DEVELOPMENT AND VALIDATION OF A SUPPORT MODEL FOR FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDERS IN GAUTENG AND LIMPOPO PROVINCES OF SOUTH AFRICA

by

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THESIS

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DEDICATION

This thesis is decicated to my late mother, Dainah Chauke. Despite her lack of formal education, she was always willing to share her knowledge, guidance, and motivation to learn.

DECLARATION

I declare that the thesis hereby submitted to the University of Limpopo, for the degree of Doctor of Philosophy in Nursing Science has not previously been submitted by me for a degree at this or any other university; that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

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15 June 2020

Sumbane Gsakani Olivia

Date

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ABSTRACT

Families with ASD children who have little support from a partner, friends, community and health care professionals report increased depression and lower life satisfaction compared to families with a good deal of social support. Social support may be a resource to boost an individual’s ability to overcome the negative consequences of stressors related to parenting a child with ASD.

The study explored and described the experiences of families and teachers regarding support of families with ASD children, then developed and validated a social support model for families of children with ASD in the Gauteng and Limpopo provinces of South Africa.

The method was qualitative, explorative, descriptive, contextual design employing a phenomenological approach and theory-generating study. Individual semi-structured and focus group interviews were audiotaped and transcribed verbatim. Eight steps of Tesch’s inductive, descriptive open coding technique by Creswell were used followed by independent coding. Purposive sampling recruited 37 participants from the selected special schools of Gauteng and Limpopo Provinces. Trustworthiness criteria adhered to were credibility, dependability, transferability, and confirmability. Ethical clearance was sought from the University of Limpopo.

The findings showed that there is a lack of social support for families with ASD children. These include difficulties in managing children’s patterns of behaviour and communication skills, severe stress related to having a child with ASD, knowledge-deficiencies associated with ASD, the burden of caring, financial constraints, lack of material and human resources within the special schools, overcrowding of ASD learners, lack of a formal curriculum, lack of schools for autistic children in the Limpopo Province, poor infrastructure, and poor school management support.

The study addressed the complex needs of ASD children and recommended that families should be assisted to build their capacity to care for, and protect their ASD children. A social support model was developed to serve as a reference framework for professional nurses in different spheres of health care and education, to promote a supportive environment for families with ASD children.

Keywords: Autism Spectrum Disorders, families, model, social support.

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ABBREVIATIONS

AAC	Augmentative and Alternative Communication
ADDM	Autism and Developmental Disabilities Monitoring
ACA	Autism Children Club
AM	Autism Malaysia
ASD	Autism Spectrum Disorder
CDC	Centre for Disease Control and Prevention
FB	Facebook
FGD	Focus Group Discussion
FSP	Family Support Process
FSS	Family Support Scale
GPPC	Gauteng Province Primary Caregivers
GPT	Gauteng Province Teachers
LPPC	Limpopo Province Primary Caregivers
LSEN	Learner with special educational needs
LPT	Limpopo Province Teachers
MH-PCP	Medical Home - Primary Care Practice
NGO	Non-Governmental Organization
PATH	Planning Alternative Tomorrows with Hope
PBIS	Positive Behavioural Interventions and Support
PRISMA	Preferred Reporting Items for Systematic Review and Meta-Analyses
PTP	Parent to Parent
RSA	South Africa
SANC	South African Nursing Council

SIAS	Screening Identification Assessment and Support
TEACCH	Treatment and Education of Autistic and Related Communication Handicapped Children
TREC	Turfloop Research Ethics Committee
UL	University of Limpopo
WHO	World Health Organization

DEFINITION OF CONCEPTS

Autism Spectrum Disorder

Autism Spectrum Disorder is a complex neurobiological disorder that is associated with restricted and repetitive behaviour and varying degrees of impairment in communication and social interaction (Russa, Matthews & Owen-Deschryver, 2015). In this study, it is, defined as a group of psychiatric conditions in children in which social communication and interaction are impaired and the child engages in limited repetitive patterns of behaviour, interests, and activities.

Child

The word ‘child’ refers to a young human being below the legal age of majority (*Oxford English Dictionary*, 2012). Children are defined in this study as individuals who are diagnosed with autism spectrum disorders and who also require health and related services of a type or amount beyond that required by children generally. The current study focusses on children with autism spectrum disorders in the Gauteng and Limpopo provinces.

Experience

‘Experience’ is a particular instance of personally encountering or undergoing something (*Oxford English Dictionary,* 2012). For the purpose of this study, experiences are defined as the life experience of families with ASD children and their care and support in the Gauteng and Limpopo provinces, South Africa.

Family

The word ’family’ is used to refer to biological relatedness, social ties, interactions, and proximity (Thompson, Seo, Griffith, Baxter, James, & Kaphingst, 2015). Family is defined in this study as the primary caregivers, adoptive parents, foster parents, grandparents, siblings and other relatives responsible for the care of children with ASD.

Model

A ’model’ is a symbolic representation of concepts or variables and the interrelationships amongst them (Polit & Beck, 2010). A model is defined in this study as a graphical representation of concepts and the linkage between them through boxes, arrows or other symbols.

Primary caregiver

A primary caregiver is a person who cares for, nurtures, loves and looks after one or more children; the role is similar to that of a parent (Seear, Kapur, Wensley, Morrison, & Behroozi, 2016). The primary caregiver is defined in this study as a person who assumes the most responsibility in caring for the health and well-being of the child with autism spectrum disorder.

Support

Support means to agree with, and give encouragement to someone or something because you want him or her to succeed (*Oxford English Dictionary, 2012*). Support is defined in this study as to give help, encouragement, and assistance to families of children with ASD.

Support model

A support model is defined as an intervention in which people actively acquire skills and information that presume to change behaviour (Schultz, Schmidt & Stichter, 2011). A support model is defined in this study as a programme designed to provide support information to families of children with ASD.

Social support

The term ‘social support’ refers to all the efforts made by the subject to find sympathy or help from others (Boujut, Dean, Grouselle, & Cappe, 2016). Social support is defined in this study as the on-going care and support of families with ASD children to minimise the negative effects of having a child with ASD through interactions with professional practitioners, teachers, and significant others.

Validation

Validation refers to the use and evaluation of empirical evidence to guide practice and practice-oriented approaches that further contribute to the development of empirical knowledge (Chinn & Kramer, 2008). In this study, validation is defined as the action of checking or ensuring the validity or accuracy of the support model for families with ASD children.

CHAPTER 1

OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND

An extensive literature suggests parents of children with autism spectrum disorder (ASD) experience a considerable amount of caregiving burden and stress compared to parents of children with other intellectual incapacities (Ekas, Lickenbrock & Whitman, 2010). Social support has been identified as an essential issue that reduces the negative psychological effects of raising a child with ASD similar to that of parents of children with alternative disabilities. Families with ASD who have less support from a partner, friends, and the community report an increase in depression and lower life satisfaction compared to families with a good deal of social support (Lindsey & Barry, 2018). Social support may be a resource to boost an individual's ability to beat the negative consequences of stressors related to parenting a child with ASD (Zaidman-Zait, Mirenda, Szatmari, Duku, Smith, Vaillancourt, & Elsabaggh, 2018). Social support serves an important function in helping parents to cope (McInnes, Fix, Solomon, Petrakis, Sawh, & Smelsonet, 2015). Additionally, it empowers those families with ASD children by giving them hope and leading them to completely appraise the situation in the longer term, successively reducing the negative impact and stimulating a positive outlook (Ekas, et al., 2010).

Positive coping methods in families of children with ASD are usually related to the presence of adequate social support (Singh, Ghosh, & Nandi, 2017). What is more, social support has conjointly contributed to reducing parenting stress, the burden of having an autistic child, and depression. A positive relationship exists between family adjustment and social support. For instance, families that have been offered more social support report that they are better able to adjust to having a child with an ASD (Ekas, et al., 2010). Equally, a combination of resilience, and physical and emotional wellbeing have been found to relate fully to social support in families raising children with ASD.

A study conducted in the United State of America (USA) by Ekas, et al., (2010) consisting of a sample of 78 families with children with ASD in the age group, two to six years, reports that social support can be divided into two forms, informal and formal support. Informal support is delineated as comprising people who are part of the interaction that embodies family, friends, the spouse, and other parents of children with ASD. On the other hand, formal support is provided through a company or an agency, providing access to health care practitioners, faculty workers, and childcare suppliers, skilled agencies, and church ministers to ensure early intervention.

Each type of formal and informal support is utilised and perceived as useful (Ekas, et al., 2010; Singh, et al., 2017). However, informal support plays a crucial role in serving caregivers who can alleviate the emotions of isolation and helplessness usually related to raising a child with ASD. Family sources of support embrace a spouse or partner, relatives, parents, the parents of spouse, a spouse’s relatives, and children. Alternative non-family informal sources of support include friends, other relatives, the friends of a spouse, parent groups, social groups or clubs, and associates. Thus, social resources linked to the family include both those that are formal and those that are informal (Zaidman-Zait, et al, 2018).

According to Singh, et al. (2017), over 90% of primary caregivers rely on their spouse or partner as a source of support, with the bulk of caregiver’s reporting that their spouse or partner was useful. Many studies have conjointly shown that mothers of children with ASD first approach their spouses for support, then approach their immediate family, and finally communicate with the parents of other children with ASD (Lindsey & Barry, 2018). This finding was supported by a study conducted with the fathers of ASD youngsters who felt no need for formal support as their spouses’ support was enough for them (Burrell, Ives, & Unwin, 2017). If their spouse is not the most effective support it is possible that he or she is also equally distressed and unable to supply effective support. Partners and friends seem to directly influence some aspects of the caregiver’s well-being, whereas family support operates indirectly by helping mothers to become or stay optimistic as they confront the challenges related to raising a toddler with ASD (Ekas, et al, 2010).

Children with autism spectrum disorders (ASD) and other developmental disabilities together with their families should be given priority for support services as support is an integral part of caring for children with ASD and other developmental disabilities. Children with ASD present with impaired social communication and interaction including limited repetitive patterns of behaviour, interests, and activities. The causes of ASD remain unknown, but multiple factors such as genetics and infectious diseases appear to contribute to the disorder (Russa, Matthews, & Owen-DeSchryver, 2015). Some children with ASD often experience chronic medical conditions, such as seizures. These symptoms are present from early childhood and interfere with everyday functioning (Uys & Middleton, 2014).

One of the values and principles of the South African National Mental Health Policy Framework and Strategic Plan, 2013-2020 (DoH, 2012) states that families and carers of those with mental illness should be provided with maximum support and integration to broaden the network of support and care. Obtaining support for children with developmental disabilities is difficult because of the stigma attached to these disabilities and the general lack of understanding of its cause, care, treatment and rehabilitation (Cohen, Marvin, Law & Lipkin, 2015).

Children with these disorders should be diagnosed as soon as possible at 18 months and thereafter, be put into specific therapeutic programmes. In order to limit the impairment of their development and require lifelong support and access to specialised services. These programmes are supported by the Mental Health Care Act 17 of 2002 section 26 (South Africa. *Government Gazette,* 2002) which states that a person suffering from a severe or profound mental disability and who is incapable of making an informed decision requires care, treatment and rehabilitation services for their health or safety, and the safety of other people.

A child diagnosed with ASD may represent a constant source of stress on the entire family unit and the health, well-being, and experiences of individual family members, across the lifespan of family members (Chiang, 2014; Greeff and Van der Walt, 2010; Kissel and Nelson III, 2014). The stress results mainly from the burden of caring for an ASD child who presents with issues of dependency, poor educational progress, social isolation, and the extremely antisocial, disruptive behaviour associated with ASD, such as tantrums, self-injuries, obsessive-compulsive behaviour and poor prognosis (Schlebusch, 2015). Families of children with ASD are challenged by a number of issues across their life span according to Chiang (2014). Key family needs include access to quality information, access to coordinated services, training in self-help skills, support from the community, neighbours, and family as well as professional collaboration and long-term planning support (Russa et al., 2015). Key needs for children with ASD include material, financial, practicing social skills approaches such as initiating social conversation, greetings, initiating games and joint attention; behavioural and pharmacological interventions; computer games to reinforce the good behaviour and educational interventions (Sadock, Sadock, & Ruiz, 2015).

Bakare and Munir (a) (2011) indicate that few studies about autism in Africa have been published. It is difficult to determine the prevalence rate of the disorder in African countries. Thus, the sample populations in the published studies do not appear to be representative of children in the respective countries, namely Nigeria, Egypt, Sweden, Tunisia and Tanzania (Abubakar, Ssewanyana, De Vries, & Newton, 2016). More controlled studies are needed to establish the role of factors, such as the age of onset, characteristics and the epidemiology of the ASD across the continent (Bakare & Munir (a), 2011). These studies could also help answer the question regarding the causes or etiology of ASD and may also shed light on the reasons for possible differences in the distribution of ASD in geographical regions (Bakare & Munir (b), 2011).

In South Africa, the Mental Health Care Act 17 of 2002, (Department of health, 2004) provides for the care and rehabilitation services offered to a person with mild, moderate, severe or profound intellectual disabilities. The vocationally related service needs of children with special needs are the responsibility of the Department of Basic Education. The Department of Health is responsible for the provision of treatment and care of a person suffering from an intellectual disability as stipulated in the National Mental Health Policy Framework and Strategic Plan, 2013-2020 (Department of Health, 2012).

