each parent plays a very big role in the options parents take or choose as treatment method for the child. After a diagnosis is obtained and the patient leaves the hospital, the bigger family often takes over by involving traditionaly related alternatives that are usually embedded in the culture:

> *I don't want parents to think that I'm going to give you a pill and your child is going to stop doing stereotypic movements, because it's not going to stop, and because I don't want the parents to have false expectations and they see that but the child isn't getting better and granny at home says no, but I would say the biggest issue is your doctor- but I know better; I think we should go home and go do this ritual.I think that is the most common reason I mean it would be somebody powerful in the family (HP3)*

Thus any form of intervention that doctors may attempt to offer such as reading relevant literature and interacting with other relevant people who are also involved in the child's treatment is usually overridden by bigger structural or systematic issues.

5.4.2.4.2 Sub-Theme: Community Empowerment

While autism has been around for a while, it is not wrong to say until today, there is a person, organisation, community or practitioner who does not know about this disorder. This lack of information, according to some practitioners, needs to be looked into and addressed in relevant structures, communities and by stakeholders who are part of the ASD community. Some negativity around ASDmay be due to a lack of community empowerment. If communities, organisations and structures are not empowered through educational campaigns and awareness, children will continue to face possible neglect, misdiagnosis, exposure to unorthodox ways of healing and several other explanations that could be harmful to them:

> *As we said earlier, there aren't enough resources, there aren't enough staff members, we lucky that we're inside the social institution when you go to the primary health they try, as long but now in the villages do we have the service and what happens to those kids that get missed but we don't have staff inside the state institution what more outside, then you are inundated with cases that are not properly managed (HP6)*

There were several and different reactions that health practitioners noticed coming from parents. Some reactions were concerning and required that parents are educated about the disorder properly. Health practioners also observed that majority of parents require support post-diagnosis. It was also mentioned that most community members still had limited knowledge of the disorder which leaves many parents in need of support about the condition.

> *but supply the families with the resources, maybe like home visits that type of thing to ensure that not check-up but support at home so like a weekly visit to educate and give ideas on what to do, more community-based care in ASD is needed, not check-ups but support (HP8)*

The need for more ASD focused home visits was something that was mentioned by health practitioners. Parents may benefit from ongoing support outside of the hospital. This could help reduce the burden on parents and improve the wellbeing of children.

5.4.2.5 CULTURALLY SKILLED HEALTH PRACTITIONERS

There is growing need for for a culturally competent health care professional in a country as diverse as South Africa . The definition adopted in this thesis defines this concept as a set of congruent 'behaviours, attitudes, policies that come together among professionals and enable effective work in situations that require cross-cultural skills'(Anderson *et al.*, 2003). The definition by Anderson (2003) is one of many different definitions that are available in the literature provided by many scientists from multiple disciplines such as anthropology, psychology, medicine and even philosophy. Other scientists agree that culture is a pattern (Morra, & Smith, 2006). This pattern includes behaving, acting, beliefs, values, relating and interacting with others, knowing and many more patterns may be included in these patterns when one is trying to understand the concept of culture. In health, culture adds other aspects and dimensions which may include people's perceptions, way of knowing and these are all related and based on each individual's culture and the meaning of illness. Culture, thus, influences how each person recognises symptoms, and in turn, interprets these symptoms (Anderson et al., 2003). In a study conducted fifty years ago by Zborowski, he found that different cultures and ethnicities understood the meaning of pain using lenses of culture and just not the biological lenses alone. In this paper, it was stated that physiological phenomena that are not unique to one group of people but universal to humans find themselves regulated and institutionalised by culture and other social phenomena (Zborowski, 1952). It is based on such studies that confirm that cultureinfluences how to people understand illness and require that health professionals become aware of these influences in people and in their patients. Zborowski (1952) furthers states that the role of culture in people is so powerful and important to a significant number of people so much that in some situations, this role may to some extent, undermine the physical and biological needs of the person, thus, putting the individual in danger for his survival. A study by (Peacock and Patel, 2008) states the importance of reflexivity for health professionals to create self-awareness and avoid ethnocentricity. In this study, health professionals were not in sync with parents and the understanding of ASD, and they understood the causes of ASD differently. Some practitioners understood the consultation of traditional healers as a form of denialism from the side of the parent and others did not know what to make of it but only as a point of respecting the other person's beliefs and choices.

5.4.2.5.1 Sub-Theme Cultural Competency

Health practitioners, in this study, were aware of the use of alternative forms of medication by a majority of parents who were attending their clinics. There were several forms of alternative options mentioned by parents according to the interviews with health practitioners. Some parents mentioned traditional medicine, rituals, attending church for prayer, consulting prophets, the use of complementary medicine and several other unorthodox explanations of the condition were brought up during interviews. Practitioners were aware that the diversity of context requires that health practitioners become more aware of their patients and be prepared to offer sufficient information to them. However, their understanding of the patient's diverse nature may not have been useful in handling culturally related issues. One practitioner mentioned a critical observation that the community that they were serving was rich in cultural beliefs:

> *…. we live in South Africa where we have eleven official languages; there's lots of different cultures, there's lots of different beliefs, I know about beliefs that within my family people might have in terms of you know holding a knife and causing a cliff flip in a pallet in a child or. So there's everybody has their own specific beliefs (HP6)*

Health practitioners, when asked about alternative medication and other forms of medicine that were available to children, seemed to have a very limited understanding of multiple factors. There were also differing views on the use of culturally bound medicine. The following are two differing views in regards to the use of alternatives:

> *So, the praying I don't see any problem unless it's making the parents not believe in the, diagnosis (HP10)*

> *I would not advocate for traditional medicine as a standard form of care because of the lack of scientific evidence research to fall back on, to say this treatment is effective (HP8)*

There were a number of contrasting views that came from health care practitioners regarding the use of alternative modes of treatment by parents. Some practitioners were for the treatment while others were against it. Some stayed neutral and respected the family's position.

5.4.2.6 ETHICS

Children are not autonomous and this means they are unable to make decisions for themselves. The concept of autonomy is complex and challenging as it revolves around the child's developing capacity to consent and is also connected to the mental capacity of a person. The child, like any human being, holds full rights as a person. In South Africa, there has been a rising debate and focus on this topic since the promulgation of the Children's Act 38 of 2005. The convention by the United Nations on the right of the child and the African Charter on the rights and welfare of the child has made some meaningful strides in involving children in making decisions that are affecting them. The emphasis that the Children's Act has made is to provide that a child is a 'right holder' and not an extension or object or property of the parents. Children with ASD often lack speech and some lack theory of mind which some researchers have seen these shortcomings as amounting to disability. The convention on the rights of people with disabilities also advocates that people with disabilities be assisted in making decisions that are beneficial to them. Therefore, the issue of rights of children and people with disabilities is critical in the health care sector and when parents make health decisions for their children with ASD. While the convention on the rights of children and the convention on people with disabilities have shed some light on their involvement in decision making, it is, however, often not clear as to how the concept of autonomy should be applied in real-life situations. In this study, none of the health care professionals who were interviewed mentioned the issue of the child's autonomy.. Surprisingly, most health care professionals were aware that parents in that particular community where the study was conducted were largely consulting other extended family structures regarding issues of treatment decisions and other treatment-related concerns of the child. It, therefore, is assumed that health care professionals approached and understood the autonomy of children with ASD in that particular context as integrated and embedded in the social context and to a large extent shaped by patients' beliefs and cultures (Stefánsdóttir, Björnsdóttir and Stefánsdóttir, 2018). Therefore, the concept of relational autonomy gives parents together with the family, permission to make decisions for their children's treatment and other medical-related care needs. As (Dove *et al.*, 2017) stated, relational autonomy places an individual in networks of others such as family, community and society and these networks or relationships are the key attributes of relational autonomy. It is further stated that permission for parents to make decisions for their children's health is based on the assumption that all parents love and have their children's best interests first (Kling, 2015). While parents may not refuse treatment that the doctor has prescribed, it is a tradition that they first consult other

family members and other networks to discuss the plan of treatment that the doctor presents to others responsible (grandparents and extended family members) for the care of that particular child. The concept of autonomy or the self, according to (Mkhize, 2006), is a western concept. In the African context, the self is communal and requires that a family dialogue is held and reaches a consensus first before a decision about the child's treatment is taken. Often, parents in this study tended to consult the larger structures such as grandparents or the elders to discuss the treatment/ therapy plan of the child with ASD. By so doing and allowing parents to consult the extended family - Mkhize (2006), this is a way of showing respect for the traditions and cultural background of the individuals involved. In this study, medical practitioners were aware of the dimension and the risks that came with involving the 'network' or the larger family structures. While the process of consulting the larger family network and other responsible family members is a cultural practice which amounts to respect, some children end up not going back to hospital to resume their therapy. Others do not make it back to the clinics to take the prescribed medication and to resume the treatment plans that are provided by health practitioners.

Often after a consultation with a health care practitioner, some parents do not return to the hospital for the child's treatment or relevant therapy sessions because of reasons that are not known. It is not always that parents' refusal of treatment is final but there are times when parents refuse the treatment as a delayed method to try an alternative like prayer or to perform other traditional rituals for the child (Linnard-Palmer & Kools, 2005). It is also often difficult to assume whether children who are taken for alternative treatments are completely withdrawn from medical treatments out of fear of being labelled or they are sent to rural areas to be hidden away and live without a purpose or a future. I cannot ignore the fact that there are cases where parents refuse medical treatment for children because of the sincerity they hold for their belief system (religious or traditional). It is difficult to understand what each parent's'true intentions and goals were for their child or the alternative was just another attempt parents explored in search of a 'cure' or remedy. That said, the fundamental question will be: what is the danger of withdrawing a child from taking treatment known to be efficacious in autism and likely to promote the child's wellbeing and possibly optimise the child's future autonomy? It is true thatparents are bound by their familybeliefs system in raising children. As much as respect and the interest of culture is important, is the interest of the child adequately represented when they are withdrawn from taking medical treatment? Often, practitioners rely on the family to make decisions and represent the child's interest but what if these decisions put the child in danger?

What happens when these decisions amount to neglect of the child's wellbeing and put the child in a debilitating state of health? So, for practitioners, does respect for autonomy trump other moral obligations such as beneficence and maleficence? Some of these questions are answered in the next chapter and some are beyond the scope of this project and will be put on hold and recommended for future research.

There is a growing need for health practitioners to understand the meaning of illness in another context that is outside of their known worldviews. Protection of children from harmful religious and traditional interventions remains a critical part of every health care worker. While the respect of culture is an important part of caring for children with ASD. The interest of the child remains the central responsibility of all those involved in the caring for children with autism spectrum disorders.

5.4.2.6.1 Sub Theme: Resisting and Rejecting Therapy

It is common for parents to reject a diagnosis of autism. To most people, autism is a fairly new disorder and its causes are unknown even to researchers. Most parents mentioned that they did not know of ASD until they came to the hospital, some parents mentioned that they only learnt about the disorder after someone had seen their child's behaviour and alerted them that there is a possibility that the child has ASD . So, based on these facts parents/caregivers may still lack understanding and acceptance of the diagnosis because of it being new and uknown still to some. This lack of understanding may be due to the common popular belief from parents and the general public that any form of illness can be cured or treated using medicine or a pill. So, when parents are informed of a disorder like ASD that has no known cure, parents often get into different modes of feelings. Hence, one doctor mentioned that the option of prescribing pills or any form of medication to treat any of the symptoms of ASD is usually the last option that they usually explore. People in general have a different understanding the disorder. One doctor mentioned that parents are in denial of the disorder:

> ……*Rejecting the child's diagnosis in my opinion it is just plain denial and they will give you multiple reasons why the child is not ill, I had a parent where we read to them the literature, they've read literature and he kept saying he's not this, he's not this, he's not and therefore he isn't* (HP3)

The understanding of a disorder differs from one person to the next and from one community to the other. Also, the acceptance process of understanding that the child carries a lifelong

disorder is often disheartening to most parents/caregivers. Also, being told that the child will require intensive therapy to reduce some of the symptoms can be a very hard call to some parents. The literature talks about 'the loss of a healthy child'. All expecting mothers expect a healthy bundle of joy. So, the news of being told that the child may not be typical may cause or induce feelings of a shock to mothers and/or other family members who are involved in the treatment process of the child. The stages of grief include the stage of denial. Parents are allowed to grieve for the loss of their healthy child. The disbelief may confuse and induce many thoughts before the mother comes to terms with the news. During the interview, the doctor mentioned how mothers rationalise the diagnosis by finding different reasons or different explanations of the diagnosis. Some and most of these explanations come from family members, friends and other community structures that the mother is affiliated with. The most common rationale that the doctor mentions was the supernatural explanation of autism:

> *members of the family believe that this is not an illness in the child but for example that the child is bewitched and certain ritual should be done (HP3)*

The doctor explains the process of calming or counselling mothers after a diagnosis had been given. This calming/counselling is done to offer mothers/caregivers solutions and to make them understand the news. It was evident that the context and background of the patient and doctor were different. There was also a notable lack of understanding of the patient's background which is much embedded in traditions and cultural explanations. The doctor mentioned also that when a parent shows signs of resistance towards understanding the diagnosis, the doctor then suggests and directs the patient to content that they could read that may explain the the disorder:

> *I often refer caregivers to literature to go and read more about the disorder (HP3)*

What is good for one patient may not necessarily be good for the other. Each patient is an individual with unique needs, values and beliefs. A one size fits all approach is often not the best approach even in patients who come from the same grouping. Health practitioners must adopt this approach when recommending solutions and treatment options to patients. While the literature is a good recommendation, many other relevant recommendations could be better known to the patient that can better deal with difficulty in accepting a diagnosis. A doctor should do all they can to offer the patient the best out of each situation.

5.4.2.6.2 Sub-Theme Harmful Therapies

Health practitioners indicated that if patients are using any form of alternative, it would be a good practice if that alternative was mentioned to the case manager directly responsible for the child. Interviews confirmed also that certain forms of alternative medication had some potential to harm children:

> *Exposing children to alternatives I think has a potential direct harm, where children are given certain substances (HP3)*

Some practitioners do not completely reject the use of alternatives, however, they mention that possible harms may be reduced if parents or caregivers open up to their doctors about the use of alternatives:

> *I would say I would feel better if it was disclosed to the case manager which in our case would generally be the doctor (HP9)*

One health practitioner emphasised the vulnerability of children with ASD. Exposure to health and harm is dependent on their parents. The child's best interest becomes a critical issue, should a parent decide for the child a choice that will expose the child to harmful situations:

> *Yeah, that's such a hard question because obviously,you'd hope that, the parents would have sort of best interest at heart and a lot of our parents do, and you know it's a child that unfortunately cannot often speak for themselves or you know don't have the ability to necessarily make their choice or their opinion heard, in certain cases so it's a hard question but there definitely I think we should also be part of these people that do advocate for our patients and you know any sort of treating team member should be advocating for those patients, I don't know if there's a sole person that I could say needs to be responsible for that but just knowing that you know I feel that I sort of play my role in advocating for my patients (HP4)*

Therefore, protecting children from harmful therapies, treatments, rituals and other forms of alternatives becomes a big task for all those involved in treating children with ASD.

5.4.2.6.2 SubTheme -Protecting Children from Harm

Concerning protecting children with ASD from possible harms associated with alternative medication , it was clear that while the obvious answer to this would say, parents are the main

responsible party. There is, however, a role that all those involved in treating and caring for children with ASD play. One practitioner mentioned that while the parent can do the role of protecting the child, but without help, this can become very difficult:

> *Parents can give love but without support and resources it will be difficult (HP3)*

Another doctor stated a point that while it is an expected responsibility for the parent to care for the child, this is not usually the case in practice:

> *Yes, we've had parents that do not come back after a diagnosis, so maybe you make the diagnosis or the doctors do make the diagnosis, we give our recommendations and we request for them to be part and follow up intervention programme with us but we've had parents that, say no I'm going to deal with this in my way (HP4)*

So, based on what the health practitioners are mentioning about parents who lack resources and those who abandon the child's planned programme to pursue what they consider the right way, it may also be responsible to look at the protection of children with ASD as a responsibility of a collective rather than it being a responsibility of a single individual:

> *All of us, (are responsible)all of us, not only the parents, aunties but the neighbours with information and understanding that everyone has it, if my child was to see , another child, behave differently rather than mocking and laughing but explain to my child that no don't laugh, it's not funny but with my knowledge I'll be able to explain maybe to a little one at the level that they able to understand that no it's not funny so when the child does this and that, this is how you can help so maybe yes other children living with autism can feel free and not be locked in the house, can be outside be playing with other children or watching them but there needs to be a safe space for them butI think with information and knowledge, if all adults, caregivers from the society if they have that, then they'll be able to better protect our children but now we find that parents are hiding their children because they somehow scared of the next person's thoughts or, or opinions that may come out of their mouth (HP5)*

There are several reasons mentioned supporting the statement that was mentioned by practitioners that protecting children with ASD require a collective effort. Parents and doctors have limited power in addressing the issue of traditional healers who are not fully trained and skilled in their roles, who pose risks of exposing children to harmful solutions and treatment.