According to the results of the study conducted by Kgole and Molepo, (2014) in Moletsi village, Limpopo Province on parents of children with intellectual disabilities showed that the parents were subjected to a negative experience related to supporting services. These include feelings of discouragement and rejection by health professionals, constraints in regard to access to health services after being referred because travel costs are expensive. These parents received poor support from relatives, friends, neighbours, and colleagues and poor community services. Poor academic support was experienced due to the lack of special schools. Emotional distress was also experiences due to the lack of emotional support.

Limpopo Province is one of the poorest provinces in South Africa with limited resources to support families and children who have developmental disabilities (Sandy, Kgole & Mavundla, 2013). There are 34 institutions for children with developmental disabilities, and none of these institutions is specifically intended for ASD children only. The enrolment of ASD learners in special schools in Limpopo Province was 249 in 2013 according to the White Paper No 6 on Inclusive Education (Department of Basic Education, 2015). On the other hand, Gauteng Province is one of the highly urbanised provinces in South Africa with the highest number of institutions that cater for children with developmental disabilities and ASD. It has 137 special schools for children with developmental disabilities of which four special schools are intended specifically for ASD children only. According to the study conducted in Gauteng by Springer, Laughton and Kidd (2013) an increase of 8.2% was recorded in the number of children presenting with features of ASD to a developmental clinic in Johannesburg during the period, 1996–2005. The enrolment of ASD learners in special schools in the Gauteng Province was 774 in 2013 according to the White Paper on Inclusive Education No 6 (Department of Basic Education, 2015).

Various theoretical models, together with the strategies and resources to meet the needs of families of ASD children were developed in western countries. This includes the Positive Behavioural Interventions and Supports (PBIS) model. It provides a useful framework for implementing family support to meet family needs over the life span. The PBIS model represents a framework for role players who provide support to families so that they can become actively engaged in developing and implementing interventions that meet the needs of the family and the child (Russa et al., 2015).

The parent educator collaboration approach includes the involvement of the parent in every phase of the special education process. Parents and school professionals share a desire to help the child succeed within an educational environment. The fundamentals of parent-teacher collaboration within a school environment include building parent rapport, developing a communication system with a maintenance plan, and creating additional special event opportunities for parent involvement (Timothy, Philip & Marshall, 2011).

The Parent-to-parent (PTP) model is a national organisation in Pennsylvania that serves to connect parents of children with ASD one-on-one with a volunteer parent who can relate to their experiences and provide information and support (Santelli, Ginsberg, Sullivan & Neiderhauser, 2002).

The Medical Home model is an aspirational attempt to treat the whole person by linking the patient to a full range of coordinated, intervention and prevention-focused services. In America, when the family with a child with ASD seeks services from their medical home primary care practice (MH-PCP), in addition to addressing medical concerns, the MH-PCP then links and coordinates family receipt of appropriate services from a range of professionals (Dickinson & Miller, 2010).

Families of children with ASD report that locating services, understanding services options and needs, and applying for services are difficult at best, particularly given the complexity of today’s system. Thus, families require help to identify and initiate services that address current needs. Once services are identified, services coordination becomes a foundation of family-centred care (Russa et al., 2015). The Family Navigator and Service Coordination model accommodates a study of this problem.

Gaps identified by the researcher in the literature was that few studies about the support of families with ASD children in South Africa have been published. Limited data exists on the experiences of families of ASD children in South Africa. Poor records have been kept on children and adolescent psychiatric disorders in South Africa. Furthermore, little is known about support models for families of children with ASD in South Africa, and, hence, there was a need for further investigation. It was against this background that the researcher developed a support model for families of children with ASD in the Gauteng and Limpopo provinces in South Africa.

1.2 RESEARCH PROBLEM

Families that have ASD children and who bring those children to the child psychiatric clinic seem to struggle to come to terms with their children’s diagnosis of ASD. Furthermore, these families seem not to be adjusting well in living with children with destructive and antisocial behaviour and who require special needs in their home. The poor educational progress of the child, poor prognosis and the demands associated with caring for the child represent a source of stress on the families (Schlebusch, 2015). This was supported by the findings of the study conducted by Greeff and Van der Walt, (2010) which stated that because of the severity of the disorder many families struggle to come to terms with their child’s diagnosis and to adjust to having a child with special needs in their home.

The cultural beliefs and values of some families of children with ASD seem to interfere with family participation in the intervention. Athari, Ghaedi, and Kosnin (2013) state that as parents try to make sense of their child’s disability, they draw on cultural beliefs and values as well as their understanding of normative development for their culture. In addition educational interventions is one of the most management strategy for children with ASD. The formal educational interventions are provided by the teachers at the special schools. Therefore teachers of children with ASD had lived experiences regarding teaching ASD children more than anyone else in the special schools. Teacher’s contributions in this study is necessary to describe the challenges, needs and support required by both ASD children and their families with regards to educational interventions.

Other models representing support to families of children with ASD in the western countries have been developed, while little is known about support models for families of children with ASD in South Africa. Children with ASD have complex needs that challenge families in unique ways. However, the needs of families of children with ASD in South Africa may not be the same as the needs of families in western developed countries due to our differences in cultural beliefs, the economic context and the social milieu in South Africa. This has encouraged the researcher to investigate this issue further. Therefore, the researcher was motivated to develop a support model for families of children with ASD in the Gauteng and Limpopo provinces of South Africa.

The subject literature also indicates that there is limited data on the challenges and experiences of families of ASD children in the rural, underdeveloped regions of the world, such as parts of South Africa (Schlebusch, Samuels, & Dada, 2016). Therefore, the study seeks to explore the experiences of families and teachers of children with ASD in Gauteng and Limpopo Province, as regions of South Africa. The results of this study guided the development and validation of a support model for families of children with ASD.

1.3 AIM OF THE STUDY

The main aim of the study was to explore and describe the experiences of families and teachers regarding the support of families with ASD children, and subsequently to develop and validate a support model for families of children with ASD in the Gauteng and Limpopo provinces of SA.

1.4 RESEARCH QUESTIONS

The following questions guided the study:

What are the experiences of families and teachers regarding the support of families with ASD children in the Gauteng and Limpopo provinces of SA?

What model can be developed to provide a framework for support to the families of children with ASD in the Gauteng and Limpopo provinces of SA?

How will the support model be validated?

1.5 OBJECTIVES OF THE STUDY

The objectives of this study were divided into three phases:

Phase 1: Empirical research and conceptual framework

- **Objective 1:** To explore and describe the experiences of families and teachers regarding the support of families with ASD children in the Gauteng and Limpopo provinces of South Africa.
- **Objective 2:** To identify and analyse the main concepts related to the support of families with ASD children that could lead to the development of a conceptual framework for the provision of social support for families with ASD children in Gauteng and Limpopo provinces in South Africa.

Phase 2: Development and description of social support model

- **Objective 3:** To develop and describe a model for the provision of social support for families with ASD children in special schools of the Gauteng and Limpopo provinces in South Africa.

Phase 3: Validation of social support model

- **Objective 4:** To validate the operationalisation of the social support model for families of children with ASD in the Gauteng and Limpopo provinces in South Africa.

1.6 THEORETICAL AND CONCEPTUAL FRAMEWORK

In this study, two theories were used to guide the process of the study and to make research findings meaningful. These were firstly, the Theory of Human Caring by Watson (2008) and, secondly, the Practice-oriented Theory of Dickoff, James and Weidenbach (1968). Watson's (2008) philosophy and science on caring theory as indicated in Alligood (2014) was adopted as a theoretical framework to analyse the experiences of families of children with ASD and provide a focus for the care and support of families with ASD children and their teachers. The practice-oriented theory by Dickoff et al. (1968) was also adopted as a conceptual framework to develop the support model that would be useful to families of children with ASD. It would serve to clarify concepts and to indicate the relationship between the concepts and it could also provide a context for interpreting the study findings.

1.6.1 Watson's (2008) philosophy and science on the caring theory

Families of children with ASD are challenged by a number of issues during their life span which requires different support services. Watson's theory of Human Caring cited in Ozan, Okumus, and Lash (2015) aimed to ensure a balance and harmony between the health and illness experiences of a person.

In a holistic approach to caring for a human, Watson (2008) states that there are mind, body and spiritual sub-dimensions. Therefore, applying Watson's Theory of Human Caring for the families of children with ASD in this study, was especially applicable because the Theory of Human Caring is people-oriented focussing on total human integrity without compromising the physical, psychological and spiritual aspects of support. The theory signifies that love is the most important source of healing.

The theory defines nursing as the process of human-to-human caring (Ozan et al., 2015) which consists of four basic concepts, namely, the healing process, interpersonal maintenance of the relationship, the caring moment and awareness of healing. The ten curative factors illustrated by Watson's theory provide a guide to the implementation of the theory in Figure 1.1.

The humanistic-altruistic system involves practicing loving, kindness and compassion for children with ASD and their families. Enabling faith-hope involves encouraging spiritual support for the families of children with ASD and also comprises a belief in the treatment and therapy services. The cultivation of sensitivity to self and others includes the provision of support assistance with recognition of feelings in order to become more genuine, authentic and sensitive to others. A helping-trusting, human care relationship involves the development of a helping trust relationship that will provide psychological support which will promote and accept the expression of both positive and negative feelings. The expression of positive and negative feelings emphasises the issue of sharing feelings of emotional support, the promotion of acceptance and understanding of the situation. Creating a problem-solving caring process ensuring that families of children with ASD are provided with different therapies to improve their children's behavioural problems and also counselling for the healing process. Transpersonal teaching-learning allows the families to be informed about ASD, mental health, self-help skills, behavioural and cognitive skills, and advocacy skills to improve their knowledge. A supportive, protective and corrective mental, social, spiritual environment provides a therapeutic environment for all levels of physical, psychological and spiritual support. Human needs assistance comprises assistance to families of children with ASD who need to be assisted to meet the basic needs of their children. The theory guides the empirical study because it deals with the support, physically, psychologically and spiritually.

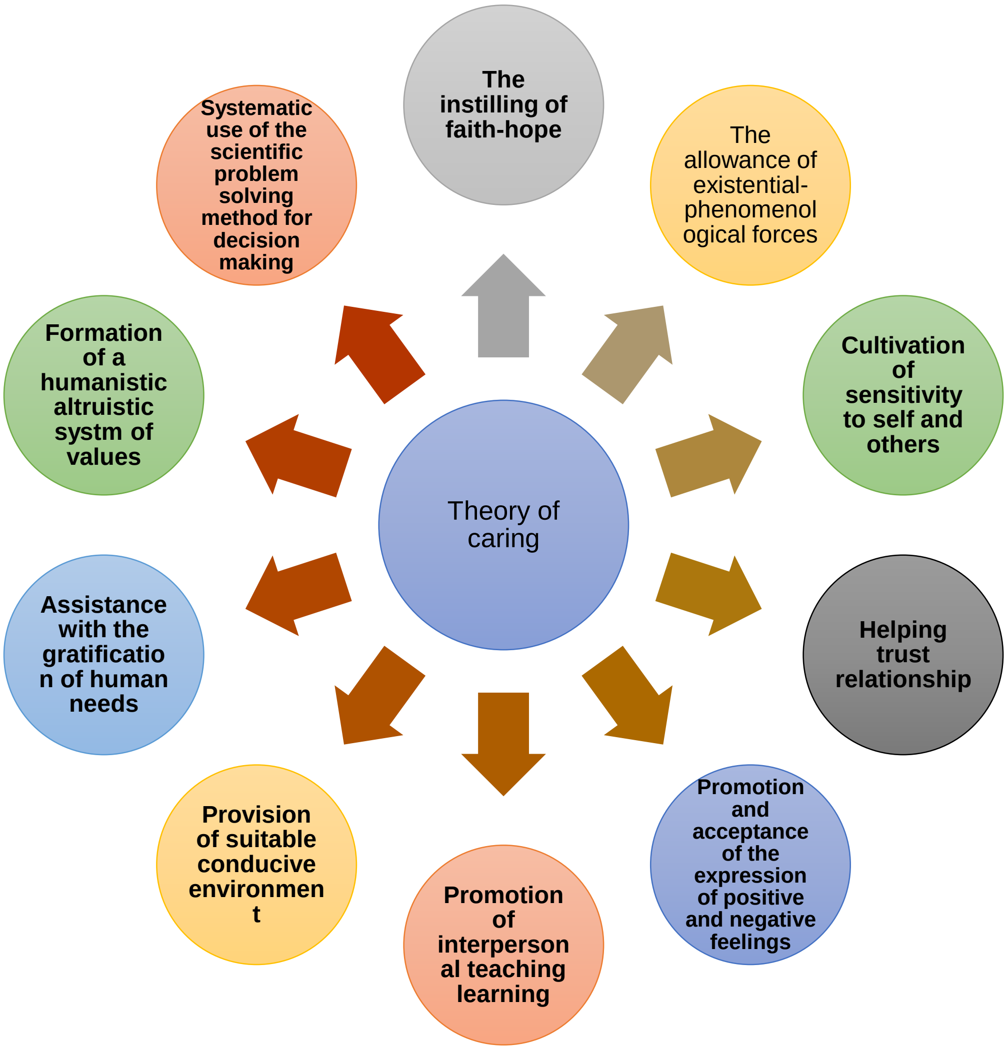


Figure 1.1: Watson's philosophy and science on caring

1.6.2 Practice-oriented theory by Dickoff, James and Weidenbach (1968)

The practice-oriented theory formulated by Dickoff et al (1968) guided the process of developing the support model for families of children with ASD shown in Figure 1.2. The main concepts of the study identified in Chapter 5 are classified according to the survey list developed by Dickoff et al (1968). The survey list highlights six activity aspects that correspond to the six questions which should be addressed in the survey. All Aspects of the activity list are important and should thus be taken into consideration to acquire a full exploration of the experiences of care and support of ASD children as perceived by families and teachers. Six questions relating to the activity aspects and used to survey activity include:

- **Agency**: who performs the activity?
- **Patiency** or recipiency: Who or what is the recipient of the activity?