5.5 TRADITIONAL HEALERS- THEMES

The following section discusses the data from interviews collected from a focus group discussion with traditional healers. A detailed background of focus group participants and the process by which the discussion was conducted are presented below.

5.5.1 Background and Setting

To access an organisation of reputable and regulated traditional healers, thorough research was conducted through the internet and by word of mouth to locate traditional healers in and around Johannesburg. After coming up with irrelevant and close to no substantial organisations from the internet, I decided to start an intensive word of mouth search from other researchers, colleagues and friends to find out if they knew an organisation that is regulated and working within the space of traditional medicine. There was one organisation around Johannesburg that was later identified which was known for specialising in traditional related healing and medicine. The organisation was well structured in paper and in reality.The gatekeeper then referred us to the relevant people at the organisation in order to introduce this research study. The intention was not to overwhelm the organisation by showing up unannounced since there are always certain protocols and processes followed when communicating with traditional healers, which is why the gatekeeper was asked to give the organisation a background of who we were and the work we were proposing to conduct with the organisation. After the invitation was accepted by the organisation a follow-up appointment to begin the process of data collection was scheduled.

5.5.2 Key Objectives of the data analysis

The main objectives of this study were followed to analyse the data collected with traditional healers that formed part of this section. The engagement and the discussion with traditional healers followed an interview guide drawn with a purpose to answer the main research questions of this project from the main data and the core part of this section. The discussion sought to understand whether traditional healers had previously worked with clients who presented symptoms of ASD and if so, how and what was their treatment approach to treating ASD. The discussion probed further and beyond the interview guide to answer the main research questions and to understand the process followed in the treatment of ASD and also to try and understand some of the ingredients and the process of making some solution that were used and administered to treat children presenting symptoms or meeting criteria of ASD. The

discussion with traditional leaders also sought to understand the ethics, guidelines and other relevant regulations surrounding the process of treating ASD and also to understand whether the process benefited the child or did not. Therefore, the following were the relevant key areas discussed with traditional healers to answer the main objectives of this study.

i. *An understanding of ASD and the relevant treatments available for children* – This section was designed to acquire the understanding of traditional healers in regards to the disorder and the known or followed approaches in treating ASD. Also, the section sought to understand the process of treatment followed by traditional leaders to healing and to compare this information with that followed by other practitioners interviewed in this study (religious and medical doctors).

ii. *The available options of treatment and their meaning to the child* – This section sought to illuminate the available treatment methods in the traditional field to treat ASD. Further to this, the section aimed to connect these options with the value and the meaning they give to the child.

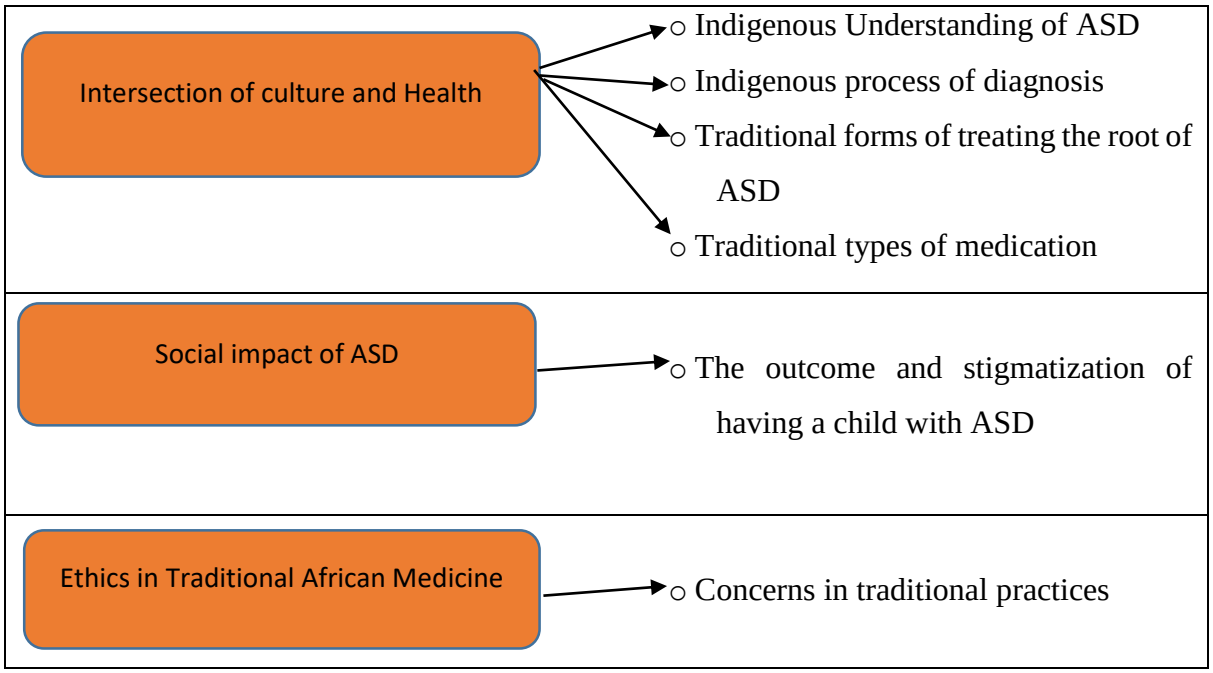
iii. *The views about the dual treatment (traditional and medical) processes available to treat ASD* – This section was designed to understand the traditional healers' views about other forms of treatment that are available to children with ASD and their views, understanding and opinions surrounding the other options.

iv. *The traditional healers' obligation to protect children with ASD* – this section was relevant to all practitioners interviewed. It aimed to navigate the reality that exists in the context of SA, where the majority of people are exposed to a pluralistic approach to treatment. It is important to understand the practitioner's obligation to treat patients and the obligation of means.

The study used a structured interview approach to conduct focus groups with traditional healers. The following questions formed part of the interview guide to collect data from practitioners. The researcher exercised probing techniques where necessary and where practitioners were finding questions difficult to answer.

In total, 3 major themes emerged from the discussion with the traditional healers. The themes were generated for the data and are discussed in the section below. The connection and relations between the themes also forms part of the below discussion.

Table 11: Traditional Healers Themes



5.5.3 FINDINGS TRADITIONAL HEALERS

The discussion of this chapter will be focused on the three major themes from the discussion with traditional healers. Table 11 above illustrates the matrix of the three themes to be discussed in this section:

5.5.3.1 THE INTERSECTION OF CULTURE AND HEALTH

African traditional medicine has long carried the stigma of not being grounded in scientific methods. This stigma has resulted in many polarised views in the health space within the South African health community. Culture and health are closely related when the focus is to understand and improve the health of people. This is sole because people across the globe understand health using different and varying backgrounds and contexts. Quite frankly, this view has brought the understanding that biological wellness is not only the complete measure of health. It was based on this view that George Engel said: “in order to understand the patient better and their suffering, clinicians ought to apply a biological, psychological as well as societal understanding of illness”. His idea was instrumental in driving away from the approach of a biomedical view of illness. Engels’ approach offered a holistic view in understanding the societal part of an illness, which encompasses culture and religion.

Traditional medicine which falls within the societal category of the biopsychosocial approach proposed by Engel has gone through a varying number of misperceptions. Some of these misperceptions include 'the colonial constructions of Africa's' "primitiveness" which still has its traces up until this day (Sobiecki, 2014). The idea of culture does not necessarily refer to rituals and events that are performed in certain ethnic groupings only but culture supersedes ethnicity or other group allegiances. For some, culture is a way of life that has been passed on from generation to another and this falls within the concept of understanding health (Napier, 2015).

The process followed in determining wellbeing in some cultures does not simply end with just consulting the services of a medical doctor. To some, an illness ought to follow a particular protocol and involves a group of people before a person is accepted to be ill or to suffer from an illness. In some cultures, illness does not necessarily equal the absence of health but could have a higher-order meaning that may be understood in the context of that particular culture only. In the case of ASD, a discussion from traditional healers revealed that an illness in the context of South Africa is understood through different lenses. It was also stated that when a person is brought in ill for treatment, a consultation to the higher power was apparent, in this instance, ancestors represented a higher power. The ailment or troubles that a child may be experiencing could not be understood using the biomedical approach only but illness is understood to be a 'sign' that represents a particular message from the other 'world'. Besides the understanding that ASD could be derived from the other world of ancestors, traditional healers also brought in the understanding of witchcraft. They explained witchcraft as an act performed by people with malice intents to harm the other. Thus, it is important to understand that each culture holds a unique method of understanding illness and its conceptual method of illness and health.

5.5.3.1.1 Sub-Theme Traditional Types of Medication

To date, no research has published the efficacy of African Traditional Medicine (TRM) when used in children with ASD. In this research, traditional healers during this discussion mentioned several forms of medicating children that they consult who present with symptoms of ASD.

Among the types or forms of medication mentioned, the following was included: *Imbiza*[11], enema, incense and *Isihlambezo and other herbs*. Imbiza is a traditional herbal solution mixed with special traditional ingredients which include but not limited to roots, leaves, bulbs and rhizomes and other various plants (Mulaudzi, Ndhlala, Kulkarni, Finnie, & Van Staden, 2011), it is often used as a multipurpose remedy and can either be administered orally or using an enema. The instructions of how the Imbiza can be taken are usually a directive from the traditional healer.

> *The child is like that because, It's 'people's things' some of the things, you get what I mean - but then again you (researcher) are also a problem as tomorrow you will become a doctor and tell us: "don't take children and peita (enema) them and futha (steam) them and all that" we do this because we want to see what can help on this child (FGTRL P25)*

The conditions and symptoms of the patient child usually determine the dosage or other forms of administering the Imbiza to the patient. Imbiza has gained medicinal status in many African spaces, however, if administered without caution it may cause poisoning if high dosages are given to the sick (Mahlangeni, Moodley and Jonnalagadda, 2018).

Taking medicine using the enema was the second type of medication that traditional healers mentioned in the discussion. Enema is one of the widely mentioned methods used and an important component in TRM and often used to administer Imbiza.The solution is, then, injected into the rectum. This is a solution mixture of traditional herbs and other ingredients that are mixed by a traditional healer to treat the symptoms of the illness. Traditional healers mentioned that the measurements for children and that of adults are usually different. However, they did not mention any differences in the ingredients or differences of herbs used in the mixture. While there are studies indicating benefits that come with the use of enemas such as improved hygiene conditions in the household with young children, there are also harms that come with this type of therapy such as toxicity that is associated with ingredients that are harmful (Van Andel et al., 2015).

Lastly, the use of incense is common in traditional medicine. This is burnt for different reasons

[11] Imbiza - is a traditional herbal solution mixed with special traditional ingredients which include but not limited to roots, leaves, bulbs and rhizomes and other various plants

but mainly involves necromancy, which is a ritual performed to connect with ancestors. It is also burnt to rid the space of bad spirits. The cleansing process is, often, led by the traditional healer or the elder member of the family after getting instructions from the traditional healer of the process to be followed.

5.5.3.1.2 Sub-Theme Indigenous Process of Diagnosis

Similar to the western form of diagnosis where several procedures are followed, the same is done in the traditional approach. Traditional healers mentioned that the steps in diagnosing or finding out the problem with the child involve consulting the ancestors. This is done by going to *umsamo*[12] to talk to the family's ancestors. *Umsamo* is a sacred or religious house/ section in a room that traditional healers use to connect with the higher power. The process is usually done by burning the incense and pleading with the family's ancestors that they 'calm' down or plead for amends on behalf of the family or those that are involved. It is usually assumed that when things go wrong such as having a child with a disability or ASD, there is something that may have angered the ancestors:

> *The problem is that autism, only white people check it; we don't check it traditionally because if you bring the child with autism to me and I check them by way of traditional, I will find different answers and different causes so, I will not come to you and say it's autism (FGTRL P43-44)*

The understanding of the differences between the two approaches was very clear in the discussion. Traditional healers were specific in their approach to diagnosis which is much different from that of western doctors. They highlighted that medical doctors may diagnose ASD but they are certain that in their consultation with the ancestors, they may come back with just not only ASD but with other issues that may have gone wrong.The problems are often communicated back by the ancestral feedback. One main contrast that they put forward was the consultation of ancestors which is where all answers are often found.

[12] Umsamo - is a sacred or religious house/ section in a room that traditional healers use to connect with the higher power

5.5.3.1.3 Sub-Theme Indigenous Understanding of ASD

There was a very lengthy debate around firstly, the name autism. Traditional healers resisted the name and debated among themselves the name that they thought was context and culture relevant. Most traditional healers mentioned that they have treated children with similar symptoms as those of children with ASD. They were, however, in disagreement with the term autism. In their discussion, they explained several explanations of why the child would have autism. The first explanation was that the mother may give birth to a child with autism because the ancestors are fighting;

> *I mean according to my understanding she's talking about a child that behaves like uhlanya[13] (insanity) right, in IsiZulu if a child can get a mother to say this child is crazy, I don't know what I can do with them. You give the child something they break it, you talk to them they just don't answer you, you teach them something they don't understand. To my understanding, she's talking about something like that (FGTRL P12)*

Traditional healers, in this discussion, define a child who is not responsive when an adult is speaking to them; a child who keeps quiet and does not talk back; a child with behavioral problems and a child who presents anger issues is classified as uhlanya (insanity). Therefore, the term autism, according to them, was not the relevant term to give to the condition of ASD. It was also stated that the term autism favours the western context of illness. They further mentioned that, traditionally, a child with autism could be a result of several traditionally related root causes.

5.5.3.1.4 Sub-Theme Traditional Forms of Treating the root of ASD

The process of treatment begins by understanding the background of the child. This involves consulting the ancestors and verifying that the surname used by the family of the child is the correct one. Traditional healers also consult with ancestors in understanding why the child was given that particular type of illness. The entire process starts and ends with ancestor consultations as opposed to the book as done by allopathic practitioners:

> *Umthombo[14], is the source where the water comes from, it comes from the ground. If you*

[13] Uhlanya- insanity

[14] Umthombo , is the source where the water comes from

do not find and close the source, the water will continue coming out. For you to stop it, you will have to take care of the source first. It's important to know where exactly, in culture the event started from. For example, when a person gives birth to a child who is a cripple. You will find that something had happened in the past that we may not have known about. It is important to follow the source, traditionally. In the end, you will uncover that the great grand parents maybe changed their surnames and this now is creating the problem in the family (FGTRL P28)

Traditional healers believed and emphasised the importance of finding the source of illness through the use of necromacy and other interventions used by traditional medicine which include ukubhula[15]. The act of ukubhula is a diagnostic process which may take different approaches. According to (Sokhela, 1984), twelve different approaches are supernaturally oriented in TRM diagnostic approach. These methods include the use of water, bones, ancestral shade communication, mentally through the assistance of ancestors, using the mirror, foretelling, prediction, laying of hands, visions, dreams ritual dancing and divination through praying.

5.5.3.1.4Sub-Theme Traditional Healing Undermined/mistrust of Western Medicine

There was resistance when asking what type of herbs are usually mixed in the solutions that are prescribed to children. Traditional healers expressed that they were not going to reveal their God-given talent. Also, they mentioned that often doctors come and consult with them and take their ancestral gifts and leave without acknowledging their hard work. This common feeling was a shared feeling among traditional healers. They all stated that they were not prepared to share their ingredients. They stated that there is a vast difference in how they understood illness when compared to medical doctors. Their understanding of illness involved consulting ancestors whereas medical doctors understood illness by consulting books. There was also a huge mistrust of the western forms of medicine such as contraceptives. They stated that these contraceptives that are taken by women are also somehow to blame for having children with autism. So, taking contraceptives interferes with the mother's system and thereby affecting the

[15] Ukubhula - is a diagnostic process which may take different methods. These methods include the use of water, bones, ancestral shade communication, mentally through the assistance of ancestors, using the mirror, foretelling, prediction, laying of hands, visions, dreams ritual dancing and divination through praying.

child's development:

That is why even now we are still fighting it, we are still trying to get the western and African to sit down and see because they come with a mindset that they know but they don't know anything, they come with a mindset of making us blind and use big words, what they do is, they compare a condition, they take a book and look and look and compare with a person from nineteen something who had something like this and that, they don't learn what may have happened for that person to get to that point but that was their way of taking our land right, they took our land, took our gold, took our minerals, it was their way (FGTRL P28)

Traditional healers expressed a lack of belief in western medicine and western doctors. There was also a shared feeling that western doctors undermined the services of traditional healers. There was also fear to go in too deep in unpacking the processes of traditional healing and the ingredients that they use in their medicine. They also stated that people (western) come to them to steal their work and later leave, the term 'people' in this context included the research team because, in their understanding, the research team was also from a university, thus, representing western ideologies.