- **Framework**: In what context is the activity performed?
- **Procedure**: What is the guiding procedure, technique or protocol of the activity?
- **Dynamics**: What is the energy source for the activity?
- **Terminus**: What is the endpoint of the activity?

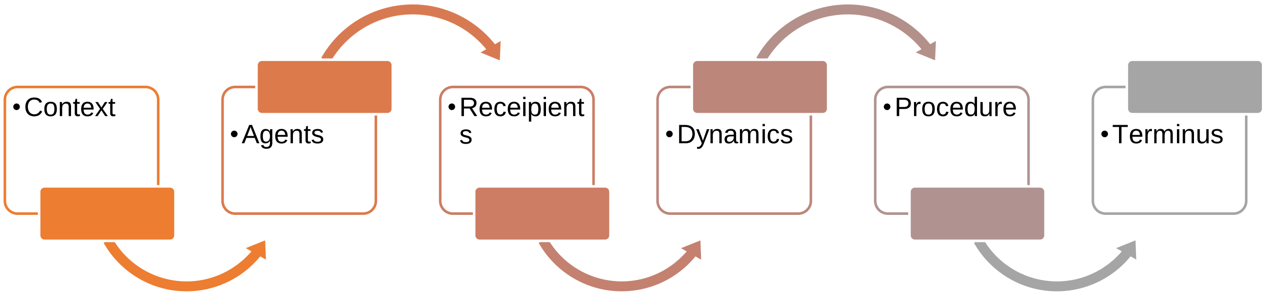


Figure 1.2: The practice-oriented theory by Dickoff et al (1968)

1.6.3 Paradigmatic perspective

Paradigm is defined as a way of looking at natural phenomena that encompasses a set of philosophical assumptions and that guides one's approach to inquiry (Polit & Beck, 2010). The paradigmatic perspective is the whole system of thinking and general orientation, and it is viewed as a system of rationalising issues (Neuman, 2006). A paradigm has meta-theoretical, theoretical and methodological assumptions which guided the research study (Babbie, 2010). In this study the theoretical paradigmatic perspectives was based on Watson's (2008) theory of caring and Dickoff, et al., (1968) practice orientated theory as described in details on 1.6.1 and 1.6.2. Methodological assumptions based on qualitative, explorative, descriptive, contextual and theory-generating study employing a phenomenological approach as described in detail on Chapter 3.

- Meta-theoretical assumptions

Meta-theoretical assumptions clarify and describe the existence of societies and human beings and all other aspects which can affect communities (Babbie, 2010). The meta-theoretical assumptions are also grounded in the researcher's own philosophy, which respects the privacy, dignity and beliefs of an individual. In nursing usually four major concepts are emphasised which includes person, health environment and nursing (Basavanthappa, 2007). The meta-theoretical assumptions of this study comprise of person, health, the community and nursing as described below.

Human beings are social being, sentiment, and rational reaction, perceiving, controlling, purposeful, and action-oriented and time oriented (Basavanthappa, 2007). Human beings in this study are families and their children diagnosed with ASD.

Health is a dynamic life experiences of human being, which implies continuous adjustment to stressors in the internal and external environment through optimum use of one's resources to achieve maximum potential for daily living (Basavanthappa, 2007). Health in this study is the experiences of families and teachers of ASD children.

Environment is the background for human interaction, where the individuals interact with both internal and external environment that generate stressors (Basavanthappa, 2007). Environment in this study is the special schools in Gauteng and Limpopo provinces of SA.

Nursing is a process of action, reaction, interaction and transaction whereby nurse and client share information about their perceptions in the nursing situation (Basavanthappa, 2007). In this study nursing is the social support model and guidelines developed to support families of children with ASD.

1.6.2.1 The context of the study

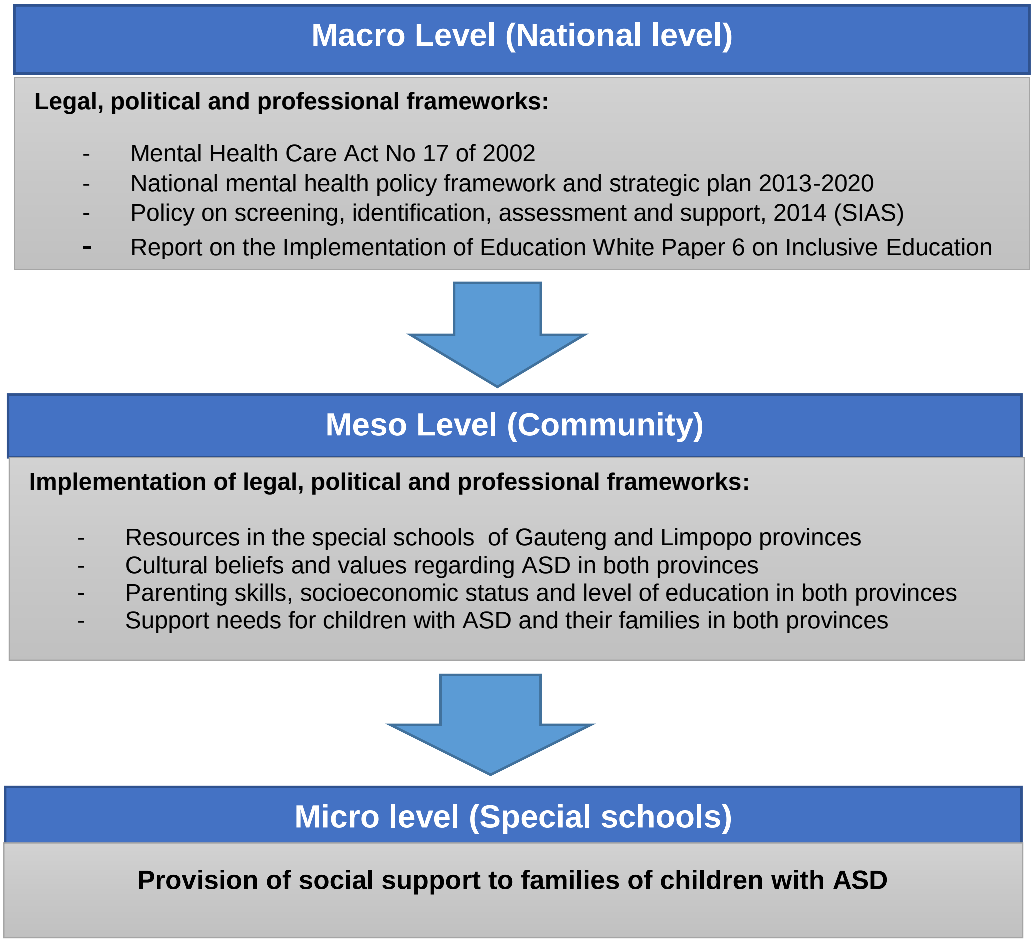
The study is contextual in that it focuses on the experiences of the families and teachers of children with ASD in the context of the special schools that provide for the needs of children with ASD in the Gauteng and Limpopo provinces. The contextual strategy concentrates on producing a specific description of the perception of families and teachers within the context of the unique setting. The study context is divided into three levels, namely, the macro level (basic education), the Meso level (community) and the micro-level (special schools).

The three levels of context are linked and have important influences on the provision of social support for families of children with ASD. Figure 1.3 shows the three different levels and how they are interrelated.

The macro-level refers to the national level and its context includes legal, political and professional framework facets characterised by various legislation that provides a guideline to the special schools on how to provide support, care, treatment, rehabilitation, and education to children with special needs.

The meso-level context refers to the community where the ASD children and their family members reside in the Gauteng and Limpopo provinces. The context includes the cultural beliefs and values regarding intellectual disability, parental skills, socio-economic status and the level of education which may have an impact on the provision of informal support to the families with ASD children.

The micro context is the special schools in the Gauteng and Limpopo provinces where ASD children are admitted. It is made up of elements, such as vision, mission, and values accompanied by strategy and strategic goals that impact on the education process within that specific institution.



Macro Level (National level)

Legal, political and professional frameworks:

- Mental Health Care Act No 17 of 2002
- National mental health policy framework and strategic plan 2013-2020
- Policy on screening, identification, assessment and support, 2014 (SIAS)
- Report on the Implementation of Education White Paper 6 on Inclusive Education

Meso Level (Community)

Implementation of legal, political and professional frameworks:

- Resources in the special schools of Gauteng and Limpopo provinces
- Cultural beliefs and values regarding ASD in both provinces
- Parenting skills, socioeconomic status and level of education in both provinces
- Support needs for children with ASD and their families in both provinces

Micro level (Special schools)

Provision of social support to families of children with ASD

Figure 1.3: Context of the model

1.7 PHASE 1: EMPIRICAL RESEARCH AND CONCEPTUAL FRAMEWORK

1.7.1 Summary of the research methodology

In this section, the research methodology used to collect data is described. It includes the setting, the population selected for the study, the data collection process and data analysis. The study adopted a qualitative, explorative, descriptive, contextual design employing a phenomenological approach and theory-generating study. A theory generating design as suggested by Walker and Avant (2011) and Chinn and Kramer (2008) was employed for model development.

Purposive sampling recruited 37 participants from the selected special schools of Gauteng and Limpopo Provinces, these includes primary caregivers and teachers of children with ASD (see Table 3.1). Primary caregivers and teachers of ASD children participated in this study as they have lived experiences with regards to caring/teaching ASD children and more knowledgeable regarding the challenges, needs and management of the ASD children.

The research design was achieved by exploring the experiences of primary caregivers and teachers of children with ASD, through semi-structured and focus group interviews to get a comprehensive overview of their experiences. Both groups of participants were involved in semi-structured and focus group interviews to describe their day-to-day experiences of children with ASD in the special schools of the Gauteng and Limpopo provinces (see Figure 3.1 & 3.2).

Two focus group interviews were conducted with the primary caregivers and teachers respectively. A total of fifteen (15) semi-structured interviews were conducted with the primary caregivers and fourteen (14) with the teachers (see Table 3.2). Semi-structured interviews was used to allow participants the freedom to express their views and open up about the experiences. Furthermore it encouraged participants to discuss more easily sensitive issues experienced when caring/teaching ASD children. Focus group were used to allowed participants to talk to one another, argue and ask questions, and was especially useful for finding out about shared experiences. A flexible interview guide (Annexure P) that provided a loose structure of open-ended questions to explore the experiences of the participants was used during semi-structured and focus group interviews to achieve the explorative design.

The data that were collected during individual semi-structured in-depth interviews were analysed using eight steps of Tesch's open coding qualitative data analysis method as described in Creswell (2014). This is outlined in the chapter on research methodology. Data were also submitted to an independent coder who also used eight steps of Tesch's open coding method of qualitative data analysis as described by Creswell (2014). A consensus meeting was set up between the researcher and the independent coder to discuss and agree on final themes and sub-themes based on the themes which emerged when the data was analysed independently.

Trustworthiness was ensured by applying the following measures: credibility by adopting prolonged and varied field experience, triangulation, member checking, and peer examination. Transferability was achieved by providing a detailed description of research methodology and purposive sampling. Confirmability was achieved by means of field notes and triangulation. As far as dependability is concerned data were analysed by the independent co-coder and the researcher and consensus was reached on the themes and sub-themes that emerged.

Ethical considerations of informed consent, confidentiality, anonymity, beneficence, and justice was observed. The findings which emerged from Phase 1 were employed to develop the support model which is part of Phase 2 of the study. A more detailed description thereof is provided in Chapter 3.

1.8 PHASE 2: DEVELOPMENT OF SOCIAL SUPPORT MODEL

The objective of Phase 2 was to develop a social support model for families of children with ASD. The social support model was developed from the study concept analysis in six steps. The approaches from which a social support model for families of children with ASD was developed involved the use of Chinn and Kramer's (2008) six proposed questions. The study followed four steps of theory building as proposed by Walker and Avant (2011) which include Step one: concepts identification, step two: conceptual framework, step three: model description and step four: validation of the model.

Identification of the concepts in the concluding statements was guided by conceptualisation as set out in Chinn and Kramer (2008). Concepts and main concepts used to develop a social support model were classified using the survey list of Dickoff et al (1968). A more detailed description thereof is provided in Chapter 6.

1.9 PHASE 3: VALIDATION OF SOCIAL SUPPORT MODEL

The objective of phase three was to validate the operationalisation of the social support model for families of children with ASD children in terms of Chin and Kramer 2008 criteria. Validation is defined as the phase in which the model developed is critically appraised to determined its scientific soundness (Grove, Burn & Jennifer, 2013). The model was validated because the potential users are the parents of children with ASD, professional nurses, and teachers working in special schools and experts in model development and child psychiatric nursing.

The guidelines to develop information about how well-developed a model is or how adequate it is in terms of its purpose were described using the three levels, namely, the macro, meso, and micro levels. These guidelines are aimed at actually putting the model to practice in families of children with ASD in the Gauteng and Limpopo provinces. A more detailed description thereof is provided in Chapter 7.

1.10 SIGNIFICANCE OF THE STUDY

This information would be used to develop a social support model for families of children with ASD that may make the contributions set out below.

Families

- To assist families with ASD children to acquire the necessary skills and knowledge regarding caring for ASD children, that are known to create family stress and possibly elicit reactions to their personal life experiences and occurrences.
- To develop a model that would not only focus on supporting families with ASD children in meeting their support needs but would strengthen and empower them to cope with the impact of having an ASD child at home.
- To provide informal supportive intervention strategies for facilitating hope to the families and to encourage the utilisation of recreational facilities in the community.
- To encourage the establishment of support groups for families with ASD children to share experiences.
- To provide a safe, calm and supportive environment.

Department of Education

- To influence basic education programmes regarding the teaching of ASD children for a positive impact on children's self-esteem, school achievement, cognitive development, and behaviour.
- To offer guidance to the special schools on strategies to support families of children with ASD.
- To encourage the academic and professional development of teachers with the necessary skills to train ASD children
- The findings of this study can be used to develop policies to reduce stigma, increase awareness about ASD and address the needs of the primary caregivers of ASD children.

Department of Health

- To offer guidance to the health establishments on maximum support to be provided to families and carers of those with ASD, and to broaden the network of support and care.
- To guide health professionals on efficient formal and informal intervention methods to lower the stress in families of children with ASD. More specifically, reinforcing factors contributing to family empowerment would result in a positive educational and developmental impact on children with ASD.
- To improve awareness about ASD, to decrease its stigma and improve access to appropriate education and support for primary caregivers
- To bridge the gap in the existing body of knowledge as the studies on the social support model for families of children with ASD in South Africa are limited.

1.11 OUTLINE OF THE THESIS

Chapter 1 The orientation of the study (Phase 1)

This chapter outlined the background of the study, the research problem, the rationale of the study, the purpose, objectives, research question and significance of the study. It identifies the theories that guided the study and the outline of the chapters.

Chapter 2 Literature review (Phase1)

This chapter outlined the literature review using steps of scoping review methodology. Literature regarding the prevalence of ASD, the experiences, and challenges of families with ASD children, the needs for support, coping strategies, and support models were reviewed. The application of Watson's theory to the literature review was outlined.

Chapter 3 Research Methodology (Phase 1)

This chapter describes the research design, approach, study site, population, sampling, data collection, pilot study, data analysis procedure, measures to ensure trustworthiness, ethical considerations, and steps for model development and bias.

Chapter 4 Analysis, interpretation of the results and literature control (Phase 1)

In this chapter, the findings of the study were analysed, interpreted, discussed and controlled through literature

Chapter 5 Concept analysis (Phase 1)

This chapter outlined eight steps of concepts analysis as highlighted by Walker and Avant (2011).

Chapter 6 Development of social support model (Phase 2)

This chapter outlined model description according to the following sub-headings: an overview of the model, the structure, context, purpose, relation statements and assumptions on which the model is based and guidelines for operationalisation of the model

Chapter 7 Validation of social support model (Phase 3)

This chapter outlines the validation of the social support model based on the criteria offered by Chin and Kramer (2008) and by a panel of experts for evaluation and

Chapter 8 Summary of research findings, recommendations, and conclusions

This chapter outlines the summary of the study, limitations, conclusion, and recommendations for the utilisation of the model for facilitation of support for families with ASD children in nursing practice, research and education

1.11 CONCLUSION

This chapter outlined the background to, the rationale for, as well as the aim, objectives, and significance of the study. Theories that guided the study namely: Watson's theory (2008) of caring and the practice-oriented theory of Dickoff et al (1968) were briefly discussed. The research design and methodology were briefly described. The methodology for the development and validation of the model, support model phases 2 and 3 were briefly discussed. The next chapter deals with literature reviewed in this study.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The previous chapter provided an introduction and background to the study. This chapter will be a literature review. This chapter provides the background information about Autism Spectrum Disorder (ASD) and the overview of the literature on ASD, including a discussion of different psychosocial support models. A broad review of relevant sources including recent articles published in journals accessed on the internet and books and other monographs about ASD and psychosocial support models available in the library is presented. The main objective of this review of the literature was to discover how other countries provide support to the families of children with ASD and then to formulate a benchmark on good practices in this regard that could be implemented in Limpopo Province to improve the psychosocial support for families of children with ASD.

2.2 CONDUCTING AN EXPANDED REVIEW OF THE LITERATURE

The literature review is an important part of the process of developing a model. A literature review functions as a means of conceptualising, justifying, implementing and interpreting a research investigation (Moule & Goodman, 2014). The literature review has provided a theoretical and empirical framework on which the model to support families with ASD children is based.

In this study, the literature review has two phases. The first phase was dealt with in step 1 which includes the introduction and background in chapter 1 and chapter 2. It helped to identify and refine the discussion on the need for a new model to support families with ASD children. The second phase is dealt with in step 2 which comprises Chapter 5 and supports the conceptual framework.

2.3 LITERATURE REVIEW METHODOLOGY

In this study, the scoping review approach was used. A scoping review is a relatively new methodology for which there is not yet a universal definition or definite procedure (Pham, Rajić, Greig, Sargeant, Papadopoulos, & McEwen, 2014; Peters, Godfrey, Khalil, Mclnerney, Parker, Soares, 2015; Peterson, Pearce, Ferguson, Langford, 2017). Yet, the first framework for a scoping review was published in 2005. There is documented evidence that several scoping reviews have been completed in nursing science of which nurses or nurse practitioners were the authors (Peterson, et al., 2017). A scoping review shares a number of the same processes as a systematic review. However, the key difference between the two review approaches can be attributed to aims and purposes (Pham, et al., 2014; Peters, et al., 2015). The main aim of the scoping review is to map the key concepts in a topic area. On the other hand, a systematic review aims to summarise answers to a specific question using the best available research (Pham, et al., 2014). A scoping review provides for more flexibility by including a diverse body of relevant literature and using different methodologies whereas a systematic review focuses on a smaller number of studies (Peterson, Pearce, Ferguson, & Langford, 2017).

The methodology of the scoping review used the six-stage process defined by Arkey and O'Malley (2005):

1. Identifying the research questions
2. Identifying the relevant studies
3. Study selection
4. Charting the data
5. Collating, summarising and reporting the data
6. Consultation (optional stage)

The review in this study includes the first five key stages. The consultation or ‘optional’ stage of the framework was not conducted.

2.3.1 Stage 1: Research question

This review was guided by the following questions:
‘What are the experiences of families of children with ASD?’
‘What are the support needs of families with ASD children?’

2.3.2 Stage 2: Identifying the relevant studies

An extensive search of literature from 2008 to November 2018 was performed using four electronic databases namely: EBSCOhost, Science direct, World cat and Google scholar with the assistance of the library information specialist. Other sources, such as newspapers and government reports were also used. The databases selected were chosen to be comprehensive and to cover a broad range of disciplines, such as nursing science, allied health science, biomedical sciences, and other multidisciplinary topics. Additional records were identified through internet searches, such as the Department of Education reports, and various policy documents. The search words used include Autism Spectrum Disorder and family experiences or family needs or family support or support interventions or social support or family support models or family challenges or prevalence or incidences. Data searches were performed from January 2017 until November 2018. The search strategy was carried out based on the guiding principles of the respective databases and included inclusion and exclusion criteria.

- Inclusion criteria

The current review sought to examine only studies that were published between 2008 and November 2018, reported in English. Articles were included if they explored experiences and the support of families with ASD children, with a focus on the family or parents and caregivers of children with ASD as the participants. The search strategy included primary research papers on both qualitative and quantitative studies.

- Exclusion criteria

Studies that have not been reported in English and that were published before 2008 were excluded. Studies that investigated the family, caregivers or parents with an ASD child but the outcome was related to the child rather than the family were excluded. Studies that focus on adults with ASD were also excluded. Intervention research was excluded because the focus of interventions would be that of deliberately changing the behaviour of interest in the individual with ASD, whereas the purpose of the research was nonexperimental and designed to understand the experiences and support needs of the family of a child with ASD. Finally, studies that examine the assessment, gender, diagnosis, and comorbidity of ASD were excluded from the study.

2.3.3 Stage 3: Study selection

A total of 53100 journal articles and two reports were identified by means of the electronic search, while an additional two reports were identified through a manual search of reference lists. The identification and selection of relevant studies were based on abstract and title information. Of these 53102 studies, 230 were duplicates and removed from screening. Of the remaining 52872 journal articles, 52771 were excluded based on the initial screening of each title that showed that the study failed to meet the inclusion criteria. Thirty-one studies of the remaining 101, were excluded after the abstracts were reviewed, and the remaining 84 journal articles were examined and assessed in full according to the inclusion and exclusion criteria. This resulted in the final inclusion of 17 articles.

The Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) flow chart is set out in Figure 2.1. It indicates the review decision process, results from the search, removal of duplicate citations, study selection, full retrieval and additional records from the reference list and summary presentation

2.3.4 Stage 4: Charting the data

Charting the data refers to the extraction of the data for a scoping review (Peters, et al., 2015) and should be a logical and descriptive summary of the results that correspond to the objectives of the review. A charting table (as shown in table 2.1) was developed as part of the protocol to record the characteristics of the included studies. The type of information extracted includes the author, year of publication, aims, objectives, sample, sampling techniques, settings, methodology, and key findings.

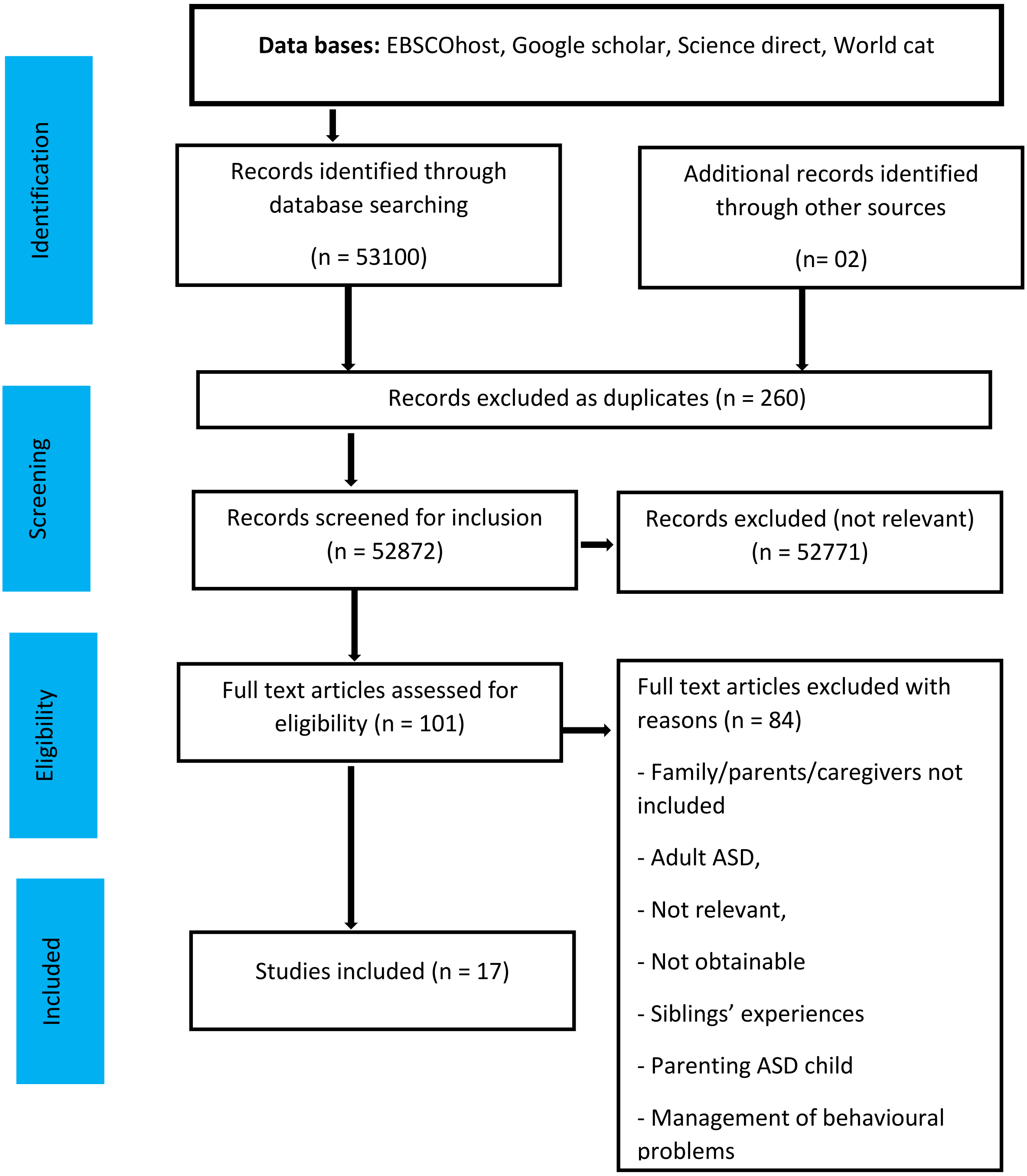


Figure 2.1: PRISMA flow diagram for the scoping review process

2.3.5 Step 5: Collating, summarising and reporting the data

This scoping review reports the evidence in respect of support models for families with ASD children. Seventeen studies met the inclusion criteria. Eight studies are quantitative, seven are qualitative and two are in the form of reports. The extracted results were classified under the following four conceptual categories: prevalence of

ASD, experiences of family and, or caregiver, support needs for families with ASD, and family support models.