5.5.3.2 THE SOCIAL IMPACT OF ASD

The stigma associated with ASD is common. It is regarded as a form of disapproval and exclusion from a larger social group when an individual's behaviour goes against the rules of the main group (Whitehead, Carlisle, Watkins & Mason, 2001). Often, social groups see those who are stigmatised as abnormal or even non-human which often justifies discrimination and creates painful experiences for those who are stigmatised. Discrimination may escalate as far as reaching actions such as hostile reactions which can also be justified and seen as normal by those perpetrating stigmatisation. On the other hand, families of those experiencing stigma can be very receptive, supportive and accepting to their family members who are being stigmatised to a large extent. Another study focusing on gender differences and stigmatisation in parents of children with ASD found that mothers experienced greater stigmatisation when compared to their counterparts (Gray& Holden, 1992). Mothers tend to be more involved in the care of children as well as in the public representation of the whole family. It was also noted that the gravity of stigma in mothers has social and emotional impact.

5.5.3.2.1 Sub-Theme The Outcomes of Stigmatisation of having a child with ASD

Most traditional healers discussed the stigma attached to having a child that has a diagnosis of ASD in the family. They attached the stigma to a form of shame attached to the entire family. Also, they mentioned, that some parents are unable to deal with a child with ASD to a point that some young parents they know have ended up abandoning their children, leaving their young to be raised by grandparents or other extended family members. Some mentioned that some children with ASD may be sent to the rural areas where the bigger family takes care of the needs and the upbringing of the child or the child is given chores such as heading the cattle or farming duties. Sometimes, children are hidden from the public and not to be seen because of the shame that is often associated with a child with ASD or even other forms of impairment or disability:

> *…. It happens that the lives of the grandchildren things are not going well when you investigate you find that the problem started a long time ago, maybe it's a question of how did the grandparents of these children get married, nobody knows, when you can try to dig even more you find that or people will tell you in the house that the grandparents of this child have never been married, they were just cohabiting, do you understand. In issues like this, we have to get those elder people married first, it is said that in most instances they are already in their graves. The process will start by just getting them first to pay the lobola[16] and followed by a wedding ceremony. This is done because things are not going well for children, the children are takalanis (abnormal). Nothing will change or improve until we find the truth of the problem, how it started. I am telling you seriously, once you fix such things from there everything becomes well….(FGTRL P16)*

They mentioned that often there may have been some actions that were or were not performed by the living family or the deceased members of the family and may require that the family performs the appeasement ceremony to ensure continued ancestral protection (Sokhela, 1984). Based on the quote above, according to tradition, when the father of the child does not pay *lobola* and not follow certain traditional processes, it is believed that non payment of lobola

[16]Lobola is a Southern African tradition where a groom's family offer cash of cattles as a sign that they welcome the new bride in the family to be a spiritual and physical member.

will anger the ancestors and somehow come back to affect the future generation, hence, there are children in the family that may end up having ASD. Most of these traditional processes, if not followed, are regarded as shameful in the family and create a particular stigma in the family name.

5.5.3.3ETHICS IN TRADITIONAL AFRICAN MEDICINE

The Traditional Health Practitioners Act 22 of 2007 is often criticised for being promulgated with low comprehensive research conducted on the topic of traditional medicine. Some criticism includes limited consultation of relevant stakeholders and key role players in the field of health care. Other concerns include the safety, quality and efficacy of traditional medicine in patients has been raised continuously. The Act provides clear guidelines and descriptions of the different kinds of traditional healers and how they should be differentiated, accordingly. However, it has been criticised for how little the issue of regulation of traditional healing should be conducted and the process to be followed.

5.5.3.3.1Sub-Theme Ethical Concerns in Traditional Practices

Several ethical concerns came up during the discussions with traditional healers. The first was a discussion around the unstandardised training process followed in traditional healing. While this procees ought to be monitored as per the Act, in many instances this process is often unmonitored or unregulated by any particular board or any regulating council. This, therefore, gives rise to false traditional healers. Those that are untrained leave room for possible harm and malpractices, which could be detrimental to children. Traditional practitioners had a very strong debate around the training of some of the other fellow diviners (sangomas) and healers in the traditional space;

> *…. with traditional healers, some are there today and gone tomorrow they've started these fly-by-night practices, just like there are also bogus doctors, there are also bogus traditional healers too. If you can find bogus practitioners here and also in the western it is there….(FGTRL P47)*

One traditional leader alluded that within the focus group, there may have been untrained

healers. It was mentioned that as much as they are all registered under the same organisation, at the time, there were no proper checks done to confirm the background training of each practitioners that was registered in the organisation. During the focus group discussion, an angry diviner wanted to test his point that some of them in the focus group were not trained, he asked the group a question about the ingredients that are used in making one of the known Isihlambezo[17] (drinkable solution),which was supposed to be basic and known by all diviners:

> *but this one doesn't know, they only heard that it's Isihlambezo, they don't know whether it's the one to strengthen the womb after miscarriage or what? so we are talking about something different. There is Isihlambezo that is used for the baby in the womb to move, it's different, when you drink that thing you must feel the reaction. Some, you can't give a person because it could make a child hyperactive. Some of the Isihlambezo that the child makes the child move in the womb this means you are forcing them to move because you have given the mother Isihlambezo, the baby keeps on rolling and can get to a point where it ties itself with the umbilical cord to point the baby dies because It was given Isihlambezo that stimulates the baby to spin and move in the womb (FGTRL P14)*

The question did not go well with other diviners in the group and the organisation leader had to intervene since the debate was derailing our progress and becoming unfocused than what it was meant to be. Therefore, the matter of regulating the traditional medicine industry is an ongoing matter at all levels including among others the traditional healers themselves. They agree that it is a pertinent and critical matter that needs addressing.

5.6 RELIGIOUS LEADERS -THEMES

This section presents and discusses the results from the religious leaders' perspective on religion and healing with a specific focus on children with ASD. All themes are detailed in this section below.

5.6.1 Background and Setting

[17] Isihlambezo - is a herbal drinkable solution used by many African women as a preventative health tonic commonly used during pregnancy

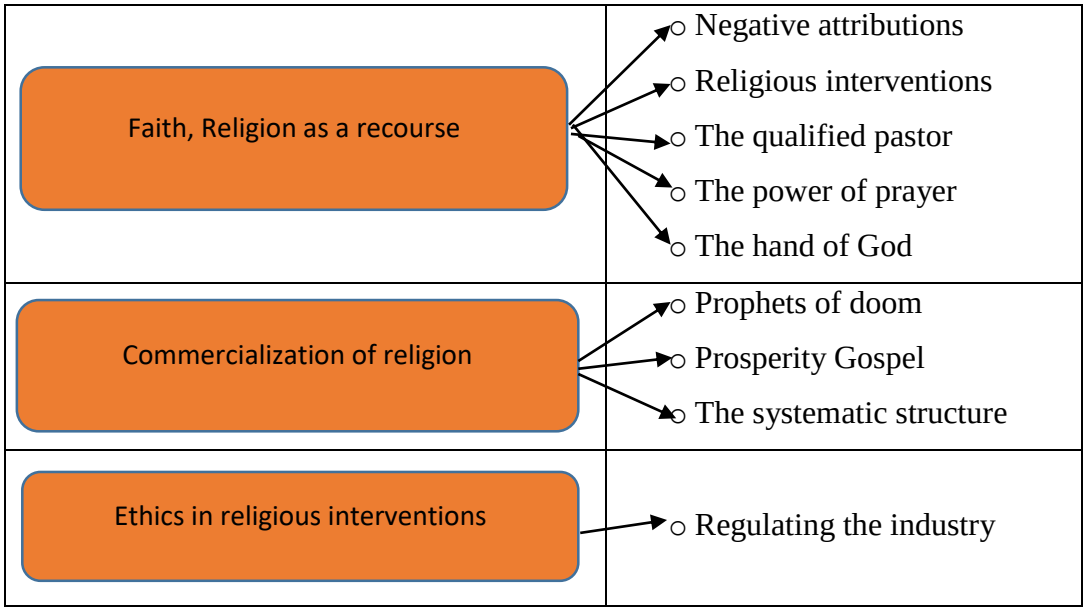
There are several religious organisations in South Africa. Identifying an organisation that was relevant and would represent the criteria required for this study was very difficult. After searching for organisations on the internet an interfaith organisation that was registered and working in Gauteng was identified.. Members of the organisation were all trained religious leaders in their respective spaces and were active reverends, pastors and prophets. The scope of religion for the organisation did not only end with Christianity but also incorporated other religious groups such as the Islam and Hindi.

A formal written request was sent via email to the PA of the Director to conduct a focus group in the organisation with members of the organisation. The feedback from the director was positive, however, one request that was communicated was that we would need to provide them with more details on ASD before commencing with the discussion. The director also stated that ASD was a new name to most of them and they were happy to journey with us in this research project since it brought an educational element to the members.

5.6.2 FINDINGS FROM RELIGIOUS LEADERS

The discussion of this chapter focused on the three major themes from the discussion with religious leaders. Table 13 below outlines the themes that emerged from the analysis of the data.

Table 12:Religious Leaders Themes



Below is a discussion of all major themes and sub-themes as emerged from the analysis of the data from the focus group discussion with religious healers.

5.6.2.1 FAITH, RELIGION AS A RECOURSE

Religious leaders, in this study, spoke confidently about religion and the role it plays in people's lives in general as well as in the health of the people. While they all acknowledged the existence and the beliefs of African people and their pluralistic approach in religion, they still believed that the power of God was superior to all other options and alternatives available to children with ASD. In as much as religious leaders spoke with such conviction, the space of religion, generally, is not without its flaws of phony religious healers who are known through media and in general..

Religious leaders explained that the power of God is beyond what a layperson could understand. They also made some connections of illness with human sin and some connections of illness being a consequence of disobedience which can be linked to some biblical scriptures. They also made an association of illness as a particular form of punishment that God has imposed on the family or the parents of the child through the child's condition.Some of these explanations echo the writing in the article entitled 'Health and healing in the bible' (Simundson, 1984). Further, the discussion explained illness, including ASD as a form of God showing or reminding his people that he is God. Simundson calls it a 'warning to those who contemplate flouting God' (1984).While the correlation of illness was made with punishment from God, religious leaders did not per se mean that a child with ASD was a punishment. Their explanation was generalized to all illnesses that lacked explanation scientifically and also traditionally. This association in their understanding was Gods revelation of his power to the family and Gods power manifesting as a particular condition within a person.

Prayer healing formed part of the discussion with the group and it was said to be one of the options that parents could explore to heal the child with ASD. While there was no religious person within the group who came forward to have had previously healed any of the children with symptoms of ASD, there was, however, one religious leader who mentioned that his senior (meaning a Bishop or a senior pastor at church) has once done prayer healing on a child who

presented some of the symptoms of ASD and the child now is improving in his condition. Some researchers place prayer healing in the category of complementary and alternative medicine (Easthope, 1998). It is not to open a new discussion about some of the issues of CAM in ASD and lack of laboratory testing; the efficacy of prayer healing also lacks such testing to confirm its efficacy on children with ASD. Also, some parents' beliefs and level of religiosity go beyond a layperson and in such instances, may be harmful to children. Most religious healers explain the process that is followed when healing a person. Some people approach religious leaders with a particular problem but in some instances, the healer will know the person's problem even before the person approaches them. This notion is in line with the work conducted on the topic of prayer healing in Iran. Some healers asked that the patient explains to them the nature of their problem but at times the healer is not told but internally knows the patient's problem and becomes the one who tells the patient the problem and its source and how the healing should take place (Javaheri, 2006).

5.6.2.1.1 Sub-Theme Negative Attributions to ASD

Religious leaders mentioned several attributions to ASD. They first mentioned the work of the devil. They explained that the devil may bring about a child with ASD to the family. They also stated that the devil uses anything to destroy any good situation. In the context of this discussion, destruction in the family may come about in a form of ASD and they explained this as the work of the devil:

> *He reveals Himself through the child or the parents or society as a whole. Yes, society as a whole so that when a child presents these symptoms or illness, you see this child is like this, then everyone will know and understand, that Jehovah, has to be glorified. let me tell you something, how can I put it, Pharaoh didn't do anything to God, Pharaoh, read the Bible carefully, he didn't have to do anything to God, he had the gods that he worshiped, you understand, but because God was angry with him that he doesn't worship Him Instead Pharaoh worshiped his other Gods. God took Israel and put them in Egypt so that He can punish Pharaoh. So, some other things, Jehovah does them for His revelation, so that one understands when they say something is a will of God when you pray for that person to God in front of a crowd, that person will be healed instantly if we say it's the will of God but if it's not the will of God then you will see the manifestation*

of that person (FGRL P32)

There are people God has intentionally put there so that He can display that He is capable of healing them, you understand, so when the pastors say it's the will of God, yes some of the things are a will of God for him to display himself and to bring about a revelation but some other things it's, it's a person's will who bewitches the other because maybe they have a problem. Others it's a will of the devil because he can, you can understand that in the spheres of contact, I the realms we've got three voices, it's the voice of yourself, the voice of the devil and the voice of God non otherwise, you understand, so you need to understand that when you talk about will, the holy spirit has a will, the father has a will, Jesus has a will, the devil has a will, people have a will, you understand (FGRL P32)

Because we live in a supernatural world, several things can bring about a child with ASD. They also mentioned the will of the people meaning that people can and may through their dark ways bewitch a pregnant mother and the child gets ASD.

5.6.2.2 Sub-Themes Religious Interventions

Religious leaders explained that several religious interventions are available in the event a child with ASD is presented to them. They stated that the power of God and the calling bestowed upon religious leaders by God is the reason why they can help people. They use deliverance and prayer to work God's miracles. They also mentioned God's grace as available to all those who believe in him. Therefore, through prayer and deliverance, some religious leaders believed it was possible for an anointed person to perfom miracles because they have been called by God to cure any form of illness and disease. They stated that God is also able to guide them to see the cause of the problem with the child and how the child is to be helped or the solution to the child's problem.

I only have faith that I'm going to bring a solution through God. So, when you bring the child to me, what do you want? You want a solution, right? If it is a spiritual matter, God is a God of order, he has an order, he talks at the same time. If it is a spiritual matter I

would tell you that you know what there is this thing that is happening it's the thing of the genes, the holy spirit once showed me that no this person is like this because the one in the family, the grandmother who passed on had the same problem, (FGRL P24)

The process is mostly centred around God's guidance from the beginning of the process of healing until the end of the process. Mostly, they believe that God somehow communicates to them a way forward in helping the child.

5.6.2.3Sub Theme-The Power of Prayer

Religious leaders explained the power of prayer. They stated that God gives them the power to heal and to help people through prayer. The power of God to most leaders is that they can do things that no ordinary person can do:

with faith everything is curable, the breach of faith allows us to use the power of God, not our power but the power of God to influence a change in somebody. So when I say a cure it's nothing that you can touch with your hands, it's nothing tangible (FGRL P23*)*

Religious leaders also stated that not all those who call themselves healers can heal or cure. They mention that each religious leader has a different prayer gift. Not all prayers can cure because of the person that is praying. A person needs to be in the right and good standing with God before they could pray for others;

there's a gift in a discerning miracle, tongues, faith, word of wisdom, word of knowledge, prophecy, discerning interpretation of tongues you know there are many gifts, you understand, so you take somebody who's got the gift of tongues, the use of the one with the gift of tongues is somebody who likes prayer, we can say intercessor, who has a gift of tongues, who knows to speak in different tongues, this person actually what they have is information (FGRL P30)

The issue of specialisation was also discussed. They mentioned that religious leaders are gifted in different forms. It is not always the case that one finds a religious healer who is gifted in all aspects. This was a very important point that was shared during the discussion. However, parents were not aware that religious leaders specialise in different aspects and not all of them

are gifted to heal people.

5.6.2.4 Sub Theme the Hand of God is Powerful

There was an agreement among the participants about the power and in the hand of God. They stated different reasons which signified that there is power in prayer and God. They mentioned that having a child could communicate different messages from God. For instance, they mentioned that God can, through his power, force a person to leave his bad ways and follow the righteous path by giving a child ASD. So, they mention that a child may not have done anything wrong but just God communicating or forcing a person to do what God wants them to do:

> *There are people God has intentionally put in a particular situation so that He can display to them that He is capable of healing them, so when the pastors say it's the will of God, yes some of the things are a will of God for him to display himself and to bring about a revelation (FGRL P32)*

Also, it was said that the disorder is somewhat the *means to an end,* the means being a child with ASD and the end being the realisation by the parent about the power of God. There was another perspective that they discussed that also explained the hand of God and its power. They said that ASD could also be a way God delivers a message to people about a particular situation which may be good or bad. This means that instead of God giving parents a healthy child he reveals himself through giving them a child with some form of impairment; They say the child is a vehicle by which God communicates with people and not necessarily that the child is at fault but a child is a sign of Gods miracles.