2.3.5.1 Prevalence of ASD

Four studies, one media report, and one government report in this review report on the prevalence of ASD globally and locally. The study of Sheldrick and Carter, (2018) report trends in the prevalence of ASD from 2000 to 2012 across the states in the USA among 8-year-olds. The study points to differences in state-level changes that prevailed between 2000 and 2012. The study indicates that the distribution of ASD varied in different states, and this trend was already apparent in the year 2000 and grew substantially throughout 2012 as a result of differences in the growth rates among states. For example, in 2010 the prevalence of ASD in Alabama grew at an average annual rate of 12% which was a slower rate of growth than those observed in other states, whereas the prevalence of ASD in North Carolina grew at an average annual rate of 28%, which was a greater rate of growth.

Similarly, a study of 372 642 children and youth younger than 18 with a principal diagnosis of ASD in Taiwan from 1996 to 2005 by Chien, Lin, Chou, and Chou (2011) reported that the cumulative prevalence of ASD increased from 1.79 to 28.72 per 10 000. The annual incidence increased from 0.91 to 4.41 per 10 000 per year from 1997 to 2005 with higher incidence detected in the 0 to five- year age group, in male children in the northern, southern, and eastern regions including urban areas. In Israel the cumulative incidence amongst eight-year-olds born between 1992 and 2009, increased ten-fold between 2000 and 2011 from 0.49% to 0.49% (one in 203 children) which was a consistent increase (Raz, Weisskopf, Davidovitch, Pinto & Levine, 2015).

A study of all children living in the Avalon Peninsula in Canada between 2006 and 2010 by Pelly, Vardy, Fernandez, Newhook and Chafe (2015) reported that 272 new cases of ASD were diagnosed within the study population. Of these 272 children, 234 were males, 74 had ASD, 130 had an autistic disorder, 56 had Asperger syndrome and 12 had a pervasive developmental disorder not otherwise specified. The incidence of new cases increased from 10.1 to 16.7 cases per 10 000 per year from 2006 to 2010. This prevalence was the highest when compared to the studies in the USA, Taiwan, and Israel and to other global populations. Hassan (2012) investigated the prevalence of ASD in children and youth aged from birth to19 years of age across seven major ethnic groups which included Bangladeshi, black African, black Caribbean and black other, mixed, Somali and white. The prevalence of ASD in Somali and black African children was 1.2% (12.1 per 1000) in the case of the black Caribbean group it was 1.1% (11 per 1000), whereas for the remaining groups the percentage was 0.55% (5.5 per 1000).

Statistics South Africa (2013) indicates that currently there are 15 million youth in the age group from birth to18years of which 150 000 possibly have ASDs (Wilford, 2013). However, Harvey and Meyer (2018) report that only 10% of people in South Africa with autism are correctly diagnosed. This finding was reported at the first conference held in Cape Town to discuss the prevalence of ASD. The conference took place at Valkenberg Hospital, April 2018 and was hosted by the University of Cape Town to mark ‘Autism Month’. During the conference it was indicated that there is little awareness about ASD in South Africa. As a result, families struggle to access the educational services needed for children with ASD and it is difficult for adults to find schools and residences that accommodate children with ASD in the wider community.

Table 2.1: Charting table

No	Author & year	Aims and objectives	Sampling & setting	methodology	Key findings
1	Raz et al (2014)	To calculate cumulative incidence rates in the total Israeli-born population	All children born in Israel 1992-2009	Quantitative study Instrument: computerised records	There was a consistent Increase in ASD incidence for children born between 1992 -2004
2	Pelly et al (2015)	To review the incidence rate for ASD children living in the Avalon Peninsula	All children living in the Avalon Peninsula between 2006 and 2010	Quantitative using retrospective and prospective data	The incidence of new cases increased from 10.1 to 16.7 cases per 10 000 per year from 2006 to 2010.
3	Chien et al (2011)	To examine the prevalence and incidence of ASD using a national database	All children who had at least one service claim from 1996 to 2005 with a principal diagnosis of ASD in Taiwan	Quantitative study	There was an increase in the prevalence and incidence of treated ASD children in Taiwan.
4	Sheldrick & Carter (2018)	To explore systematically differences in state-level ASD prevalence.	Medical and educational records from 2000 to 2012 from the states of the USA.	A quantitative study using secondary data from bi-annual ADDM reports.	State-level heterogeneity in the prevalence of ASD grew substantially through the year 2012 as a result of differences in the growth rates among states.
5	Broady et al (2017)	To investigate caregiver's perceptions of stigma in caring for a child with autism.	Fifteen caregivers from Sydney and the south coast regions of New South Wales, Australia,	An exploratory study using semi-structured interviews	Four domains of stigmatising experiences were identified: lack of knowledge, judgement, rejection, and lack of support.
6	Hartley et al (2017)	To compare the daily couple experiences of parents of children with ASD relative to a comparison group of parents of children without disabilities	174 couples who had a child with ASD relative to 179 couples who had a child without disabilities	Interviews and questionnaires for demographic data completed a daily diary entry via online surveys	Parents of children with ASD reported less time with a partner, lower partner closeness, and fewer positive couple interactions than the comparison group.
7	Gorlin et al (2016)	To examine the experiences of families living with a child with severe autism.	22 participants from 11 families.	Van Manen's phenomenological approach	Six essential themes were identified.

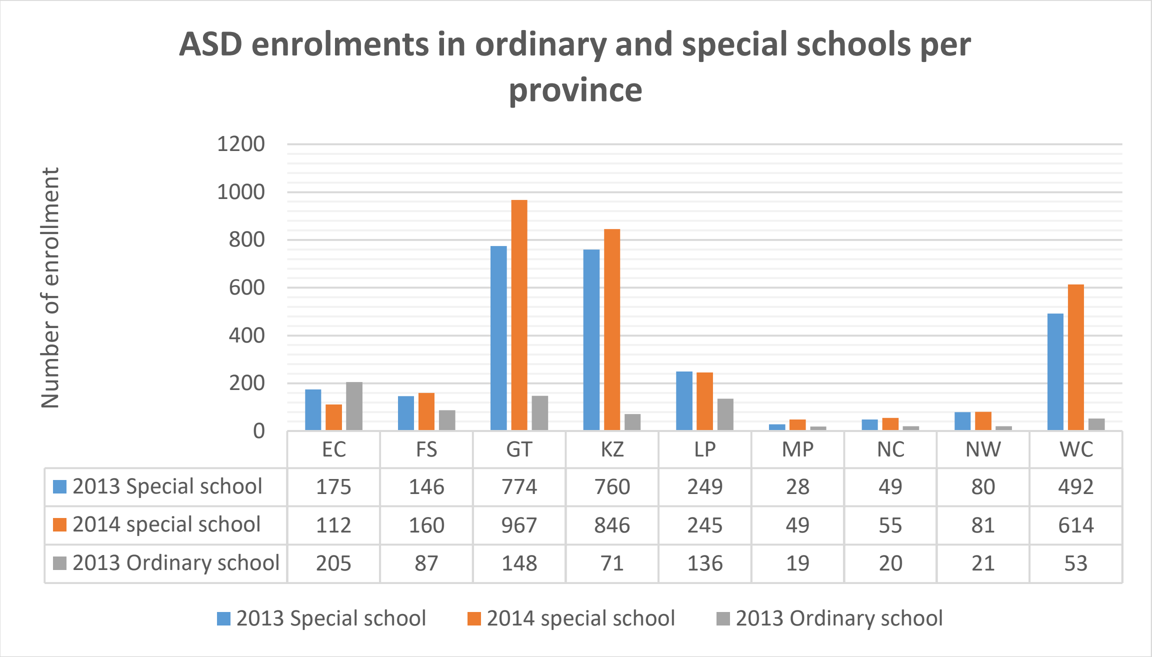
8	Hoogsteen & Woodgate, (2013)	To explore the lived experience of parents of children with autism living in a rural area	28 parents from multiple rural communities from the mid-western Canadian province.	Phenomenological approach	Parents acquired multiple roles and faced many unmet needs, parents were determined to strive for balance within the family.
9	Sim et al (2017)	To identify key factors associated with negative co-parenting experiences in parents raising a child with ASD	Parents of 142 children with ASD	Quantitative study	Family stress due to the child's diagnosis, effects of the diagnosis on parents' relationship with their other children and distance traveled to the nearest medical facility found to have an association with co-parenting relationships.
10	McIntyre & Brown (2018)	To examine the utilization and usefulness of social support	78 American families with children (2–6 years) with ASD	Quantitative study	A combination of formal and informal supports found to be helpful to mothers of children with ASD,
11	Coffee et al (2015)	Examined the types of social support messages exchanged between parents of children with ASD who communicate via Facebook	3637 messages including both postings (381) and comments (3256) gathered from August to November 2013	A qualitative study using the deductive content-analysis approach.	The highest percentage of messages offered dealt with informational support followed by emotional support.
12	Searing et al (2015)	Examined the perceived availability and helpfulness of supports used by caregivers of children with ASD in New Zealand,	92 caregivers	A quantitative study using Family Support Scale	Spouses were rated as the most helpful support followed by professional helpers
13	(Schultz, et al., 2011)	To review parent education programs for parents of children with ASD	30 articles on parent education programmes for parents of children with ASD published in peer-reviewed journals beginning in 1987.	Qualitative study	76% of the articles involved a one-on-one training approach, 40% relied on a manual or curriculum, 86% included data on parent and child outcomes, and 70% used single-case designs to evaluate program effectiveness.
14		To compare the experiences of teachers dealing with students with ASD in different classroom environments.	A total of 245 teachers	Quantitative study self-report questionnaires	Specialised teachers perceive their teaching as a challenge, can count on receiving help from colleagues, use more problem-focused coping strategies and social support seeking behaviour.
15	(Department of Basic Education report, 2015)	Report on the implementation of education white paper 6 on inclusive education			
16	(Harvey & Meyer, 2018) Media report	Autism largely misdiagnosed in South Africa			

As the current study focuses on the families of ASD children in the special schools the total enrolment of learners with ASD in South Africa was analysed both in an ordinary and special school. The Department of Basic Education statistics shows that there is an increase in enrolment of learners in the category of ASD in the special schools of South Africa. In each of four enrolment reports in the special schools focusing on the years 2011, 2012, 2013 and 2014, it was noted that the number of enrolments of ASD learners increased when compared to previous years. For example, it was estimated that the total number of enrolments in 2014 was higher than in 2011, 2012 and 2013. (see Table 2.2) Annual Special School Survey, 2011, 2012 and 2013. Although the number is indicated as not reliable.

Table 2.2: Annual ASD enrolments

Year	**Total number of ASD enrolment**	**Type of school**
2011	2190	Special school
	2760	Ordinary school
2012	2852	Special school
	1209	Ordinary school
2013	2753	Special school
2014	3129	Special school

Figure 2.2 depicts the total number of ASD enrolments per province between 2013 and 2014. Gauteng Province (GP) was noted as having the highest number of ASD enrolments in the special schools followed by Kwazulu Natal (KZ), whereas Mpumalanga Province (MP) was noted as having the lowest number of ASD enrolments amongst all the provinces of South Africa (Department of Basic Education, 2015).



	EC	FS	GT	KZ	LP	MP	NC	NW	WC
🟦 2013 Special school	175	146	774	760	249	28	49	80	492
🟧 2014 special school	112	160	967	846	245	49	55	81	614
⬜ 2013 Ordinary school	205	87	148	71	136	19	20	21	53

Figure 2.2: ASD Enrolments in ordinary and special schools per province

2.3.5.2 Experiences of family, parents and caregivers with ASD children

Four studies in this review reported the experiences of family and, or caregivers with ASD children. The study of 11 families with severe ASD children conducted by Gorlin, McAlpine, Garwick, and Wieling (2016) reported six major challenges related to the care of a child with ASD. First, families experience ASD as mysterious and complex because it is an unobservable and unforeseeable condition with diagnostic challenges. The results are similar to the study conducted by Nagib and Williams (2018). Second, families described types of severe autism behaviour which are more difficult to manage as the child grows. They discussed a range of significant autism-related behaviour that they encountered each day which included self-injurious behaviour, such as, head banging, biting their fingers and arms, throwing themselves into furniture, not sleeping during the night and tantrums. The results agreed with the results of the study conducted by Davis and Finke (2015).

Third, families described impaired communication resulting in isolation between the family and the child. Fourth, they experience severe stress from lack of sleep, managing the child's developmental delays and behaviour, coordinating and financing services, and anxiety about the child's future. The results agree with the results of the study conducted by Nagib and Williams (2018) and Davis and Finke (2015).

Fifth, families described the extreme isolation from friends and the public related to the child's severe behavioural problems and impaired communication challenges. The families discussed their inability to physically leave home because of the child's needs. The results are in agreement with the study conducted by Russa, et al. (2015). Sixth, the last essential lived experience identified was a strong dependence on their families and the compassion they developed for others. To find the necessary physical and emotional support, nuclear and extended families together with their friends should support each other. However, the findings highlighted the extensive challenges of families who have a child with severe ASD, identified needed resources, and illuminated how families formed hybrid families for additional support. The results are similar to the study conducted by Nagib and Williams (2018) and Davis and Finke (2015)

In contrast, a study of fifteen caregivers conducted in Sydney by Broady, Stoyles and Morse (2017) determined the caring experiences of the families of ASD children and how they perceived encounters with the stigma attached to children with ASD. Four domains of stigmatising experiences were identified at school, in public, and among family and friends. First, a lack of knowledge was seen to be a major cause of stigmatising experiences since within their own family and friendship circles comments are made that the children are naughty and that there is nothing wrong with them (Werner & Shulman, 2013). Second, caregivers felt personally judged by others because of their children. This is an extension of a lack of knowledge about the nature of ASD. These results agree with the results of a study conducted by Werner and Shulman (2013. Third, caregivers experienced rejection directed at the caregivers and children. Families felt a lack of courtesy shown towards them when their children were rejected. Fourth, caregivers experienced a lack of support, and felt that schools, families, and friends did not support them in caring for their child or improving their child’s educational experiences. Ultimately, the study contributed to a broader understanding of social experiences among caregivers of children with ASD and with regard to caring and stigmatisation the results are similar to the study conducted by Werner and Shulman (2013).

The study by Hartley, DaWalt, and Schultz (2017) examined the daily experiences of 174 couples who had a child with ASD compared to 179 couples who had a child without ASD. Parents completed a 14-day daily diary in which they reported their daily interactions with their partners as follows: time with the partner, partner support, partner closeness, positive and negative couple interactions, level of positive and negative affect. The findings show that parents of children with ASD reported a lower mean daily level of time with a partner than parents in the comparison group. The level of childcare associated with ASD may reduce the available time for spending with one’s partner. With regardto partner support, there was not a difference in the mean daily level of partner support between parents of children with ASD and the comparison group. The results were similar to the study conducted by Davis and Finke (2015). Fathers of children with ASD reported a lower mean daily level of partner closeness than fathers in the comparison group due to a reduced time with the partner. Parents of children with ASD reported a similar mean daily number of negative couple interactions, such as critical comments or expressions of anger and, or frustration, but a lower mean number of positive couple interactions, such as jokes, intimate acts, and fun activities that parents without ASD children enjoy. The study did, however, find associations between daily couple experiences and parent effects were stronger in parents of children with ASD than parents of children without the disability. Findings were similar to the findings of a study conducted by Schultz, et al. (2011).

The lived experience of 28 parents of children with ASD living in a rural area of a western Canadian province was explored by means of a phenomenological approach by Hoogsteen and Woodgate (2013). Findings revealed that ASD became centered within the family thereby affecting how parents parented. The findings contributed to a broader view of parenting an ASD child since it also includes three things: multiple roles; an intense focus on their child's needs; and finding a balance.

The study indicated that parents of ASD children were found to perform multiple roles and responsibilities in their home and community. These resulted from the behavioural problems of the child who needed more direction, repetition, and supervision. The results are in line with the study conducted by Ahmadi, Zalani, & Amrai, (2011). Parents became teachers, advocates, problem solvers, organisers, coaches, tutors, disciplinarians, and primary caregivers. Other parents had to change occupations or even resign from their jobs to care for their children. Another experience was that the parents dedicated their lives to their child, sacrificed a part of themselves and a part of their other children to provide for their child with autism. These led to increased challenges, such as chaotic and disruptive days, parental mental disorders, and marital stress or breakdown. Parents sacrificed a part of themselves and a part of their other children to provide for their child with autism (Arabiat, Whitehead, Foster, Shields, Harris, 2018). Lastly, parents had to learn to find a balance between their needs and the needs of their children. These include: taking time to learn about autism, and seeking out available support from within the community. Receiving this support was crucial to maintaining balance and, therefore, maintaining their sense of well-being (Hoogsteen & Woodgate, 2013).

In addition, a quantitative study was conducted in Western Australia by Sim, Cordier, Vaz, Netto, and Falkmer (2017) to identify key factors associated with negative co-parenting experiences in parents raising a child with an autism spectrum disorder. The results showed that three factors were associated with negative co-parenting relationships. Firstly, the family experiences stress associated with having a child with ASD. Social support has been shown to help alleviate this stress. The results were similar to the studies conducted by Nagib and Williams (2018) and Davis and Finke (2015).

Secondly, the diagnosis affects parents’ relationship with their other children due to the time-demands of caring for a child with ASD. The results were similar to the results of a study conducted by Hartley, DaWalt and Schultz (2017). Thirdly, the stress related to the distance travelled to the nearest medical facility is a factor. Results showed that 19% of parents travelled more than 30 km to their closest medical centre. The travelling and the associated time demands were expected to place a seemingly endless strain on the family due to the chronicity of ASD and the child's ongoing medical and therapy requirements (Sim, Cordier, Vaz, Netto, & Falkmer, 2017).

2.3.5.3 Experiences of teachers of children with ASD

The schooling of children with ASD can take place in different contexts, namely in regular classes, in specialised classes within an ordinary school, or in a specialised institution (Ruble, Usher, & McGrew, 2011). Teachers working with ASD children reported experiencing job-related stress and burnout (Boujut, Dean, Grouselle, & Cappe, 2016). Aggressive behaviour, in particular, is most difficult for teachers to manage and is associated with high levels of stress (Nistor & Chilin, 2013). The level of stress of teachers working with children with ASD is positively correlated with emotional exhaustion and depersonalisation and is negatively associated with a sense of personal accomplishment (Ruble et al. 2013). These authors also found that emotional exhaustion is negatively associated with support from management. Educating students with autism probably presents teachers with some of the most significant instructional challenges due to impaired communication (Ruble, Usher, & McGrew, 2011).

2.3.5.4 Support needs for teachers

A study conducted by Boujut, Dean, Grouselle, and Cappe (2016) with a sample size of 245 teachers measured perceived stress, social support, coping strategies, and burnout. Specialist teachers perceive their teaching of ASD children as a challenge. They can count on receiving help from colleagues, they use more problem-focused coping strategies and their behaviour shows that they often seek social support, and are less emotionally exhausted than teachers in regular classes.

2.3.5.5 Coping strategies for teachers

Good training, experience, and tailored classroom conditions are reported as being the most used coping strategies for teachers in France (Boujut, Dean, Grouselle, & Cappe, 2016).

2.3.5.6 Support needs of families with ASD children

Four studies in this review examined the perceived availability and helpfulness of supports used by family and caregivers with ASD children. The word social support was used across the studies. It is identified as an important protective factor in caregivers' capacity to cope with stress in caring for a child with ASD (Searing, Graham, & Grainger, 2015). A study of 92 respondents using convergent, parallel mixed methods was conducted in New Zealand to identify the perceived availability and helpfulness of support by caregivers of a child with ASD. The Family Support Scale (FSS) an 18-item self-report instrument and one optional free-text question was used to measure the number and perceived helpfulness of supports drawn on by caregivers (Searing, et al., 2015). Most forms of formal and informal support were perceived as available to caregivers. However, caregivers described considerable challenges with accessing and maintaining access to formal support, such as, parent education, child development services, respite care, and disability-specific services. The partners of caregivers were rated as the most helpful support in agreement with the study by McIntyre and Brown (2018). The results showed that the understanding of family members and friends of how ASD affects the everyday life of the child and family, their non-judgemental support, genuine love, and acceptance of the child for who he or she is were perceived as caring or helpful by the parents.

The results also indicated that knowledge of ASD, empowers both caregivers and family members to take some control over their child's disability and increased their confidence in accessing services and where to find support. The results were similar to that of the study by Werner and Shulman (2013). Furthermore, other parents were often mentioned as helpful as they could share their knowledge together with lived experiences. Findings highlighted the importance of accessing support from physicians for the diagnosis of the child, requesting intervention services for children with ASD, and having access to the right person to care for their child were perceived as helpful. The results were similar to the study conducted by Russa, et al (2015)

Similarly, the study of a community sample of 78 American families with children with ASD in the age group, two to six years was conducted to examine the utilisation and usefulness of social support using Family Support Scale (FSS) and interviews (McIntyre & Brown, 2018). Findings indicated that caregivers used both formal and informal forms of support. Over 90% of primary caregivers relied on their spouse or partner, family doctor or pediatrician and professional helpers and school or daycare centres as sources of support. Furthermore, obtaining information specific to autism from different sources, parental satisfaction with the diagnostic process and the current services offered to families with a child with ASD and the family's gross annual income was positively associated with the utilisation and helpfulness of family support. This finding is consistent with Searing, Graham, and Grainger (2015), who identified positive support benefits associated with spouses.

The study of Roffeei, Abdullah, and Basar, (2015) examined the types of social support messages exchanged between parents or caregivers of children with ASD who communicate via Facebook (FB). FB pages benefit especially from interpersonal relationships at both individual and collective levels due to the reciprocative nature of the messages in which an individual would post questions and, or thoughts and other members would comment, validate, or offer responses to the original posts. A total of 3 637 messages including both postings (381) and comments (3 256) were analysed from two FB autism support group pages, namely: Autism Malaysia (AM) and Autism Children's Club (ACA). The study identified five types of social support messages, namely, informational support, emotional support, network support, esteem support, and tangible assistance (Bender, Jimenez-Marroquin & Jadad et al., 2011; Kang, DuBenske, Shaw, Gustafson, Hawkins, Shah, McTavish & Cleary, 2012; Wentzer & Bygholmb, 2013)

Informational support

Informational support messages are concerned with advice posting messages, referrals to experts websites and other online or offline resources, situation appraisal messages for reassurance, teaching messages to provide factual or technical information about various aspects of ASD, and postings to share information about personal experiences. This is similar to the types of informational messages identified in the study conducted by McIntyre and Brown (2018) which indicates that knowledge is the absolute key.

Emotional support

Emotional support messages are concerned with sharing and describing emotional and psychological encounters that normally represent the need to seek comfort. These include relational support (relationship) for friends and companions within the communities. The messages reflect physical or virtual affection, sympathy, empathy and understanding, encouragement, prayer, consoling, gratitude, and congratulations. Relational support was identified in the studies conducted by McIntyre and Brown (2018), Searing, et al. (2015), Wentzer and Bygholmb (2013) which indicate that a spouse or partner and friends are the greatest source of support for families with an ASD child.

Network support

Network support messages are concerned with support for community connections. It reminds communities that members should never have to struggle alone in difficult times but should participate in discussions or group activities by joining the groups. The findings correspond with the findings of the study conducted by (Kang, et al., 2012)

Esteem support

Esteem support messages are related to members' perspectives concerning a situation in terms of beliefs, actions, thoughts, or emotions. Some offered praise (compliments) for positive comments. The results were consistent with the results of a study by Wentzer and Bygholmb (2013), Bender, et al. (2011)

Tangible Assistance

Tangible assistance messages are concerned with offering necessary help to others, such as volunteering to do online research related to ASD (Roffeei, et al., 2015). The study did, however, unveil types of social support messages offered and requested in online communities of facebook autism groups.

2.3.6 Models for providing support to the families of children with ASD

There are limited studies dealing with the models that focus on support for families with ASD children. \Most of the existing evidence focuses on training programmes for families with ASD children. The following is a summary of the service-delivery model used in the United States of America for families of children with autism.

- **Service delivery models**

In response to addressing issues concerning family context and quality of life, several models of service delivery have been developed (Becker-Cottrill, McFarland, Anderson, 2003). One model is an ecological or eco-behavioural approach to providing services for families.

- **Eco-behavioural approach**

In particular, the subject literature has shown that families of children with ASD experience more stress than families of typically developing children (Hartley, et al., 2017; McIntyre & Brown, 2018). In an eco-behavioural approach to providing family training services, these influences are taken into account, and programmes are developed to meet the needs of each family. These programmes are based on family values and situations and are more likely to be successfully implemented and maintained (Becker-Cottrill, et al., 2003).

One eco-behavioural approach to service delivery is the wrap-around process. A wrap-around process is a family-centred approach that stresses interagency collaboration, the use of formal and informal support services, and services tailored to the needs of the family. A team of individuals, including the family, extended family, neighbours and appropriate health care personnel assist in the development of a plan. Plans developed are directed at providing the support necessary to meet the needs of the family and child. Plans are people-directed and based on the individual or team, rather than system-directed and based on the service provider. A resource coordinator facilitates the team process. Typical users of this approach are families of children with ASD (Becker-Cottrill, McFarland, & Anderson, 2003).

- **Parent educator collaboration model**

As the context of this study is special schools, a model that focuses on the interaction between the teachers and families is of importance. Schools are important environments in which children, families, educators, and community members have opportunities to learn, teach, and grow (Sugai, et al., 2000). Russa, et al., (2015) states that there is a critical need for universities, parent training, and information centres and other state training organisations to make training an effective approach to collaboration.