> *So, you find that it's not the child's fault, it's the parent's fault and as a prophet you can be able, if you are a real man of God to see that the problem is with the parent, God is looking at the parent, to be good and then everything and children will be good (FGRL P36)*

God's power could be in different forms; they also stated that having a child with ASD could mean that parents are being tested or paying their fair share of trials and tribulations from God.

> *you can explain to the mother that it's not like there is something that the mother has*

done or the child has done, …. maybe God is testing you through the child and God wants you to be …sometimes they say God can punish the children because of the parents and the parents because of the children (FGRL P35)

There are several reasons that religious leaders discussed as a reason for having a child with a disorder like ASD. The reasons ranged from God showing his power to those that says God is reveling himself in a different form. A variety of these reasons were interesting and very contrasting and needed further depth in understanding. However a clear message from traditional leaders was that the child is by no means at fault but the environment may be the reason why the child acquired the condition. They explain the environmental factors using the religious lense applying the notion of God and his power over people.

5.6.2.5 Sub Themes-The Qualified Pastor

The group spoke about the qualification of a healer. The healing space, according to the discussion, is not just for any person who prays but as discussed, it is for the righteous and the gifted only:

It is mentioned there's a gift in a discerning miracle, tongues, faith, word of wisdom, word of knowledge, prophecy, discerning interpretation of tongues you know there are many gifts, you understand…. (FGRL P30)

It was also stated that prayers are different; some can reach and get God's attention and others just stay here on earth and not go where they are intended to go and to reach.

……you understand but this person doesn't function in healing, doesn't function in deliverance, is not called for that, so you can bring your child, they take the child to a pastor, the pastor prays for the child and it becomes like God doesn't hear, only that the problem is not that God doesn't hear, God heard the prayer alright but the person that is not their platform (FGRL P30)

The discussion clearly outlined the different qualifications that religious healers are supposed to have and it explained why some people may pray and nothing happens and others pray and

something happens. When nothing happens, the person praying may be likely to be not gifted in the healing space and maybe gifted in other religious specialisations.

5.6.2.2 COMMERCIALIZATION OF RELIGION

The body of literature defines commercialisation in various ways and approaches. There is a large body of work in sociology that has been done to understand the concept of commercialising religion. This part of the discussion is pertinent to this literature because most parents, practitioners and participants mentioned money and religion. Though their understanding may not be philosophical or academic they are much aware or affected by this commodification of religion. Some religious leaders mentioned the growing culture of folk religion and making religion a profession. This section is not to criticise the space of religion; I tread carefully to offer my views in a topic where even 'angels are afraid to thread'. However, the space of ASD is a fertile ground for folk medicine and in this study, there are small traces that even the space of religion as an intervention is not so sacred as one would have expected.(Agboadannon and Dossoumou, 2018) speak about the concept of 'new prophets whom they associate with poverty. They mention that the 'new prophets' are now everywhere, marketing themselves on television, flyers and even radio stations. Agboadanon and Dossoumou (2018) further state that Africa, as a continent, has the largest number of fake prophets who claim to heal and offer overnight miracles and claim to improve people's lives. There are so many reasons why parents of children with ASD may be conned and coerced into believing overnight healing by prophets in search of a cure for the child with ASD.

5.6.2.2.1 Sub Themes Prophets of Doom

The religious space is not holier than thou space; it is not without its scandals and its hoax and pretentious pastors. The healers agreed that many prophets are false and are praying on people's desperate problems. Some claim to cure diseases on national TV for different reasons. Some pastors have even gone to spray people with detergents and pesticides for popularity and glory.

> *I want to come with practical things, I was with Pastor MR on TV the other day and he was claiming to cute TB, I'm saying this because it was on TV so it's a public platform is not a secret and they wanted to confirm that Pastor MR cured the baby's TB the child*

was in ICU. I refused, I said TB is curable after six months (FGRL P47)

Religious leaders also stated that the congregants themselves could have an impact on how the pastor sees himself. They could overrate his gift and make the pastor the person that he did not plan to become. They called this process the 'crowd agenda'.

5.6.2.2.2 Sub Theme-The Systematic Structure

Religious healers stated several points that they found to be of concern and that could taint the religious space. These points may also lead to questions of morality and virtue in the religious space. The over-commercialisation of churches was one of the points that were concerning to pastors. They also stated that the congregants have a way of thinking that drives glory and is rooted in materialism:

The church people will design a new pastor when they see that this man preaches better, then start to make them a prophet and yet they arrived there as a mentor or a son of the main pastor, to learn. But people change you and make you something else to a point that you end up break away from my main church, run away from the main pastor who was training you and make a shack somewhere and those who like bitter things will come to you.Because they have designed you to become this thing of which ordinarily you were never meant to be that. But because there is money involved and they will also buy you a car and choose you a wife and all that (FGRL P41)

They mentioned that congregants themselves are more attracted when are presented with things that require them to pay money. By paying, they have this belief that the prayer is authentic and will yield results.

5.6.2.2.3 Sub Themes Prosperity Gospel

It was stated that Black Africans believe in miracles and instant outcomes. When a parent receives the news of ASD, they may get into a shock mode and be driven by the desire to find help for the child. It is possible that most parents may get themselves in situations where they find themselves in search of miracles and instant solutions that will help their child.

You see, so it depends on whether that person is seeing progress because black people

believe in miracles or instant things , instant change,this means that the person will come, maybe the pastor would pray for them then they would tell them no this one is not an instant thing, it will take time, they will think that maybe I want something from them because right now the Bible says something but now pastors they do the opposite. The Bible says freely you received, the gift of God is not an achievement, nobody works for it (FGRL P 44)

Religious leaders also mention that parents come to them wanting miraculous solutions for whatever condition they may be experiencing. They also mention that parents get into a state of denial, even, when they are told that the condition may not be treated instantaneously.They will not take the explanation because they expect some form of magic from the religious person.

5.6.2.3 ETHICS IN RELIGIOUS INTERVENTIONS

Since this study is not a theology project, it will not delve deeper into the history of the church and the councils that regulate this space. It, however, will look and be guided by the objectives of this project which seek to understand the ethical components of two interventions that are regarded to form part of the alternatives that parents of children with ASD use in their endeavours to help their children diagnosed with ASD. One of the interventions that this study focused on was the use of religious interventions as a treatment method or option chosen by parents to assist in the care of their children. Most religious leaders interviewed in the study were largely from the Pentecostal denominations since they have become largely common and popular in South Africa. Pentecostalism has developed to be known and focused largely on the prosperity gospel. Some are driven by popular culture. Pentecostals believe that it is God's will for those who believe to enjoy riches, good health and prosperity (Coleman, 2000; Ukah, 2005). Conventional Christian denominations have been replaced by the rise of Pentecostalism which has mushroomed in almost every corner of the country so much that one can even find a welcome greeting,'Holy Spirit Power,' even when boarding a public service bus (Haynes, Bialecki, Coleman, Daswani, Kaunda, Tomlinson & Haynes, 2020).Some researchers further state, what often makes Pentecostal churches more popular compared to the unconventional denominations in society is their claim of having the ability to combat forces of witchcraft (Newell, 2007). The article by Newell further argues an important point that sits relevant in this research. He argues that Pentecostal churches may be caught unintentionally by this

unknown process of attempting to understand this force or power that creates a link between witchcraft, illness, misfortune, prosperity and the capacity to heal. He says this might just be the new form of witchcraft discourse in itself. In this period that we are facing of popular culture, the need for ministerial ethics becomes imminent and urgent. Ministerial integrity and morality ought to be automatic, however, as (Trull, & Carter, 1993) state, this is neither simple nor automatic. The authors further refer to Ministerial work as a Profession stating that this 'profession' is also guided by certain ethics. The book emphasises that the use of the bible to make moral choices and the correct interpretation of the bible is important.

5.6.2.2.1 Sub Theme Regulating the Industry

It was stated that the religious space needs regulation to clear out of false prophets. They also mentioned that a lack of regulation of religion may be the reason why there is a rise of prophets who use detergents and other substances. While they stated that it is often difficult to change a person's belief system, they warn congregants and the general public about false prophets:

> *…. it's just that we need to make awareness to people you see, that there are pastors who can maybe do dangerous things on a person but to say to a person they must stop is just like leading a horse to a river, you see you cannot force the horse to drink the water (FGRL P 43)*

Also, they suggested the creation of structures that will inspect and address the rising culture of false prophets. The involvement of the government was another point that was discussed during the discussions. The government can play a role in intervening in the issue of false prophets that are on the rise in the religious spaces. They also mentioned the role that council of churches can take in the regulation of religion and in protecting vulnerable people who continue to seek a cure or a solution for ASD and other challenges that they may encounter in their lives.

5.7 Concluding Remarks

This chapter contained the main finding of the empirical component of this study which was a combination of interviews from parents of children diagnosed with ASD, practitioners

employed and working with children diagnosed with ASD, religious leaders in the Johannesburg area and traditional healers that are based in different locations of the City of Johannesburg. This chapter, provided details of the findings with relevant quotes that were extracted from transcribed discussions with all participants. All verbatim quotes provided the reader with the key points and thesis information that would provide the reader with better understanding, trustworthiness and the reliability of the process followed in analysing the data thematically. The chapter also provided figures and tables that assisted in processing the findings of the project. This empirical chapter was designed to assist the reader with a guide that will support in understanding the next normative chapter which will synthesise this work and conclude the argument.

CHAPTER 6: SYNTHESIS OF FINDINGS

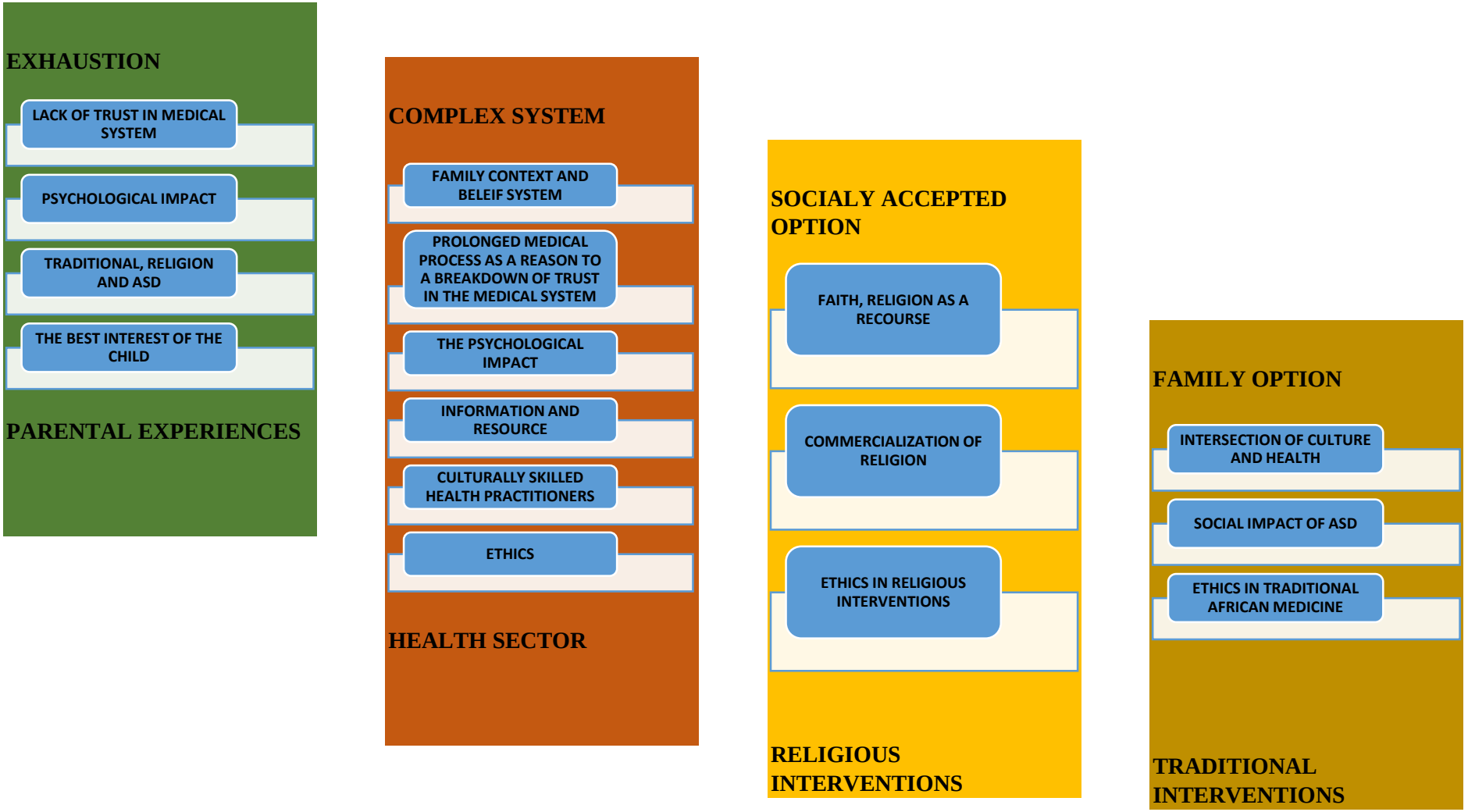
6.1 Introduction

The previous chapters provided a detailed analysis of this research by looking at the four different cohorts which formed part of the emperical component in this study namely: parents, health practitioners, traditional healers and religious leaders. The four groups were identified as part of the study in order to better understand ethical obligations that arise from the effects of cultural and religious treatments and beliefs on the wellbeing of children with ASD. Then, this current chapter provides a synthesis of the findings of the literature. It discusses the findings as presented in Chapter four and where applicable, links the literature to the research objectives and the theoretical framework underpinning this research study. Thus, this chapter presents an in-depth description of the mentioned interventions that parents used in their continuous struggles of helping their children with ASD. It highlights the parents' contributions and possible harm to children with ASD.

This chapter will be structured based on the following topics. In this section, a discussion of of the main findings of the study from each group of participants is seen below followed by a comparison of the relationship between findings and the main objectives of this project.

Then, the chapter further looked at the description of the previously mentioned interventions used by parents in their journey to assist their children with ASD and highlight the known benefits and harm that are possible when children are exposed to such interventions. In addition, a detailed discussion of harms and benefits used as alternatives to treat children are provided below. Later, the chapter engaged with the understanding some of the differences in the diagnostic processes of ASD and the treatment methods available for the disorder. Lastly, the chapter discussed the possible collaboration of the three approaches to healing that exist and their benefits to children with ASD.

Table 13: Synthesis of Study Findings



6.2. Brief discussion of findings – Parents

It was seen from the previous chapters that there was a sense of low trust levels from the parents towards the medical system. It was therefore important to determine whether the low levels of trust are related to health practitioners imposing authority on patients or other factors that may be creating this. As previously understood, the South African context is rich in diversity of culture, race, language, religion and ethnicity. It is thus important to draw from the understanding that cultural relativism ought to be central in research of this nature where diversity of language and culture is apparent. As previously mentioned in the method section, the research followed a non judgemental approach in order to understand some of the key critical factors that are key in this study and that are central in answering the research questions of the study.

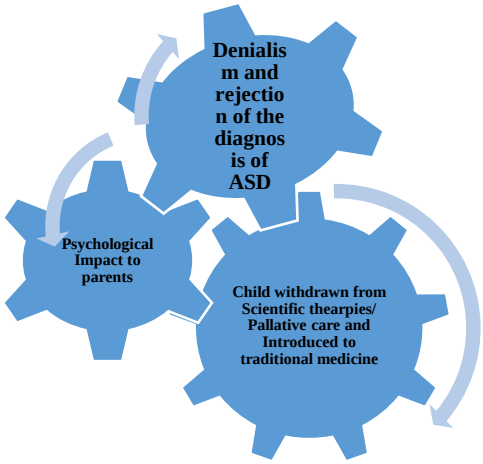
This diversity presents a number of challenges in the country's health care system. The concept of Ubuntu which translates *I am because we are* has a huge role in bringing about compassion and foster a relationship between patients and health care practitioners. Parents bring in their world views when approaching the illness of their children, these worldviews are often informed by their religious background or cultural beliefs. On the other hand, health care practitioners have their world views, and this may influence the decisions they take in the treatment of their patients. These different world views of doctor-patient often do not converge and this creates misalignment between the patient and the practitioner and may lead to a breakdown of trust.