One promising practice to train educators to collaborate with families of ASD children for educational planning is the Collaborative Model for Promoting Competence and Success (COMPASS) model for ASD students and children. COMPASS builds competencies in consulting and develops ASD knowledge by working with families and teachers through a systematic, empirically-based consultation programme. In this training model, specific steps are described as to how teachers work as part of a collaborative team with families and other school professionals to define goals, establish educational priorities and evaluate the progress.

- **Wisconsin's parent educator initiative model**

This is one of the programmes utilised during parent training as a means to create a stronger parent-educator partnership. Within this programme, regional level individuals work to train and coordinate district-level parent volunteers to provide information, support, and consultation to parents. Staff receives training on topics, such as communication, ASD, transition, parent involvement, conflict resolution and the defusing of emotions. These individuals are trained to mentor parents of children with ASD in special education on the processes, resources, and information that will make them successful team members in the Individualised Education Program (IEP) meeting. This programme is general enough to meet the needs of families with children with a variety of disabilities, and also has the potential to reach a large group of parents with information, training, and support and thus to increase impact (Schultz, Schmidt, & Sticher, 2011).

- **Medical home model**

Families of ASD children struggle with care that is not well-coordinated and information that does not match the needs of the developmental stage of the child. The medical home model is an aspirational attempt to treat the person in totality by linking the patient to a full range of coordinated, intervention and prevention-focused services. The medical home model is a means to improve services for ASD children and other developmental disabilities. It was developed, applied and implemented in the USA (Russa et al., 2015).

A medical home model is an approach that provides comprehensive primary care. A medical home is defined as primary care that is accessible, continuous, comprehensive, family-centred, coordinated, compassionate, and culturally effective (Model, 2008). The medical home model is an aspirational attempt to treat the person in totality by linking the patient to a full range of coordinated, intervention and prevention-focused services in the United States. It links and coordinates the family's and the child's receipt of appropriate services from a range of professionals and agencies, such as speech therapists, psychologists, and social workers when a family of a child with ASD seeks services through periods of developmental transition from childhood to the transition to adulthood (Russa et al., 2015).

A goal of the patient-centered medical home model is to foster continuous healing relationships. The family is considered an important part of the team for caring for the child with ASD, and the family's beliefs and values are taken into account when health care decisions are made. Another aspect of the patient-centred medical home model is diligent attention to detail concerning regular follow-up health care appointments as well as referral to specialists. Screening procedures are conducted to improve overall health outcomes, by preventing complications. Screening procedures are done thoroughly as it prevents the extensive need for additional secondary and tertiary care (Model, 2008). It is associated with a decrease in financial costs for families.

2.4 INTEGRATION OF THE THEORETICAL FRAMEWORK WITH THE LITERATURE REVIEW

Watson's Theory of Human Caring (2008) is applied to the reviewed literature, to guide the current study. Provision of support to families of children with ASD is a challenging task as it includes formal as well as informal support strategies. Thus, Watson’s theory of caring (2008) is applied to the provision of support to families of children with ASD. Caring for families with ASD children in accordance with this theory will require attention to all these spheres through the creation of a caring moment and application of the clinical Caritas processes (Alligood, 2014). Figure 2.3 illustrate the integrations between reviewed literature on support for families with ASD and the ten Watsons theory (2008) caring factors.

Experiences of families and teachers (Previous studies)

Family:

- Multiple role, Intense focus on the child's needs
- Communication challenges, Severe behaviour challenges
- Severe stress, Severe isolation
- Less time with partner, Lower partner closeness
- Fewer positive couple interactions
- Stigmatisation due to lack of knowledge
- Stigmatisation due to judgement, Rejection
- Lack of support
- Effects of diagnosis on parents' relationship with other children
- Distance travelled to the nearest medical facility

Teachers:

- Stress, burnout, instructional challenges
- Emotional exhaustion, teaching challenges, difficult to manage behavioural challenges

Watson theory caring factor related to the reviewed literature regarding experiences of families and teachers of ASD children is

Promotion and acceptance of the expression of positive and negative feelings

Families and teachers support needs (Previous studies)

Family:

- Understanding supporters, family love
- Acceptance of the child
- Knowledge of ASD
- Finding the right carer
- Social support & tangible assistance
- Spouse & grandparents' support
- Friends' & relatives' support
- Other parents' support & professional support
- Informational support
- Network support
- Esteem support
- Emotional support
- Church/ministery

Teachers:

- Help from colleagues, social support
- Use of problem-focused coping strategies

Watson theory caring factors related to the reviewed literature regarding the support needs of families and teachers of ASD children are:

- Provision of suitable conducive environment
- Helping trust relationship
- The instillation of faith-hope
- Formation of a humanistic altruistic system of values
- The allowance of existential-phenomenological forces
- Cultivation of sensitivity to self and others

Coping strategies (Previous studies)

Family

- Finding a balance
- Strong dependence on family

Teachers

- Training & experience
- Tailored classroom conditions

Family support models:

- Service delivery model
- Medical home model
- Wisconsin's Parent Educator Initiative model
- Parent educator collaboration

Watson theory caring factor related to the reviewed literature regarding coping strategies of families and teachers of ASD children are:

- Promotion of interpersonal teaching learning
- Systematic use of the scientific problem-solving method for decision-making

Figure 2.3: Integration of Watson's theory with the literature

2.5 CONCLUSION

The aim or purpose of this chapter was to review the results of other studies with regard to the experiences, support needs and models according to which families who live with a child with ASD function. A scoping review methodology was used to review the literature. The goal of the literature review was to include only those studies that have addressed the research questions between 2008 and 2018. Overall, the results were somewhat surprising. The study's findings illuminated the increased prevalence and incidence of ASD globally. Extensive hardships challenge families who have a child with ASD. Required support resources were identified and different models for family support were discussed and explained.

The chapter that follows will discuss the research methodology used in this study.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

The preceding chapter reviewed literature relevant to this study. This chapter includes research approach, research design, study setting, population, sample and sampling procedure, sample size, data collection methods, recruitment procedure, measures to ensure trustworthiness, ethical considerations, and pilot study.

Research methodology considers and explains the logic behind research methods and techniques which are chosen to guide all the processes of the study (Mitchell, 2012). This chapter describes in detail the research design and the methods that were used in this study which have led to the development and validation of a support model for families of children with ASD. These include the research setting, research design, population, sampling, data collection, data analysis, measures to ensure trustworthiness and ethical considerations.

3.2 STUDY SETTING

The research was conducted at public special schools in the Gauteng and Limpopo provinces of South Africa. Limpopo Province is considered to be the most rural province in South Africa comprising mainly poor communities. The province is situated in the northeast of South Africa and is made up of five districts, namely, Vhembe, Mopani, Capricorn, Sekhukhune, and Waterberg. Thirty-three public special schools cater for the needs of the child and adolescent psychiatric disorders and other developmental disabilities. Fifteen special schools in the Capricorn district, Six in the Sekhukhune district, four in the Waterberg, four in Mopani and four in the Vhembe district. There are no special schools that focus specifically on ASD in this province, but all children with developmental disabilities are enrolled in the special schools. Figure 3.1 illustrates the map of Limpopo Province showing the selected special schools for the study per district using unique codes for anonymity (www.municipalities.co.za).

Figure 3.1: The Limpopo Province Map showing the selected special schools for the study per district

Gauteng is the smallest province in South Africa, but it is highly urbanised and the most populous province in South Africa. Gauteng is divided into three metropolitan municipalities, the City of Ekurhuleni, the City of Johannesburg and the City of Tshwane metropolitan municipalities, as well as two district municipalities, which are further subdivided into six local municipalities. There are roughly137 special schools in Gauteng Province, of which 101 are public special schools: 21 in Ekurhuleni, 31 in Johannesburg, seven in Sedibeng, 28 in Tshwane, and 14 in the West Rand. There are eight schools for focused learning consisting of six in Johannesburg, one in Tshwane, and one in the West Rand. There are 28 independent special schools consisting of five in Ekurhuleni, 17 in Johannesburg, one in Randburg, three in Sedibeng and two in Tshwane. Four public special schools focus specifically on autism, namely, Johannesburg Hospital School, Randburg Special School, Unica School, and Westrand School. Figure 3.2 illustrates the map of the Gauteng Province showing the selected special schools with unique codes (www.municipalities.co.za).

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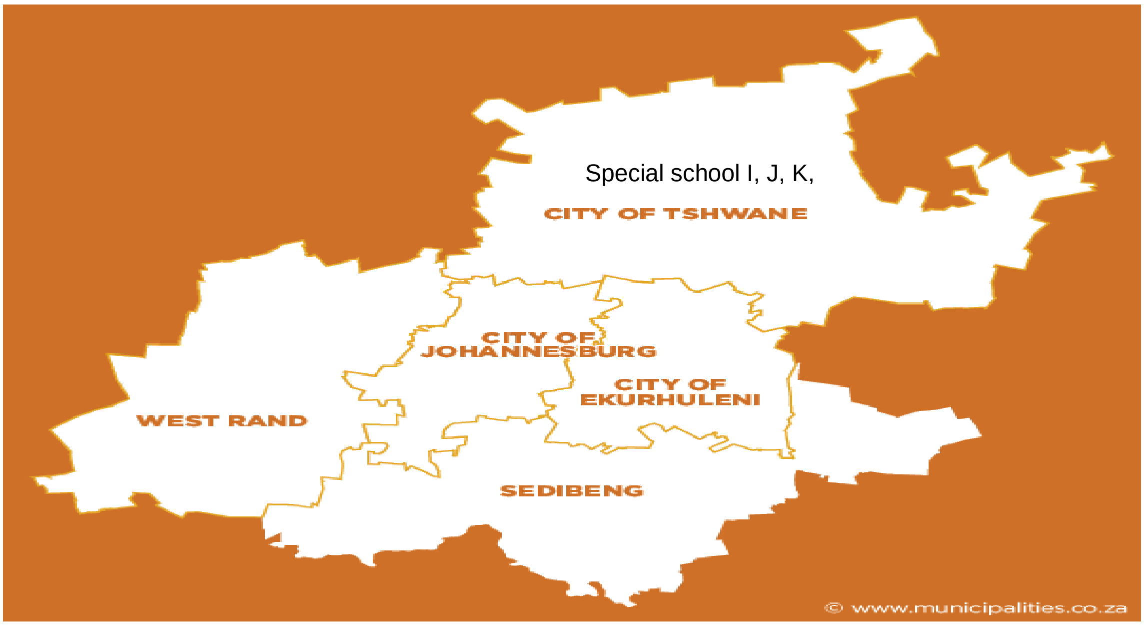


Figure 3 2: Gauteng Province Map showing the selected special schools for the study

3.3 RESEARCH APPROACH

Qualitative research is an umbrella term covering an array of interpretative techniques that seek to describe, decode, translate and otherwise come to terms with the meaning of certain more or less naturally occurring phenomena in the social world (Teherani, Martimianakis, Stenfors-Hayes, Wadhwa, & Varpio, 2015).

3.3.1 Reason for using qualitative research

In this study, the researcher selected qualitative research to explain, clarify and elaborate on the experiences of families of children with ASD. The aim was to develop concepts that could help to understand the experiences of families of children with ASD. Qualitative research was the most suitable method for this study because of its emphasis on the lived experience of the families and teachers of children with ASD. The qualitative method investigates the human life experience. Therefore, the study interpreted the everyday experiences of families and educators as they were involved in caring and training ASD children. It was also used because it explores health-related experiences where little is known, and enables the researcher to gain insight into the experiences of families of children with ASD (Rosenthal, 2016).

3.3.2 Characteristics of qualitative research

The researcher considered an instrument for data collection and resultant data that comprise primarily words or narrative descriptions. Participants were purposively selected for their experiences with the phenomena under study. It relies on a smaller number of participants. The data from the selected participants were rich in detail. The methods for data collection were less structured since semi-structured and focus group interviews were used (Hyett, Kenny, & Dickson-Swift, 2014).

3.4 RESEARCH DESIGN

The research design is the framework or guide used for the planning, implementation, and analysis of a study (Teherani, et al., 2015). It is the plan for answering the research question. Different types of questions demand different types of research design, so it is important to have a broad preparation and understanding of the different types of research designs available. A qualitative, explorative, descriptive, contextual design employing a phenomenological approach and theory-generating study was used in this study. As already mentioned, a qualitative design was used to explore and describe the experiences of families and teachers of children diagnosed with ASD.

3.4.1 Phenomenological research design

A phenomenological research design, according to Yüksel and Yıldırım (2015), refers to an inquiry paradigm, an interpretive theory, a philosophy, an analytical perspective, a major qualitative research tradition or a research method framework. An explorative and descriptive design was used as it is embedded in the phenomenological design to explore and describe the experiences of families and teachers of children diagnosed with ASD.

- The strengths of phenomenological research design

According to Hyett et al. (2014), the central strength of a phenomenological approach is that it provides both philosophical and methodological support in attempting to capture and express the meaning of significant human experiences in a rigorous manner. It also gives others deeper insight into what life experience is like. In the current study, a phenomenological approach was appropriate because during Phase 1 the researcher conducted empirical research by means of which the participants were asked a central question and clarity seeking questions that explore the day-to-day experiences related to the care and support of ASD children.