Often, Several concepts are mentioned when defining the concept of trust in medical care. In their study, (Davies & Rundall, 2000) they group seven concepts and call them 'collective expectations', these are the concepts that patients hold as expected from the medical service system. Firstly, Davies and Rundall mentions the concepts of knowledge of the health practitioner, which relates to the in-depth understanding of the condition presented by the patient (2000). Regularly, a diagnosis of ASD takes long to obtain due to many reasons that include the issue of putting a label onto the child and a lack of resources as previously mentioned in earlier chapters of this study that SA is under-resourced in health care. Therefore, a delayed diagnosis in many patients may incite several feelings and emotions and later lead the patient to take matters in their own hands. Some parents may interpret delays as a lack of knowledge from medical practitioners, which may result in many patients giving up on the health system some removing children completely from the system and resort to seeking

alternative forms of treatments. Further, the article speaks about several other concepts such as skills, competence, fairness and behaviour as true agents (best interest of patients), beneficence and integrity (Davies & Rundall, 2000). While all these concepts are important, parents were dissatisfaction from the public health medical system, some of the reasons were that some parents felt that the health practitioner team may have been unable to meet their expectations , hence they opted for other treatment methods.

Some parents have experienced a series of psychological challenges during the creation phase while finding their way into the medical system. Some of these challenges stem from the public having limited understanding or no information regarding the treatments of a child with ASD. As a result, parents get into an anxious or depressed state or having feelings of not being fully supported by those around them. In some cases, parents experience denialism because of shock, loss and shattered hopes from receiving a diagnosis. Some rejected and denied a diagnosis based on understanding that their child may be faced with the possibility of some impairments or that the child may be fully dependant on them for all their lives. This denialism lead some parents to a desperate and helpless state and they began to explore avenues that may provide them with hope, a substantial explanation of the child's condition or some relief from distress. This type of denialism as stated from some interviews resulted in parents delaying the help seeking process for children. When children receive medical treatment programmes as mentioned in Chapter 2, they are in a good position of improving some of the symptoms of ASD such as speech and receiving medication for some of the stereotypical challenges. The downside of delaying medical treatment and early interventions is that some of the symptoms may no longer be reversed if the delayed treatment period is longer and this could be harmful or damaging to the child. Figure 3 below presents the process and impact of parental psychological impact and its trickle-down impact on the health of the child.

Figure 8:Denialism and its Impact on the child with ASD



In this study, most parents used religion and traditional medicine as alternative treatments for children with ASD. Previous studies have mentioned many risks and harms that are associated with the use of traditional and other dangerous religious interventions. Tabel 14 below presents some of the alternatives used by parents in this current study.

Table 14: Description of Traditional and Religious Treatment opted for parents in Treating ASD in Children mentioned in the study

INHALING	DRINKABLES	RECTUM INSERTIONS	CONNECTING WITH THE SPIRITUAL WORLD	OTHER TRADITIONAL PRACTICES
➢ Incense ➢ Burning of Substances or other animal-related objects	➢ Solutions and Concoctions ➢ Imbiza	➢ Enema	➢ Calling of Ancestors ➢ Prayers ➢ Graveyard Visits ➢ Rituals/ Amasiko	➢ Oils ➢ Holy Water ➢ Ropes ➢ Cuts, Marks (Incisions)

Some of the listed treatments have been discussed in the literature as options that could be harmful and have potential for harming people. Many studies have provided evidence against the use of some traditional medicine stating that they may cause injuries or even result in a fatality (Popat *et al.*, 2001). In this current study, many parents mentioned the use of enema. There is a body of literature stating some of the dangers that are associated with the use of

enemas in children with ASD (Van Andel, Van Onselen, Myren, Towns & Quiroz, 2015). Additionally, these studies state that the use of some ingestibles may lead to preventable deaths. While there are benefits in using traditionally related interventions, the harms outweighed the known benefits. So, it was evident from the discussions that there is still a very large gap and the need to close the widening bridge between western and traditional approaches to health. Certainly, parents are consulting traditional healers for their children with ASD but this information is often withheld from medical doctors. Since the harm associated with the use of traditional interventions has been noted in the past and this study has revealed that parents are, indeed, consulting traditional forms of healing in children with ASD, there is, therefore, a need to create awareness to parents about the choices they make in treating children with ASD (Popat *et al.*, 2001). A more detailed description of the mentioned interventions from parents will be discussed later in this chapter.

6.3 Brief discussion of findings - Health Professionals

The main themes that emerged from the discussion with health professionals included developing strategies that will be ideal enough to approach a treatment plan for the child, and that is embedded in therapy and applies the pill as the last resort (No pill approach). Another central part of the findings included empowering and educating parents and health practitioners likewise in helping parents of children with ASD.

A more common and critical concern was that medical doctors were sceptical of forging a working relationship with other alternative approaches since there are no proper regulations in place that regulate many traditional alternatives available in SA.

In light of the fact that South Africa is a diverse nation and as a result of its diversity people in the country interpret health and illness in different ways and forms. The country's medical belief system anchors on religion such as Christianity, Islam, Traditional African religions, Judaism and Hinduism to name a few.

Most parents of children with ASD attend public health institutions and are faced with several challenges daily when it comes to treating their children with ASD. Over the years, there has been an increase in asylum seekers and migrants from other African countries looking for better opportunities in SA, this has increased the number of people residing in urban areas. Some of these asylum seekers are parents of children with ASD. In the discussion with these parents,

they mentioned that they come from far and wide in the search for a treatment for their children with ASD. Resultantly, this strains the health sector (Matthews and Van Wyk, 2018).

In 2018, the then Minister of Health Aaron Motsoaledi mentioned this in his controversial speech, which was later attacked as being somewhat borderline xenophobic. The speech was delivered at the nurses' summit; the minister stated that the health system is under serious strain from illegal migrants who overburden the country's clinics and hospitals (Heleta, 2018). There are, however, contrasting views regarding immigrants and the health care system. Poor management has been one of the many reasons mentioned by others for the failing public health services (Heleta, 2018). Baragwanath hospital, which is situated in one of the most popular and historic townships in SA, is home to approximately 1.2 million people and about 355 000 households. The hospital is under strain from several challenges such as lack of staff, not enough beds, lack of specialists and wards that look after mentally challenged patients are neglected and poorly managed (Census, 2011, n.d.; News 24, 2019). Baragwanath hospital is known for being a flagship hospital in SA but that being said, the hospital is said to be crumbling because of poor management and governance (News 24, 2019).

Most patients at Baragwanath hospital are black and are mostly from Soweto and other nearby areas. The locations and the type of patients that visit Baragwanath hospital is bound to cause cross-cultural challenges for healthcare practitioners working in the hospital. The first striking barrier that was also visible during the data collection process was the issue of language. Most patients spoke African languages and were not confident in conversing in English. The opposite was the case with health care practitioners; most were English speakers and a minority were able to converse in African languages. It is also worth mentioning that those who were able to communicate with patients in African languages were trained in the western biomedical approach to health. Medical practitioners who understand diverse cultures do not necessarily qualify to be called competent because based on the article by (Kumagai and Lypson, 2009), this translates to medicine being at the core of socio-historical context. The article further states that when a medical practitioner understands different contexts and diverse backgrounds they are offering the highest quality of medical care regardless of the individual's background such as race, gender and social status. In this study, it was evident that health care staff had a different worldview to that of patients and their understanding of illness was different from that of their patients. While the health care staff were aware of the common factor of consulting alternative forms of treatments or patients using a dual system of care, there were very few health care workers who took time to navigate the meaning why most patients were almost all

inclined to use of a dual system. understandably, this may be because of the issues of lack of resources and that staff were overstretched with responsibilities as a result they could not engage and understand better their patients. The misalignments between a practitioner and a patient may create several communication issues. Regardless of language and cultural issues, patients want to be understood beyond the obvious issues. When this understanding is absent, many challenges may occur such as the patient losing interest and losing trust in the medical system, thus, opting for the system that could make them comfortable, understood and that provided them with a sense of belonging. Issues of culture are, thus, critical and may determine health outcomes; when patients are dissatisfied, they are likely to develop psychological morbidity.

6.4 Brief discussion of findings - Traditional Healers

There were important themes discussed which emerged from the discussion with traditional healers working with children diagnosed with ASD. Traditional healers rejected the western form of approach as undermining their traditional approach to treatment. Also, they agreed on the important point of standardising and regulating the traditional healing industry to protect children against the dangers of being exposed to untrained and unregistered healers.

The collaboration between allopathic doctors and traditional healers did not seem to be an option that was considered or even possible for traditional healers. There was a concern from traditional healers that they did not trust allopathic doctors because they do not respect their work and knowledge. In this study, the findings are in line with (Sorsdahl, Stein and Flisher, 2010) where they found that traditional healers felt that allopathic doctors do not treat traditional healers with the respect they deserve. Besides, there was a sense that medical doctors and other scientific groups such as researchers wanted to steal their known secrets and God-given gifts and healing talents. Widely, the traditional healing industry is accepted by Africans as an alternative to medical treatment. The majority of patients consulted at least with one or more traditional healers for the child's condition. Some striking findings from traditional healers in this study were that there was no known term for Autism Spectrum Disorders used by Traditional healers. Secondly, there was and still no standard manual used for diagnosis. Thirdly, there is no consistent regulating board that regulates the Industry of Traditional Medicine. Fourthly, there is no transparency of the ingredients used in traditional medicine given to patients, treatment dosages have no standardised measurements and guidelines and

dosages for children and adults may be the same depending on the traditional healer's assessment.

6.4.1 No Known African term for ASD

The above points regarding the status of traditional healers and religious leaders who engage in dangerous healing practices are concerning especially when dealing with children and their health care. It is predicted that there are about 270 000 people diagnosed with ASD in South Africa and this number increases by 5000 per year (Springer *et al.*, 2013). A study conducted in Johannesburg revealed that between 1996-2005, there has been an increase of 8.2% of children presenting with ASD features. It is alarming that after all the developments and progress done around the issue of ASD, traditional healers, to date, still categorise a child with ASD as 'mentally challenged' because of a lack of a more descriptive and fitting term to define the condition. Then, this suggests that any atypical condition within the traditional healing space is, thus, grouped or boxed together without a more descriptive and exclusive term to fit that particular disorder. The lack of a term is a problem that may cause harm to children with ASD. It is recorded that many African children are hidden away; others are tied up and not diagnosed medically. This is closely related to the fact that when illness is unknown and nameless and does not have a known biomedical cure or causation like ASD or even HIV, then, traditional healers often see lucrative opportunities for entrepreneurship. This opportunism is not only evident in traditional healers; even western medicine has gone through an array of trial and errors to treat children diagnosed with ASD. From 1940 to the current day, several therapies have been introduced as options that are available to treat the condition. Briefly, other therapies have been mentioned in the literature review. Indeed, it is evident that ASD has become a fertile ground for quackery (Herbert, Sharp & Gaudiano, 2002).

6.4.2 No standard diagnosis manual

The South African Government has travelled a long journey in the regulation of the traditional healing sector. The history of traditional healers and regulations dates back to the pre-1994 regime from the previous non-democratic dispensation where there was a ban on traditional healers because the then administration regarded traditional healing as witchcraft and a form of sorcery hence the witchcraft suppression act of 1957 (Richter, 2003). Due to the traditional nature of the healing, which is largely embedded in culture and tradition, health in the African

context, therefore, is not regarded as a biological phenomenon but wellbeing, which combines the body and the spirit. Traditional healers believe that a disease is not caused by any biological disorder or malfunction or germs but by the tension and aggression between social and malevolence of supernatural forces (Okwu, 1979). It is based on these complex understandings of illness that African traditional medicine approach diagnosis in a much broader and complex manner. Based on the discussion with traditional healers, getting a diagnosis involves the process of consulting with ancestors. As mentioned by traditional healers there is a relation between the child's condition of ASD and supernatural forces. The second step in diagnosis involves the origin of the forces that are at play in the child's condition, often it is the ancestors or in other circumstances, they mention witchcraft or a particular ritual that is missing or that needed to be performed for the child. Once the cause is determined, then, the diagnosis is often completed and the appropriate prognosis is often determined such as what rituals, medicine or a referral, if it needs to happen, is, then, communicated to the patient. All this process of diagnosis and healing does not happen in the consultation room between a patient and the healer but in the traditional healing space, diagnosis involves the patient, members of the family and even the community at large. Therefore, healing is frequently tailored to fit the individual's circumstances and which include family affairs, societal, physical, spiritual and physical wellbeing (Okwu, 1979).

6.4.3 Regulating board for Traditional Healers

It is mentioned that there are over 200 000 traditional healers in South African and about 70% of the people in the country use the services of Traditional African healers (Moagi, 2009). Traditional healers have formed over 100 different associations around the country that will regulate the industry. The introduction of the Traditional Health Practitioners Act in 2004 was the first step taken by the SA government in regulating the traditional health space in SA. This Act was later amended in 2007. The main purpose of this Act was to bring about a body that will formalise and regulate the 200 000 traditional health practitioners in the country and to meet the following tenets. First, it was to form an interim council of traditional health practitioners. Second, it was meant to develop a regulatory framework that will focus on the efficacy, quality and safety of traditional health care. Last, it was formed to offer a professional management system of registration, training and conduct of traditional health practitioners, trainees and clarity on the different categories of traditional health practitioners

The council has made substantial progress and has a representative from different sectors such as the Health Professions Council of South Africa, legal experts, a member from the pharmacy association, representatives of traditional healers from each of the 9 provinces and community members (Street, 2016). The Act states that no person will be allowed to practice without valid registration as stipulated in Act 21. The Act also allows for SA citizens to only be allowed the registration to practice as a recognised healer in the Republic. Further to this, there are important documents stipulated as a requirement for registration such as proof of training and the highest qualification of the candidate. However, (Street, 2016) mentions that it is unclear according to the Act, what then happens should the candidate fails to produce the documentation to the regulating body. Besides, the Act requires that a candidate writes an entrance examination, which attracts costs (Duvenhage and Louw, 2017). This thick discussion shows evidence of the substantial work conducted in the regulation of South African traditional healers and registration thereof. However, the enforcement of the Act may be a challenge to achieve since there are several unregulated traditional health practitioners in the country still, inspite of the Act being in place. This was also echoed and acknowledged by traditional practitioners during the discussion of this study. The challenges that are attached to the rigid requirements of the Act include financial, time and other administrative challenges. According to (Duvenhage and Louw, 2017), time costs that are attached to developing training content to train traditional healers and the costs attached in administration are some of the challenges that delay the effective implementation of the Act. The downside of the delays is the mushrooming of unregulated associations that will take opportunities to exploit and to cash out from this delayed process. A recent study conducted in Limpopo province in SA showed that several traditional practitioners who took part in that particular study were registered with the different associations of which some were not recognised by law (Maluleka, 2020). It is, thus, clear that there are still a very large number of traditional healers working outside of the health care system in the country despite the government passing laws.

6.4.4 Transparency on the Ingredients used in Traditional Medicine

It is evident based on the literature and the discussions in this study that the knowledge of African medicine is largely attached to cultural heritage and sentimental value systems. Often, this knowledge is kept secret and undocumented to protect the knowledge of the ancestors and to keep tradition within those who are rightful owners of the tradition. In this study, doctors

mentioned that parents often mentioned they also used traditional paths to seek help for the child. In most cases, parents were unwilling to mention to allopathic practitioners' details of medication that traditional healers give to the child.

Also, traditional healers were sceptical to divulge the ingredients of the medicine used in treating their clients. Traditional healers claimed that there were scientists who were scouting to steal indigenous knowledge from them, therefore, they were unwilling to describe what components were in the solutions that they gave their clients. Understandably, indigenous knowledge theft is indeed one of the problems that has misappropriated the intellectual property of many indigenous people. According to the Medical Research Council (MRC), SA is indeed rich in knowledge systems and biodiversity. They also mention that medicine that comes from natural plants treats about 90% of human diseases. The article by Mail and Guardian acknowledges that some of the indigenous plants are valuable and known to be effective but warns against the use of products claiming to cure illnesses, which is mostly the case in ASD (Mail & Guardian, 2013).

6.5 Brief discussion of findings - Religious Leaders

The data analysis of this project discussed major themes that emerged from the focus group discussion. Religious leader's themes emphasised the supernatural world and its impact on health. Also, they mentioned commercialisation and popular culture that has influenced the religious space. Further, they agreed on regulating and formalising the religious healing domain to protect families and children from being taken advantage of by the 'ungifted' prophets of doom and gloom.

Africans believe health is not only biological but an interaction of biological, social, spiritual and religious interactions of a person that defines illness. Therefore, it is no novel discovery that religious leaders in this study acknowledged the existence of the supernatural world as one of the causes of ASD. It was mentioned earlier that about 70% of South Africans consult or use the services of traditional healers. This does not necessarily mean that their religion should be placed under question but rather this confirms the depth of the belief in African traditional health care. There is a multiplicity of therapy when it comes to treatment for illness in South Africa. Since religious leaders were all African in this study it was not surprising that witchcraft was brought into the discussion. According to religious leaders interviewed in this study, one

of the reasons among many that they metioned was that ASD could be caused by witchcraft. However, they were of the view that the only approach to healing ASD would be prayer which was an approach to healing that was different from that of traditional leaders. Also, religious leaders believed in prayer as the onlysolution for the treatment of ASD. As much as they believed that prayer was a solution, their faith was based largely on an African worldview. While this study is not focused on Afrocentricity or African world view, it is, thus, important to acknowledge the African worldview of understanding illness that emerged from the discussions in this study. Later publications from this thesis will focus on developing the theme of African centred epistemologies that may be marginalised in the health care sector.

As mentioned earlier, South Africa is a nation of plurality, with many cultures, languages and even religions.

Majority of South Africans professes that they are of the Christian faith leaving the 20% to other religious groups such as Hinduism, Judaism, Islam and a minority who regard themselves as traditionalist or not belonging to any specific religion (Jyväskylä University, 2002). With all this rich history and culture in the country, people have not stopped seeking what is 'new'. This search often leads to breakaways from the traditional old churches to people forming new independent churches. Often, those who breakaways from these traditional mother churches claim different reasons as the main driver to break away such as misalignment of values, dissatisfaction with the principles of the mother church and sometimes the calling from the holy spirit to open a new church. In most cases the breakaways are largely motivated by material and financial gain and less motivated by the gospel and spreading of the good news (Biri, 2012; Masenya, 2018). This type of action may be defined as the commodification of the church, which is turning church services into money-making activities such as demanding payment for healing the sick congregants etc. (Masenya, 2018). Additionally, the article states that pastors from Pentecostal churches know how to use people's needs by promising them miracles and other forms of luck and when these miracles do not happen, they blame the faith of the person. In some instances, people are asked to give even more (Masenya, 2018). In this current study, parents believed that their children may be treated through prayer to the extent that others would watch TV programmes that were popular in healing. Some even asked the child to touch the TV screen while the pastor on TV was praying. Mainly, this was done with the hope that miraculously, the child will be healed. Pentecostals have a long and prominent history in healing which they call deliverance from demonic forces, prophetic utterances and decrees (Anderson, 2009).

Many African people believe in the power of God. Pentecostalism has gained great popularity in many people placing Pentecostalism as the most experiential movement in Christianity (Pondani, 2019). While these newly formed churches have gained popularity in society they are not without any flaws. There have been some prophets that have been accused of engaging in dangerous healing practices through media and by other social structures, which have left many platforms in shock and in confusion (Pondani, 2019). Recently, a pastor claimed to cure an illness using a known pesticide to cure cancer and HIV in Limpopo, South Africa.

The use of harmful objects when exercising healing and deliverance is fast growing in many churches and has become controversial. Such objects used have many physical implications to the human body and health, therefore, the religious healing space is not without dangers to parents looking for healing for their children with ASD. There are many cases of pastors who engage in dangerous healing practices such as feeding hair, drinking petrol, feeding snakes and riding on congregants' backs like horses- all in the name of healing (Pondani, 2019).

The commission for the promotion and protection of the rights of Culture, Religious and Linguistic Communities (CRL Rights Commission) stated the dangers posed by other healing practices performed on congregants. Dangerous healing practices are seen throughout the country. It is unfortunate that these kinds of breakaway churches thrive in humble communities where there are many vulnerable and those who lack education. Mothers of children with ASD undergo a series of emotional processes seeking help for their children to a point that they may end up exposing children to any form of help with the hope of finding ther right help for their child with ASD. Some parents from the current study mentioned some of dangerous practices which were intended for their children with ASD. The following section below discusses the harms and benefits of using religious and traditional practices for children with ASD.

6.3 Comparing Harms and Benefits for alternative forms of treatment to ASD

This section will interrogate the benefits and harm that are associated with the use of the mentioned alternatives in this study. Previous chapters have explored the options that parents used as a means of helping their children. In this section, a detailed description of the outcomes of using these alternatives is discussed in-depth.

Table 15: Benefits and Harms in Alternative treatments used in this study

Harms	Benefits
Herbal Intoxication and Poisoning	Connectedness
Injuries (Psychological and physical)	Meaning
Ineffective Delays	Hope

6.3.1 Harms

6.3.1.1 Herbal Intoxications

As mentioned earlier, traditional remedies are a popular option for many Africans seeking health care. This study showed consistent results in the literature on the use of traditional remedies. Many parents interviewed mentioned that they have consulted with a traditional healer to help their child with ASD. Majority of traditional remedies have not gone through scientific testing or randomised trials to determine their efficacy. Many traditional remedies are safe and have health benefits for those who use them. While some traditional remedies are deemed safe and beneficial, others have a high risk of side effects and even intoxication may be possible. The effects of traditional remedies may be even greater to children given their sensitive system that is still developing. In a study conducted in the Eastern Cape province of SA, the majority of participants confirmed the use of traditional medicine on their children (Tindimwebwa & Dambisya, 2003). Some of their reasons include pressure from others and their beliefs and culture (Tindimwebwa & Dambisya, 2003).

Several plants have become known in certain cultures as remedies for certain illnesses. Many traditional plants form part of traditional medicine, which are known in African cultures for their safety but there is a caution against continuous use of these plants which may lead to some injuries or harm such as respiratory issues, chronic liver issues and in some cases liver failure (Ghorani-Azam, Sepahi, Riahi-Zanjani, Alizadeh Ghamsari, Mohajeri & Balali-Mood, 2018). Cases of children with ASD given herbal mixtures by parents are evident in the literature. A case of a 12-year-old boy with ASD who was admitted to an emergency department by his parents presenting seizures is one example of the many negative effects of traditional remedies (Jangid, Panchal& Reddy, 2020). The article mentions that the young boy was given herbal medicine by his parents to detoxify the child's body in order to reduce behaviors associated with autism. Parents administered medication and doses of water using an enema. This was administered to the child 2-3 times a week (Jangid, Panchal & Reddy, 2020). As mentioned, many parents do not disclose to their doctors that they are or have consulted a traditional

practitioner. This non-discloser limits the collaboration and also the effective intervention from allopathic doctors. Besides, non-disclosure to doctors hinders proper help which could help allopathic practitioners to understand the other approaches and offer caution about the possible dangers that may occur in using them in children.

6.3.1.2 Injuries

There has been much media coverage that have highlighted some of the dangers associated with religious practices that some churches perform to church congregants. Some of these include dangerous practices that are physical and others may be psychological. In this study, mothers mentioned an array of activities that were done to children that may be deemed dangerous. This section discusses religious traditional practices that may cause injuries or harm people. The section will, firstly, discuss the physical dangers of both religious and traditional practices and conclude with the psychological dangers of the practices.

6.3.1.2.1 Physical Dangers

This section refers to activities performed during religious and traditional practices that may injure, harm or bring any form of hurt physically. Dangerous practices are done under the emblem of healing or helping people. Most parents lack knowledge about the effects that these practices have on individuals and children. The notion that the body, identity and culture are all interwoven in some cultures are some of the reasons why some parents would explore multiple forms of healing to assist their young ones with ASD. Also, most cultures believe that children are owned by the family and are unable to make decisions for themselves. This is the case in SA, however, the question of the best interest of the child is crucial in issues of health when it comes to children.

The use of an enema is a common practice in the African community. Enemas are often used to cleanse the body from harmful substances. Research confirms the dangers of using enema at home which may have implications when the administration of this is negligent to the child may result in grave medical injuries such as rectum injuries, and in some cases, full-thickness burns to the rectum (Mshumpela, Brisighelli and Westgarth-Taylor, 2020). These injuries may be prevented if parents are fully aware or educated about the possible dangers of administering enemas at home.

There are also possible psychological implications in some of the practices mentioned during interviews in this study. There were mentions of children that were deeped into water which may not only be physically dangerous but psychological also. When adults make a treatment decision, the interest of the child must be considered.

6.3.1.3 Implications of Delayed treatment

There is a body of literature which states that early diagnosis and interventions produce more positive outcomes in the development of a child with ASD (Helt, Kelley, Kinsbourne, Pandey, Boorstein, Herbert, 2008; Rogers& Lewis, 1989). In an effective system, ASD can be diagnosed at an age as early as 2 or 3 years old. That said, parents face many challenges that delay the process of a diagnosis such as an unresourced system like the one in SA. The lack of staff and resources is a matter that has received most media attention but not much has been done. The millions of patients that are serviced by the hospital are the ones that experience these challenges in the hospital. It was mentioned earlier in this study, that a diagnosis of ASD is not an overnight process but one that may take months to obtain. Some patients end up fatigued and eventually abandon the allopathic health system and move on to seek other options for their children.This is because the medical system is under strain and takes long to provide a clear diagnosis for the child. Such issues are bound to lead patients in despair and even lose confidence in the medical health system and to a certain extent, creating a feeling of unmet expectations (Lau, 1989). Apart from the failing medical system, some parents withdraw from continuing with the medical treatment for the child out of their free will. The medical team interviewed in this study mentioned that parents would opt out of the treatment plan and take up other alternatives that are available for the child on their own or from the advice of the family. These decisions are often respected by the medical team especially the ones that are culturally competent. However, they may raise questions about whether the interest of the child was considered or not. Taking children out of therapy may deprive them of early treatment benefits that may provide them with a better chance of improving the child's brain development (Huai, 2017).

In the African context, issues of consent are not individual decisions but one that requires the family or in some cases, the community as a whole to be involved. Because of such issues, the concept of the 'best interest' of the child becomes complex. In such cases, medical health practitioners may try to express the importance of keeping the child in therapy, especially, in the early stages of the childs' development while the brain is still elastic and when chances of

development are still large. Children with ASD who receive early intervention and educational support are more likely to gain the following (Autism Spectrum Disorder Foundation, no date):

1. Essential Social Skills
2. React Better in Society
3. Potential for a Better Life.

The ASD foundation further mentions that early interventions do not only benefit the child but also may assist the parent in understanding how to support their child with ASD. They also assist children improve their health psychologically, emotionally and also help start early a relationship with specialists and other organisations who are focused on helping children with ASD.

6.3.2 Benefits

This study did not only focus on the harms associated with the use of traditional medicine and religious interventions in children with ASD but also attempted to identify the benefits of using such alternatives in the health and wellbeing of children with ASD. This section discusses the benefit that emerged during the data analysis of the data of the research study.

6.3.2.1 Connectedness

The concept of social connectedness is widely used in most disciplines such as psychology, sociology and criminology. Therefore, there is no fixed definition that may fit all these other disciplines. However, this concept, in simpler terms means relations between people. It has been determined in the previous chapters that the African worldview is by far the opposite of the western approach. There is a strong sense of collective, wholeness interdependence and relationships in African approaches.In fact the notion of *I am beacause you are* which is derived from the African Philosophy of Ubuntu clearly emraces connectedness and relations amongst people. In this context, culture is seen as an integral part of human development, not just a feature of this variable but as a factor that moulds all the aspects of human development (Ebersöhn, Sefotho, Mampane, Loots, Omidire, Sherman, & Nxumalo-Tsebe, 2014). Social connectedness is said to be a central part of care and support in African Indigenous Knowledge

Systems (IKS). A report conducted by the Samuels foundation on connectedness and IKS mentions the following about this topic:

'Indigenous beliefs and practices expand the realm of relational connectedness to a 'continuity of connectedness', which transcends the realm of the living to include relationships to the ancestors, in addition to relationships among the living. In the continuity of connectedness, spiritual capital and cultural capital are as important as social capital' (Samuels Foundation, P 4).

There is a great sense of care for children in the African worldview, that child care from birth to childhood ought to encompass the following (Samuel& Uwizeyimana, 2017):

1. Material Assistance
2. Spiritual Assistance
3. Psychological Assistance
4. Corrective measures (Mental, Spiritual and Physiological)

Therefore, in the African worldview, a form of atypical or a disorder may need interventions from a collective which include: the family elders and known healers are often brought in to assist the family deal with the issue of the child. In this study, parents and family ties played an integral part in the treatment decision of the child with ASD. Such connectedness brought a sense of harmony in the family and strengthened family trust in other networks and traditions that have been formed over time (Samuel & Uwizeyimana, 2017).

The notion of continuity of connectedness merely states that people share their resources as a way of expanding communal capital to address the challenges that they may encounter and to promote wellbeing (Samuel & Uwizeyimana, 2017). Therefore parents act according to what they know and what informs their cultural belief system when involving the extended family system in the process of deciding treatment for the child.

6.3.2.2 Meaning of life

Parents of children with ASD experience more than usual stress when compared to parents of typical children. The demands associated with caring for a child with ASD range from changing the family schedule, changing family dynamics, misconceptions about the child's condition and family interference are amongst many reasons mentioned in the literature as causes of parental stress (Iadarola, Pérez-Ramos, Smith & Dozier, 2019; Simelane, 2020). In fact, to some parents, their worlds may seem meaningless and coming to an end after hearing

their child's diagnosis. It takes a while for many parents to come to terms with a diagnosis of ASD. To some, the mourning of a loss of a healthy life becomes overwhelming and the process of denial for others is usually imminent. To overcome this period, parents find ways of regaining meaning in life. Once parents accept the child's condition of ASD, there are several other ways that they could find meaning in life, for example, parents could turn to religion as a source of meaning. The concept of meaningfulness is defined as 'the importance of being involved as a participant in the process of shaping one's destiny as well as one's daily experience'(Antonovsky, 1987). Parents who use religion as a form of mindfulness believe that God knows what is best for them and their child (Keong, 2016). In this study, most parents turned to religion for answers to cope with the condition of the child. Research supports the notion that negative life experiences are a factor at the beginning of a meaningful life process (Vohs, Aaker and Catapano, 2019).

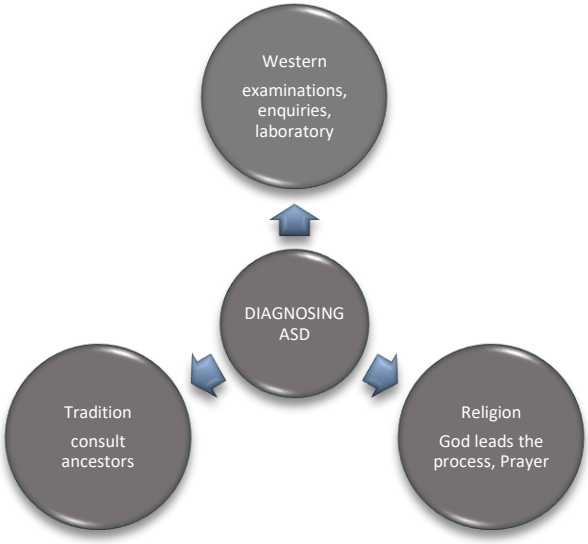
6.3.2.3 Hope

Agency, goals and pathways are an important concept in defining hope. Agency means the ability to initiate and the ability to set a specific goal. The pathways component means finding ways of achieving a particular goal. These goals can vary from one person to the next; they may either be short or long term goals. Goals, therefore, must be valuable and challenging enough for someone to invest in their pursuit. When parents hear the news of a diagnosis of ASD, many of them lose any goals of an effective child-parent relationship that they may have had. According to (Snyder, 2002), this loss may be viewed as a barrier to goal pursuit. When parents feel helpless in helping their children, they may develop negative emotions about the goal of helping their children. Therefore, parents, in this study, created alternative pathways (moving from allopathic to traditional or religious interventions). Most parents in this study were able to find different pathways of helping their child even after receiving a diagnosis of ASD, which may cause a shutdown of hopeful thinking. According to (Hastings, 2009), hope is an integral part of keeping the psychological well-being of mothers with children diagnosed with intellectual challenges. Parents, in this study, presented characteristics of high hope people. According to (Monsson, 2010), people with high hopes can determine whether the goal is impossible and develop more possible strategies of achieving a goal and replace one goal with another if one goal is proving to be ineffective. Parents, in this study, had a positive outlook about the condition of the child and optimistic amidst all the challenges they experienced.

6.4 Differences and disparities in the method of diagnosing ASD

The three healing approaches have differing methods of uncovering the disorder. As stated in the discussion with traditional healers, they mentioned that medical doctors consult the book and traditional healers consult their ancestors. The same with religious leaders, they also explained that God shows them the source of the problem. This section of the chapter compares and contrasts the methods of diagnosis of the interventions that were consulted by parents.

Figure 9:Diagnosis of ASD in all 3 approaches



The need for multiple forms of healing in South Africa is increasing. A large amount of South Africans use both allopathic and traditional health systems of health. This means that ASD is approached in multiple approaches to health. People move from one system to the next in search of meaning and to find solutions for their children. In the western health system, a diagnosis of ASD is often based on behavioral criteria and developmental history of the individual. The system of diagnosis has changed over the years and the current diagnostic manual, was released in May 2013 (Diagnostic Statistical Manual of Mental Disorders (DSM 5 American Psychiatric Association). The following symptoms must be present for a diagnosis of ASD to be confirmed: 1) social communication and 2) restricted and repetitive behaviors. The process also includes developmental monitoring of milestones and developmental screening which involves questions about the child's development. As an added assessment, a

comprehensive evaluation using relevant ASD screening tools is conducted for a diagnosis to be obtained. Even after all this process, some doctors may hold a diagnosis until all other assessments and medical processes have been conducted.Doctors can also hold a diagnosis because labeling a child is not a process to be rushed but treatment is often their main concern.

Traditional African health system on the other hand, diagnosis is a little different compared to the allopathic health system. It is important to mention that in the Traditional African Health approach, there are different methods of diagnosing. Traditional African healers use a method of bone throwing and physical examination. Bone throwing is a form of obtaining the history of the individual and to triangulate the information provided by the patient with the supernatural world of the ancestors. The second part of the process of diagnosis is the physical examination of the patient which includes checking the patient physically. In this study, much was mentioned about examining the child, physically, which included the examination of the tongue. The tongue was a common discussion during interviews with parents. It was as a reason they suspected as a cause for the child to lack communication.

It is only after these two methods of diagnosis, then, traditional healers would provide a treatment method for the patient. Traditional healers often do not have an efficient and effective regulating body that guides their practice and their scope. They treat young and old almost without any difference,there is not much distinction between children and adults in terms of a diagnosis; the process often stays the same.

Faith healing or religious healing have different categories. Some Pentecostals call themselves ‘born again’ some are plain Christian and others Zionist Christian churches. Zionists are also known as ‘lebone’ and often known as possessed by the holy spirit (Mokgobi, 2014). They are also known for foretelling the future and how to avoid possible misfortunes in the future (Mokgobi, 2014).

All three methods were a choice to many parents in the study and they seem to be no overlapping processes in all the system. These methods diagnose differently and they understand the causes and treatments of ASD differently.

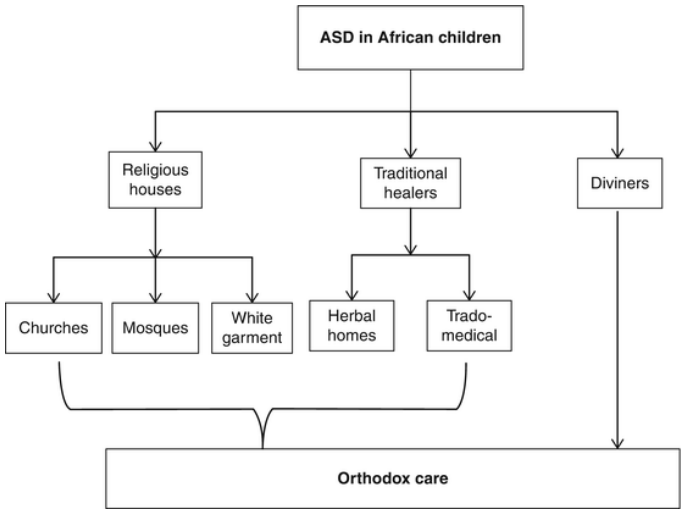
6.5 Possibility of Collaboration of the three Approaches to healing exist and is the collaboration of any Benefit to Children with ASD.

According to Bennett, relativism "implies that we have no basis for judging other people and cultures, and certainly no basis for declaring some better than others, let alone 'good' or 'evil'" (Bennett, 2012). The evidence provided in this thesis shows clearly that help-seeking patterns of parents of children diagnosed with ASD are still largely a multiple approach to healing. The order of consultation was not consistent and did not form part of the scope of this research study. Whether parents consult the allopathic health sector first or last was not largely the focus of this research study. However, what the study found was, parents still largely use multiple perspectives in healing and approaching ASD after a diagnosis is found. The main driving factor behind consulting these different approaches is often the fact that parents are continuously looking to answer questions of the causes and to better understand the condition of their children. Parents are often in search of answering questions such as *what* caused ASD, *how* it came about that the child has ASD, *who* caused the child to have the disorder and even questions such as *why* does the child have the disorder, are some of the questions that are driving parents to continue seeking help. The approaches to health differ significantly between allopathic health practitioners and other sectors. Allopathic health practitioners such as medical doctors, psychologists, speech therapists, occupational therapists to name a few were part of this research study. The allopathic group of health practitioners approach health using scientific knowledge and other scientific technologies in approaching health and healing (Kreitzer, Kligler & Meeker, 2009).

The traditional health sector, on the other hand, relies on the knowledge passed from one generation to the next, which often is verbal and to a limited extent, in writing (World Health Organization.Programme on Traditional Medicine, 2002). In the traditional medicine space, there are different realms. The first is the real world where living beings live and the second is the spiritual world where ancestors live. The third approach that emerged during discussions was religious healing. According to (Froise, 2000), a large number of South Africans belong to churches that believe in healing. These churches are often referred to differently in other literature but in this research study, we group them because they respond to one common need (Modiko, 2011). Parents of children, in this study, used all three health approaches for their children diagnosed with ASD. Therefore, this study is a strong case to present for a more collaborative health approach in the treatment of ASD in South Africa. This study is in line

with other studies that have previously confirmed the multiple approaches to help-seeking parents of children diagnosed with ASD (Bakare & Munir, 2014). The figure below is adapted from an article written to discuss pathways to care for children in Africa. This figure is a replica of the process followed in South Africa to care for children with ASD. The article calls this process a 'tortuous' process to care.

Figure 10:Pathway to care for children with ASD



Source: (Bakare & Munir, 2014)

Several studies have looked at the integration of traditional healing into western medicine (Courtright, 2000; Green, 1998; Hopa, Simbayi, & Du Toit, 1998). Several comments and concerns have been noted as barriers towards a more efficient collaboration. The following are some of the barriers cited in the literature. Firstly, there will be an unhealthy form of competition between approaches i.e. economical. Then, there is a perception from the western practitioners that traditional healers may harm their clients because of their unscientific nature of their practice. Besides, western practitioners may perceive traditional healers' practice as illegal. Also, the collaboration may promote illegitimate traditional healers. Furthermore, the health care space is under strain financially as mentioned earlier.There is currently a number of issues that have been mentioned such as the weak administration and shortage of staff thus, bringing on-board more practitioners may crash the health care sector. Moreover, while other countries have attempted to intergrate other approaches into the health care system, there is no

effective existing model around the globe that could be followed to integrate the health approaches. Lastly, the level of secrecy on the part of traditional healers in fear that their ideas and intellectual property will be taken away from them may hinder the collaboration process and create hudles.

Despite all the above-mentioned barriers, many people to date are individually using multiple systems to approach health for themselves and their children. ASD is no different; the delays of a more collaborative approach do not preclude parents from approaching all forms of health to help their children.

6.5.1 The way forward in treating ASD in South Africa

Parents hop from one system to the next in search of answers and more effective treatment for their child with ASD. There are several dangers mentioned by researchers that are possible if the systems of health do not communicate with each other on what therapies or medications are being administered to the same patient for the same illness (Mokgobi, 2014). It is further stated that continued use of more than one system may cause psychological dissonance for some people who use multiple approaches. The tolerant approach that is being used to treat traditional healers does not necessarily solve the problem. Acknowledging traditional leaders but not accepting them may be disconcerting for some in the health care space. The issue of collaboration is one that can only be unravelled by the South African authorities together with all relevant stakeholders in the health care sector (Health Practitioners Council, Traditional Healers and Religious Healers). A more comprehensive approach in treating ASD could offer families and children with ASD holistic care in the treatment of ASD. There is, therefore, an urgent responsibility from the South African Government to finalise regulations of traditional health practitioners and create an active board that will regulate the traditional health sector. The integration will come as a benefit to South Africans since most of its population anyway approach health through different lenses and not just on a biomedical approach only.

6.6 Conclusion

The need for a more integrated approach in treating and improving the health of children diagnosed with ASD is important in SA. The problem does not end with talks and conferences; it now threatens the health of children. Children continue to be exposed to all forms of approaches whether the health sector is integrated or is still in the process of integration, the

fact remains, parents will not wait for a more intergrated health system they will do what they deem necessary to help their children. The body of knowledge continues year on year to provide evidence of the way South Africans approach illness and understand illness. The are many facts and real evidence that prove that parents are indeed using a multiple approach to healp children with ASD. More delays in integrating the systems of health may be more damaging than anything to the health of children with ASD. While there is much done in regulating traditional medicine such as moving from being classified as ‘derogatory’ or witchcraft to a more tolerated system of health supported by the Traditional Practitioners Health Act (22 of 2007), much still needs to be offered and implemented by the South African authorities working in this space.

CHAPTER 7: CONCLUSION, RECOMMENDATIONS, AND LIMITATIONS

7.1 Introduction

This chapter presents the conclusion, recommendations and limitations of this research study. The first section of this chapter is an overview of the study. Later, it is followed by a short discussion of the objectives underpinning this research study. Based on the findings of each research objective, recommendations are made for each to improve the decisions opted by parents in the treatment methods of children with ASD. Limitations of this research study are also made for future researchers to focus on and improve upon.

7.2 Overview

Two objectives underpinned this research study. The first objective was aimed at understanding the benefits and harms that exist in using alternative forms of treatment (traditional and religious) in children with ASD. The second objective of this research study was to understand the ethical responsibilities that are derived from alternative treatment methods in the wellbeing of children with ASD. To fulfil the two objectives of this study, an empirical component was conducted through interviews and focus groups. Parents/ caregivers of children diagnosed with ASD were interviewed to understand their treatment approaches for their children diagnosed with ASD. The interview process was guided by an interview guide. Religious and traditional healers working in treating children with ASD were approached and focus group discussions were held. Each group (religious and traditional) was visited for a discussion of the topic of helping children with ASD.

This thesis is divided into six chapters which are designed to fully answer the two main objectives of this research. The first chapter is an introduction that gives a clear picture of the thesis and the problem statement of the research. Chapter two of this research study offers a thick review of the literature. The literature covers the definition of the important terms and also the known treatments in treating ASD and the efficacy of these therapies available. It also covers illness approaches in South Africa, considering that the country is diverse and rich in language and culture. Furthermore, Chapter two indicates the process of diagnosis in treating ASD in the context of SA. Chapter three of this thesis is the methods chapter. The methods

chapter provides the methodology adopted in answering the objectives of this study. The study was a bioethical analysis study with an empirical component to understanding the reality that exists in treating children with ASD. Chapter three also provided the processes followed in analysing the data and some of the important ethical considerations of the study are discussed in this section. The findings of the empirical component are discussed in detail in Chapter four of the thesis and relevant quotes are provided to clearly show the results of the interviews. Chapter five of the thesis is the synthesis of the findings and an ethical discussion that draws largely from the findings in Chapter 4 of this study. This current chapter is the final one providing a conclusion of the study and recommendations for future research.

7.3 Profile and Summary of Sample

Parents, allopathic practitioners, traditional healers and religious leaders formed part of the empirical component of this project. The inclusion and exclusion criteria are listed in table 3.1 of this thesis. All parents were accessed at the CHBH in Johannesburg. Every participant was channelled to the interview research office by allopathic practitioners after checking and meeting all the criteria for the study and screening the child for all inclusion criteria. Parents and health care practitioners at CHBH were interviewed to gain an understanding of the treatment process for children with ASD. Traditional leaders were approached from an organisation of traditional healers based in Johannesburg. The organisation was asked to alert their members who may have treated a child with symptoms of ASD. The researcher provided a brief discussion of the characteristics of ASD with the leader of the organisation so that when recruiting members of the focus group the relevant people are invited. Thereafter, focus groups were conducted with all traditional healers who met the criteria for this research study. Lastly, an organisation of religious leaders in Johannesburg was also approached via their administration office. A brief presentation of the charecteristics and symptoms of ASD were discussed with the director in order to ascertain that relevan religious members were invited for the study. After permission was granted, a focus group discussion with religious leaders was conducted to understand the process followed in healing children that may have symptoms of ASD.

7.4. The objectives of the study

This section of the chapter discusses the major findings and conclusions for each component of the study. All recommendations will be made available to relevant boards that participated in this research study.

7.4.1 Objective 1

- To explore the nature of the cultural and religious practices and beliefs that children with ASD are exposed to and the beneficial or harmful effect of these on their well-being.

Several practices were mentioned in this study that formed part of the treatment process of children with ASD. The following lists are the practices mentioned during the interview process of this study:

i. Inhaling of smoke from different traditional herbs
ii. Drinkables of different traditional solutions and concoctions
iii. Rectum insertions and use of enema to insert solutions or other muthi to children
iv. Connecting to the spiritual side (Prayer, rituals, Visits to Graveyards)
v. Other practices (Holy water, Oils, ropes, incisions or cutting)

It can, therefore, be concluded based on the above list that children are indeed exposed to many rituals. This list above does not necessarily cover the entire spectrum of all alternative interventions available to parents of children with ASD. The study further analysed the benefits and harms of using some of the listed practices in children. Below, the list of harm and benefits is shown in table 16.

Table 16: List of Harms and Benefits on Children with ASD

Harms	Benefits
Herbal Intoxication and Poisoning	Connectedness
Injuries (Psychological and physical)	Meaning
Ineffective Delays	Hope

based on the table above, it can be concluded that some of the practices may be harmful to children as per discussion in Chapter 5. The study acknowledges the benefits of using alternative treatment methods listed above in children diagnosed with ASD.

7.4.2 Objective 2

- To articulate and normatively defend the ethical responsibilities that arise from the described benefits and harms derived from the cultural and religious practices and beliefs that children with ASD are exposed to.

The normative component of this study discussed the implications of using the alternative treatment in children and ethical responsibilities that arise when children are exposed to traditional and religious forms of treatment. It was first discussed that evidence shows that the majority of South Africans continue to use traditional healers and the majority of South Africans regard themselves as Christians. Thus, ignoring the help-seeking behaviours of South Africans may cause more harm than good. Based on the literature that states that South Africans use multiple systems of health, this picture does not exclude ASD. The section also discussed the responsibility of the authorities in South Africa for a more accelerated approach to finalise the regulation of the (Act 22 of 2007) which will inform the regulation of the traditional healing sector. Taking children to alternative forms of treatment removes them from the known therapies that may improve their health. The normative section also discussed the implications of delaying treatment for children diagnosed with ASD.

7.5 Limitations of the Study

This section of this chapter looks at the limitations of this entire study. This section is common to all research projects and does not affect the integrity of the study but strengthens it by acknowledging some of the issues for future improvement.

The sample was mainly taken from participants who attended CHBH only, which limited the sample to a specific group of participants. Therefore, most parents, in this study, were Black Africans and from a similar world view of understanding illness. However, this was overlooked based on the literature stating that the majority of the South African population are Christians. Also, the demographics of the study would not have changed the findings that

much seeing that 79.2% of South Africans are Black Africans which puts the majority of the country's children exposed to the use of traditional and religious forms of treatment. Besides, the scope of the discussion may be limited because the researcher of this project is a psychologist and does not have long experience in the field of Bioethics. However, much effort has been added to answer both research questions and to highlight some of the important aspects that may be points of focus for parents with children with ASD and also for authorities to focus on the protection of children with ASD.

7.6 Recommendations for future research

Given the above-stated limitations of this research, the following recommendations may be beneficial for future researchers in the topic of alternative treatments in children diagnosed with ASD. It is recommended that a similar study be conducted in rural hospitals of South Africa to understand further what are other practices done in different contexts of the country to children diagnosed with ASD. It is the view of the researcher that more advanced traditional practices are performed in deeper rural areas where culture and tradition are more prevalent than in urban cities like Johannesburg. Also, future studies are recommended to include other religions and racial groups to understand what alternatives are available to treat children diagnosed with ASD. This will provide a holistic understanding of the benefits and harms that children may be exposed to in the country as a whole and not only in the Black African worldview.

7.7 Conclusion

The chapter provided a clear conclusion of this research study. The first part of this study provided an overview of this thesis. Furthermore, an outline of each chapter was provided. The chapter also discussed the sample that was studied to give this research more empirical depth. The chapter also discussed the two objectives that underpinned this study. To conclude this study, limitations and recommendations for future research were discussed.

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Appendices

Appendix 1

Semi-Structured Interview Schedule: Parents

1. Tell me about
2. What cultural practices does the family believe about the child's condition?
3. Can you talk me through some of these practices?
4. Have you explored helping the child using this practice?
5. What were the benefits of this? (If 4 is yes)
6. Did it cause any harm? (If 4 is Yes)
7. What was the reason for not exploring the practice (If 4 is no)
8. What religious practices does the family believe in that can help the child?
9. Please describe these practices.
10. Have you explored helping the child using this practice?
11. What were the benefits? (If 7 is yes)
12. What were the harms? (If 7 is yes)
13. What was the reason for not exploring the practice (If 7 is no)
14. What can society do to protect children if some of these practices (cultural or religious) prove to be harmful to the child?
15. What can be done to strengthen the societal obligation to the protection of children with ASD from cultural and religious practices?
16. What measures exist out there to protect children exposed to harmful cultural and religious practices?
17. What can society, in general, do to improve the well-being of children with ASD?
18. Can you think of interventions that can be implemented to improve the well being of children with ASD?
19. If some of the practices are harmful what can we do to protect children from harmful cultural practices and at the same time preserve our cultural beliefs?
20. In your opinion what cultural practices are right to perform and which ones are not right?
21. How do you determine the rightness and the wrongness of a practice?
22. In those that are wrong or harmful, what can be done in that situation?
23. In the beneficial practices, what can be done to improve them?

Thank you for your participation

Appendix 2

Semi-Structured Interview Schedule: Practitioner

Practitioners (Neurologist, Psychologists and General Practitioners)

1. What is your involvement with children diagnosed with ASD?
2. Tell me about the process involved in diagnosing a child with ASD?
3. How much involvement there is between you and the parent/s?
4. In your experience, how do parents react when they are told about the child's condition?
5. In your experience and interaction with parents, have you come across parents who reject the child's diagnosis?
6. What would you say is the reason they reject the diagnosis?
7. What can you say about parents who seek alternative forms of treating their children with ASD?
8. Have you come across such parents who seek alternative forms of treatment?
9. What is usually the reason for them to seek other forms of medication?
10. Can you tell me what usually are these kinds of alternative medication?
11. Do you think it is right for parents to take their children to alternative forms of medication?
12. If 11 yes/ No why? Tell me more.
13. What can you say about the issue of exposing children to other forms of medication, in terms of their well-being?
14. As a practitioner can you share in your opinion who is obligated to protect children with ASD?

Thank you for your participation

Appendix 3

<u>Focus Groups Interview Schedule Cultural and Religious Practitioners</u>
Cultural and Religious healers

Interviewers Instruction: Explain the Disorder Comprehensively

1. Based on my explanation of Autism Spectrum Disorders, have you treated a child with the condition I have explained?
2. Tell me how often do you consult with these children?
3. Who usually brings the child?
4. What would you say is the cause of the Disorder?
5. What do you usually tell parents is the cause of the disorder?
6. What do you advise parents on how the disorder can be treated?
7. Do you think the practice of cultural and religious rituals you perform can be beneficial to the wellbeing of the child?
8. If yes – How?
9. If No- why is then the practices of cultural and religious rituals performed?
10. Do you think the ritual may cause any form of harm to the child?
11. If yes – What form of harm?
    i. What can you do to prevent this from happening?
    ii. What can the parent do to protect the child?
12. Do you think it is fair or right for anyone to prevent this ritual from being performed?
13. If yes or no – Expand, please.

Thank you for your participation.

Appendix 4

Demographic information Sheet:All Participants

Details of Participant

1. Child Psuedonym			
2. Gender			
3. Nationality	**African/Black**	Zulu	
		Xhosa	
		Sotho	
		Setswana	
		Tsonga	
		Venda	
		Pedi	
		Swati	
		Ndebele	
		Other	
	White		
	Coloured		
	Indian	Hindu	
		Muslim	
		Christian	
		Other	
	Other		
4. Date of diagnosis			
5. Has the child gone through any traditional related rituals because of his/her condition of ASD	Yes	No	
6. If yes, explain what type of rituals?			
7. Has the child gone through any religious related rituals because of his/her condition of ASD	Yes	No	
8. If yes, explain what type of rituals?			

Appendix 5

Demographic information Sheet: Child

Details of Child

1. Child Pseudonym			
2. Gender			
3. Nationality	**African/Black**	Zulu	
		Xhosa	
		Sotho	
		Setswana	
		Tsonga	
		Venda	
		Pedi	
		Swati	
		Ndebele	
		Other	
	White		
	Coloured		
	Indian	Hindu	
		Muslim	
		Christian	
		Other	
	Other		
4. Date of diagnosis			
5. Has the child gone through any traditional related rituals because of his/her condition of ASD	Yes	No	
6. If yes, explain what type of rituals?			

7. Has the child gone through any religious-related rituals because of his/her condition of ASD	Yes	No
8. If yes, explain what type of rituals?		

Appendix 6

Consent Form: Focus Group Participation

Title of Research:

Ethical obligations that arise from the effects of cultural/religious practices and beliefs on the well-being of children with Autism Spectrum Disorder

Researcher: Ayanda Simelane

I …….. agree to participate in this research project. The research has been explained to me and I understand that my participation will involve discussing with other members. I understand that my identity will be known to other focus group participants and the researchers cannot guarantee that others in these groups will respect the confidentiality of the group. We will ask you to sign below to indicate that you will keep all comments made during the focus group confidential and not discuss what happened during the focus group outside the meeting.

Please circle the relevant box

I agree that the researcher may use anonymous quotes

in her research report YES NO

I agree that the interview may be audio recorded YES NO

I agree that the researcher may take photos of me (but not my face) YES NO

I agree that the information I provide may be used anonymously by other researchers following this study YES NO

_____
(Signature)

_____ (Name of participant)

_____ ____
(Date)

Appendix 7

Consent Form: Individuals

Title of Research:

Ethical obligations that arise from the effects of cultural/religious practices and beliefs on the well-being of children with Autism Spectrum Disorder

Researcher: Ayanda Simelane

I …….. agree to participate in this research project. The research has been explained to me and I understand what my participation will involve.

Please circle the relevant box

I agree that my participation will remain confidential	YES	NO
I agree that the researcher may use anonymous quotes in her research report	YES	NO
I agree that the interview may be audio recorded	YES	NO
I agree that the researcher may take photos of me (but not my face)	YES	NO
I agree that the information I provide may be used anonymously by other researchers following this study	YES	NO

_____(Signature)

_____(Name of participant)

_____(Date)

Appendix 8

Steve Biko Centre for Bioethics
School of Clinical Medicine
University of the Witwatersrand, Johannesburg

Dear Sir/Madam

My name is Ayanda Simelane and I am a PhD student in Bioethics and Health Law at Wits University in Johannesburg. As part of my studies, I have to undertake a research project, and I am investigating the *Ethical obligations that arise from the effects of cultural/religious practices and beliefs on the well-being of children with Autism Spectrum Disorder (ASD).* This research project aims to find out and to give an account of the ethical obligations towards children with ASD that arise from the effects of cultural and religious practices and beliefs on the well-being of such children.

As part of this project, I would like to invite you to take part in a focus group discussion, which will take place at a venue convenient to you. This activity will involve a discussion which will be facilitated by a researcher. The focus group discussion will involve a group of 6-12 participants and will take around 60 minutes. You are also invited to complete a short demographic questionnaire which will take approximately 10 minutes.With your permission, I would also like to record the interview using a digital recording device.

You will not receive any direct benefits from participating in this study, and there are no disadvantages or penalties for not participating. You may withdraw at any time or not answer any question if you do not want to. The interview will be completely confidential and anonymous as I will not be asking for your name or any identifying information, and the information you give to me will be held securely and not disclosed to anyone else. I will be using a pseudonym (false name) to represent your participation, in my final research report. If you experience any distress or discomfort, we will stop the interview or resume another time. If you need some support or counselling services following the interview, these are available

free of charge or at a minimum cost at *Emthonjeni Centre*, 1 Jan Smuts Ave, Wits University, Braamfontein, Johannesburg, South Africa.

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If you have any questions afterwards about this research, feel free to contact me on the details listed below. This study will be written up as a research report which will be available online through the university library website. If you wish to receive a summary of this report, I will be happy to send it to you upon request. If you have any queries, concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Human Research Ethics Committee (non-medical), telephone + 27(0)11 717 1408, email hrec-medical.researchoffice@wits.ac.za/Shaun.Schoeman@wits.ac.za

Yours sincerely,

Ayanda Simelane, Simelane.ayanda1@gmail.com ,0784379608
Prof Kevin Behrens, Kevin.behrens@wits.ac.za,

Appendix 9

Steve Biko Centre for Bioethics
School of Clinical Medicine
University of the Witwatersrand, Johannesburg

Dear Sir/Madam

My name is Ayanda Simelane and I am a PhD student in Bioethics and Health Law at Wits University in Johannesburg. As part of my studies, I have to undertake a research project, and I am investigating the *Ethical obligations that arise from the effects of cultural/religious practices and beliefs on the well-being of children with Autism Spectrum Disorder (ASD).* This research project aims to find out and to give an account of the ethical obligations towards children with ASD that arise from the effects of cultural and religious practices and beliefs on the well-being of such children.

As part of this project, I would like to invite you to take part in an interview discussion, which will take place at a venue convenient to you. This activity will involve a discussion guided by an interview question guide facilitated by a trained researcher. Interviews will take around 60 minutes; you are also invited to complete a short demographic questionnaire which will take approximately 10 minutes.With your permission, I would also like to record the interview using a digital recording device.

You will not receive any direct benefits from participating in this study, and there are no disadvantages or penalties for not participating. You may withdraw at any time or not answer any question if you do not want to. The interview will be completely confidential and anonymous as I will not be asking for your name or any identifying information, and the information you give to me will be held securely and not disclosed to anyone else. I will be using a pseudonym (false name) to represent your participation, in my final research report. If you experience any distress or discomfort, we will stop the interview or resume another time.

If you need some support or counselling services following the interview, these are available free of charge or at a minimum cost at *Emthonjeni Centre*, 1 Jan Smuts Ave, Wits University, Braamfontein, Johannesburg, South Africa.

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If you have any questions afterwards about this research, feel free to contact me on the details listed below. This study will be written up as a research report which will be available online through the university library website. If you wish to receive a summary of this report, I will be happy to send it to you upon request. If you have any queries, concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Human Research Ethics Committee (non-medical), telephone + 27(0)11 717 1408, email hrec-medical.researchoffice@wits.ac.za/Shaun.Schoeman@wits.ac.za

Yours sincerely,

Ayanda Simelane, Simelane.ayanda1@gmail.com ,0784379608
Prof Kevin Behrens, Kevin.behrens@wits.ac.za,

Appendix 10

GAUTENG PROVINCE
REPUBLIC OF SOUTH AFRICA

Department of Paediatrics and Child Health
Metabolic Unit
Chris Hani Baragwanath Academic Hospital
P. O. Bertsham
2013

5th December 2017

The Research Protocol Review Committee
Chris Hani Baragwanath Academic Hospital
Soweto
Johannesburg
South Africa

Dear Madam/ Sir

I would like to inform you that **Ayand Simelane** has been given a permission to conduct her research study in the Department of Paediatrics at Chris Hani Baragwanath Academic Hospital. The title of her study is: **"Ethical obligations that arise from the effects of cultural/religious practices and beliefs on the well-being of children with Autism Spectrum Disorder."**

While she has been given permission to conduct this study, she cannot start with data collection until she has provided the Department with Ethics Committee Clearance Certificate.

Yours Sincerely

Professor UK Kala
Acting Head of Department of Paediatrics
Chris Hani Baragwanath Academic Hospital

Appendix 11

Research Office

HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)
R14/49 Simelane

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER: H17/11/52**
PROJECT TITLE	Ethical obligations that arise from the effects of cultural/religious practices and beliefs on the well-being of children with Autism Spectrum Disorder
INVESTIGATOR(S)	Mrs A Simelane
SCHOOL/DEPARTMENT	Bioethics/
DATE CONSIDERED	17 November 2017
DECISION OF THE COMMITTEE	Approved
EXPIRY DATE	12 December 2020

DATE 13 December 2017 **CHAIRPERSON** pp (Professor J Knight)

cc: Supervisor : Dr K Behrens

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University. Unreported changes to the application may invalidate the clearance given by the HREC (Non-Medical)

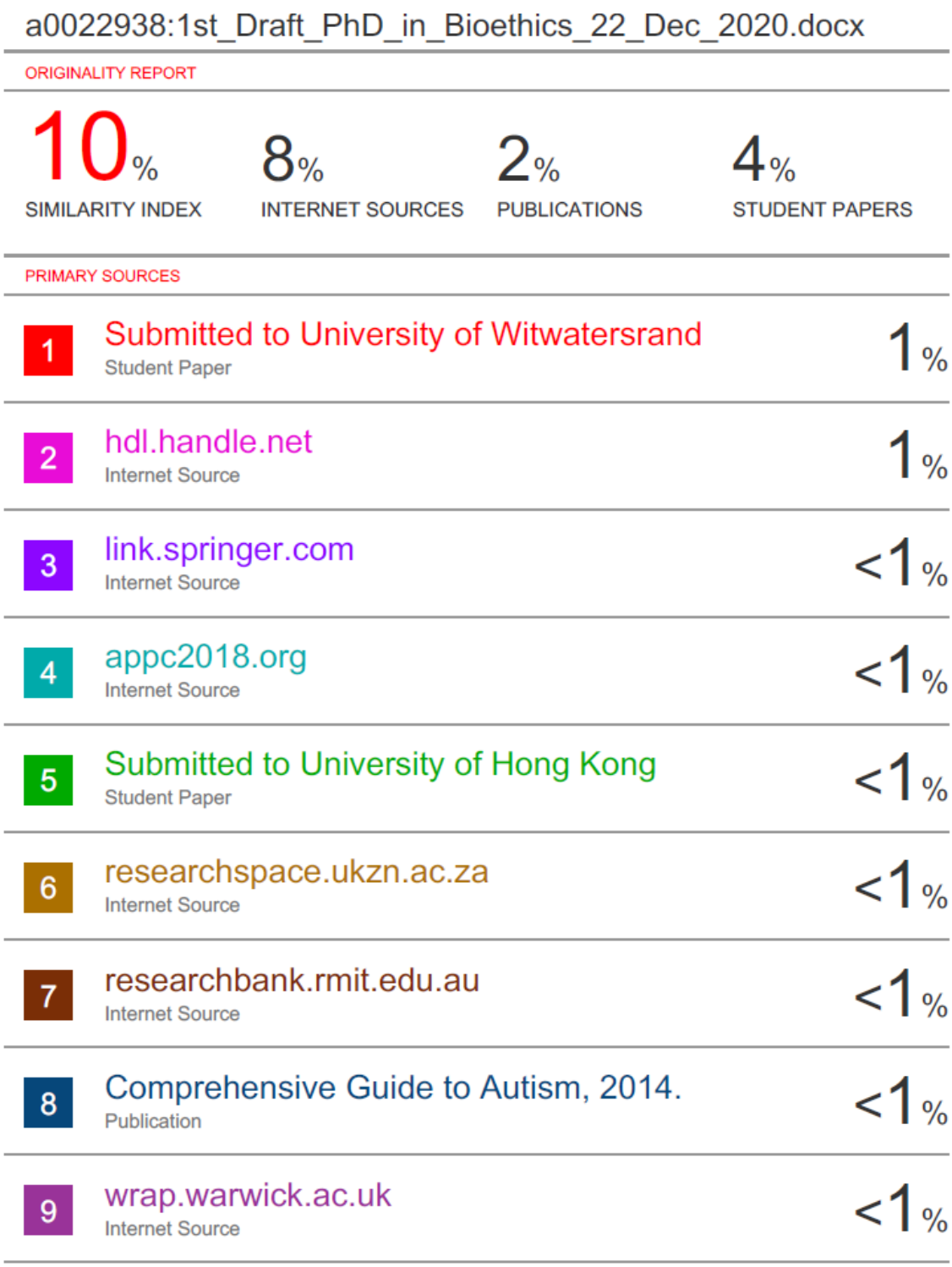
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to completion of a yearly progress report.**

_____ **Signature**

_____/_____/_____ **Date**

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

Appendix 12



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ORIGINALITY REPORT

10%	8%	2%	4%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	Submitted to University of Witwatersrand Student Paper	1%
2	hdl.handle.net Internet Source	1%
3	link.springer.com Internet Source	<1%
4	appc2018.org Internet Source	<1%
5	Submitted to University of Hong Kong Student Paper	<1%
6	researchspace.ukzn.ac.za Internet Source	<1%
7	researchbank.rmit.edu.au Internet Source	<1%
8	Comprehensive Guide to Autism, 2014. Publication	<1%
9	wrap.warwick.ac.uk Internet Source	<1%