- Types of phenomenological research

Phenomenological research is generally divided into two types: descriptive phenomenology and interpretative phenomenology (Yüksel & Yıldırım, 2015). Only descriptive phenomenology is discussed in this study as it applies to the study.

- *Descriptive phenomenology*

A descriptive phenomenological design demands the careful description of ordinary conscious experiences of the everyday life of the families and teachers of children with ASD. It involves the following four steps as indicated by Polit and Beck (2010): bracketing, intuiting, analysing and describing.

- *Bracketing*

Bracketing is one of the central ideas in phenomenological research design. It means that the researcher has to set aside all of his pre-judgments and his previous experience about the phenomena and approach the field with an open mind, imagination, and intuition (Rosenthal, 2016). In this study, an informal pre-interview with the teachers and families in the special schools were arranged to explain the outline of the study and its purpose. Its aim was to aid both in exploring and isolating pre-conceptions about the subject of the research. During data collection, all participants were asked central questions about the context of the research subject, and they were encouraged to ask questions of the researcher.

The researcher did not influence the interview in any direction or change what was said.

- *Intuiting*

Intuiting is the process of actually looking at phenomenon by those who experienced it. It focuses on the participant's awareness of, and energy relating to the topic and absolute concentration and complete absorption in the phenomenon (Polit & Beck, 2010). The researcher was immersed in the experiences of the families and teachers of children with ASD. The researcher collected data by listening attentively to what was being said, without unnecessary interruptions, nodding her head, smiling, and looking interested and making encouraging noises (e.g. 'Mmmm' "Okay") as participants shared their experiences.

- *Analysing and describing*

Descriptive phenomenology seeks to understand whether researchers draw on complete descriptions that enclose a full range of everyday life experiences, which are gathered by participants and communicated through what they have heard, seen, felt, remembered, acted on and decided (Moule & Goodman, 2014). Analysis aims to discover the understanding, wisdom, and possibilities from any new perspectives (Moule & Goodman, 2014). It offers a picture that allows readers to draw interpretations and meaning for their own use.

In this study, a semi-structured interview guide of open questions was used to explore the experiences of families and teachers of ASD children. These questions allowed them to talk fully about their lives with ASD children. All audio-recordings were transcribed verbatim and the researcher read the transcripts while listening to the recordings and corrected any spelling or other errors. Coding and theming were done to identify the topics, issues, similarities, and differences that were revealed by the participants. The relationships between or amongst the concepts were defined.

3.4.2 Descriptive research design

According to Lambert and Lambert (2012) descriptive research design is used when little is known about a particular phenomenon. The researcher utilised this design because little is known about the experiences of families with ASD children in the Limpopo and Gauteng provinces. It can either be qualitative or quantitative. A descriptive design describes what actually exists. It also describes different categories of information.

- Reason for using descriptive design

A descriptive design was adopted to assist the researcher in obtaining complete and accurate information for the development of a support model by allowing the families and teachers to describe their day-to-day experiences regarding the phenomenon studied. As already mentioned, to achieve the descriptive part of the study, semi-structured and focus group interviews were conducted.

- The advantage of descriptive design for this study

A descriptive design demands the careful description of ordinary conscious experiences of everyday life (Polit & Beck, 2010). In this study, the descriptive design was appropriate because the day-to-day regular experiences of families and teachers of ASD children were described.

3.4.3 Explorative research design

An explorative research design according to Van Wyk (2016) is the most useful and appropriate research design for those projects that address a subject about which there are high levels of uncertainty and ignorance about the subject, and when there is very little existing research on the subject matter. The present study had to be exploratory as little is known about the support model for families of children with ASD in the Limpopo and Gauteng provinces. Thus, there is a need for further investigation.

- Reason for using an explorative research design

  The main aim of exploratory research according to Van Wyk (2016) is to identify the boundaries of the environment in which the problems, opportunities or situations of interest are likely to reside.

- The advantage of explorative research design for this study

Van Wyk (2016) explains that an explorative research design is usually characterised by a high degree of flexibility and lacks a formal structure. The explorative research design was appropriate in this study because the researcher aimed to develop and validate a support model for families of children with ASD by exploring the participants' views regarding the care and support of ASD children through semi-structured and focus group interviews. These interviewing methods were based on a flexible topic guide that provides a loose structure of open-ended questions to explore the experiences of the participants.

3.4.4 The contextual design

A contextual research strategy aims to describe and understand events within the concrete, and natural context in which they occur (Babbie, 2010). This means that the study was done where the needs of ASD children are catered for, namely in special schools of Limpopo Province which is a rural area and the Gauteng province which consists mainly of urban areas. The research had to take place within the South African context as the study was conducted in the Limpopo and Gauteng provinces of South Africa.

- Reason for using a contextual research design

The contextual research design was appropriate in this study because the present research study intends to develop a support model for families of children with ASD within the South African context by describing and gaining understanding of the experiences of the participants within the actual environment in which the needs of children with ASD are cared for.

- The advantage of contextual research design for this study

Subsequent discussion with the families and teachers shows the power, influences, pressures, and emotions that operate in the Gauteng and Limpopo special schools environment that play a role in the support of families with ASD children.

3.4.5 Theory generative design

Theory generative design is research that clarifies and describes relationships without imposing any preconceived ideas (Chinn & Kramer, 2008). This approach requires the simultaneous process of collecting, coding, and categorising data and forming concepts and relationships based on the data obtained. Watson (1985 as cited in Chinn and Kramer 2008) states that theory is the grouping of knowledge, ideas and experiences presented symbolically to illuminate a phenomenon. The ideas are expressed by word symbols that are connected (relationship) and explain why things happen the way they do. The explanation of how things are is referred to as creating conceptual meaning.

Conceptual meaning emanates from the thoughts of families and teachers which are described in words (concepts). It conveys thoughts, feelings, and ideas that reflect the experiences of families and teachers to the fullest, which is not possible when a concept is defined. This means that ideas and thoughts are used to represent experiences; and differentiating between concepts that seem to be related and staying focused. “Conceptual meaning is a mental picture of the nature of concepts or the phenomenon, and how it is perceived in human experience” (Chinn & Kramer, 2008).

The purpose of theory is to enhance the understanding of the phenomenon under study. In this case, the phenomenon is support for families of children with ASD. However, it is presented as a model in this study since it will not be tested but rather critically appraised. Models are visual representations of perceptual phenomena (theory) (Chinn & Kramer, 2008) and, thus, this approach was deemed suitable for this study, as the researcher envisaged developing a support model for families of children with ASD based on empirical data obtained from the field and a review of the relevant literature.

3.5 Population

According to Creswell (2014) the target population is the total population that forms the focus of the study. In this study, the target population is all families and teachers of children with ASD in the Limpopo and Gauteng provinces. Families and teachers of children with ASD have lived experience regarding caring/teaching children with ASD. The study population is a subset of the target population from which the sample is taken. The researcher recruited families and teachers who fitted the inclusion criteria for the study and were accessible locally.

3.6 Sampling

Sampling in qualitative research aims to identify a specific group of people who have characteristics relevant to the phenomenon being studied (Creswell, 2014). Sampling refers to the process of selecting a portion of the population to represent the entire population (Polit & Beck, 2010). It is inductive and depends on the purposeful selection of participants. In this study, a non-probability, purposive criterion sampling technique was used to obtain 17 primary caregivers and 12 teachers in Limpopo Province, two (2) primary caregivers and six (6) teachers in Gauteng Province of SA. Purposive criterion sampling was used as predetermined inclusion criteria to focus on participants having shared characteristics (Palinkas, Horwitz, Green, Wisdom, Duan, & Hoagwood, 2015). The sample size in qualitative research is not determined by fixed rules, but by factors, such as the depth and duration of the interview and what is feasible for a single interviewer (Creswell, 2014).

The participants were selected from eight special schools were selected from Limpopo Province while three were from Gauteng Province as illustrated in Table 3.1.

Table 3.1: Study participants

Province	**District or metropolitan**	**Name of the special school**	**Number of caregivers**	**Number of teachers**
Limpopo	Capricorn	Special school A	2	2
Limpopo	Capricorn	Special school B	1	2
Limpopo	Capricorn	Special school C	2	2
Limpopo	Capricorn	Special school D	2	1
Limpopo	Waterberg	Special school E	4	0
Limpopo	Waterberg	Special school F	3	1
Limpopo	Sekhukhune	Special school G	3	1

Limpopo	Mopani	Special school H	0	3
Limpopo Province		**Total**	**17**	**12**
Gauteng	Tshwane	Special school I	1	3
Gauteng	Tshwane	Special school J	1	1
Gauteng	Tshwane	Special school K	0	2
Gauteng province		**Total**	**2**	**6**
Grand Total			**19**	**18**

The sample size for interview studies as indicated by Hyett Kenny, Dickson-Swift, (2014) is usually much smaller not exceeding 50 participants, although this can vary with the research questions asked. Creswell (2014) states that there are no rules for sample size in qualitative inquiry. In other words, the sample size depends on the aim of the study and what is possible, given the time and resources available.

- Inclusion criteria

Inclusion criteria are characteristics that the prospective participants must have if they are to be included in the sample (Ingham-Broomfield, 2011).

This study included:

- All the primary caregivers of the children diagnosed with ASD in the selected special schools of the Gauteng and Limpopo provinces of South Africa as they have lived experience in caring for ASD children.
- All the teachers of the children diagnosed with ASD in the selected special schools of the Gauteng and Limpopo provinces of South Africa as they have lived experience in teaching children with ASD.
- All primary caregivers and teachers of children with ASD in the selected special schools who are willing and able to participate to ensure voluntary participation.
- Teachers who had ASD children in their classes when the data was collected to ensure that they spoke of recent experiences.

- Exclusion criteria

Exclusion criteria are those characteristics that disqualify prospective participants (Ingham-Broomfield, 2011). The following participants were excluded:

- All primary caregivers and teachers of ASD children in the selected special schools of the Gauteng and Limpopo provinces who were not willing or able to participate to promote voluntary participation.
- Teachers who had past experience of teaching ASD children and who did not have ASD children in their classes in the past year to avoid considering past experiences

3.7 Pilot study

The research techniques, methods, demographic data questionnaires, and interviews were first piloted at Moletsi Centre. The setting was convenient for the researcher and it resembles the one used for the intervention. Two primary caregivers and two teachers of children with ASD participated in the pilot study before proper data collection was undertaken using semi-structured interview questions. To see how well the technique, method, and interviews would work in practice and if it could subsequently be adapted and modified accordingly. The researcher used the same selection criteria for the pilot study as for the final intervention.

The outcomes of the pilot study were divided into two categories, namely practical considerations and data collection methods.

The practical considerations which needed attention included:

- *No measures to ensure that participants would be in the special school for the interview*

Distance and employment status were not used as selection criteria for primary caregivers. The pilot study consisted of primary caregivers who were both staying far from, or near the school, and were employed or unemployed. Two primary caregivers who were recruited for the pilot study were not able to be at the special school. Although they were willing to participate, one of them resided at some distance from the school and did not have money for the transport, while the other caregiver was on duty. Thus, there was a need to conduct focus group interviews in the special schools that are specialising in ASD as there would be many participants.

- *Language of participants*

Language was not used as selection criteria for the differential selection of the participants of the pilot group. The pilot group consisted of primary caregivers with Sepedi as a home language. Although they could understand and speak a little English, the primary caregivers could not freely communicate in a language which was not their home language. The sessions were, therefore conducted in a mixture of Sepedi and English. For this reason the need to incorporate different languages in the interviews was recognised.

- *Data collection methods*

The demographic data questionnaires and the interview guides had to be piloted first to find out whether it was effective, inappropriate or too complicated. The demographic data instruments for primary caregivers and teachers did not require any revision as none of the group members complained about the clarity of the information. Questionnaires were completed without any difficulties. Revisions that were required and which came to the fore when the primary caregivers' interview guide was pre-tested is discussed in the following paragraphs.

The researcher found it necessary to rephrase one question and to add two questions to the interview guide. During the introduction one primary caregiver indicated that she did not know what autism is, and that she only knew that her child is intellectually disabled. There was, therefore a need to add a question that would explore participants' knowledge with regard to ASD. To assess the knowledge that they had gained, and their educational and training needs, the following question was added to the interview guide: "Can you describe your level of knowledge concerning ASD"?

After the researcher asked the participants about the challenges that they come across when living with the ASD child, it became clear that there was a need to explore in greater depth the participants' opinions about ways in which their problems could be overcome. To involve them in planning strategies relevant to their various challenges, the following question was also added to the interview guide: "What do you think should be done to overcome the challenges"?

Participants seem not to understand clearly when asked to describe their needs as the family of a child living with ASD. The question was rephrased to: "What are your needs as the family to be successful in taking care of this autistic child"? The piloted interview guide and the revised interview guide for the primary caregivers are indicated below.

- *Piloted interview guide for primary caregivers*

Central question

Please tell me in detail, all the experiences you have with your ASD child concerning care and support?

Probing questions

- What are the challenges that you experienced as the family of a child living with ASD?
- What are your needs as the family of a child living with ASD?
- What is your present coping mechanism as a family living with an ASD child?

- *Revised interview guide for primary caregivers*

Central question

Please tell me in detail, all the experiences you have with your ASD child concerning care and support?

Probing questions

- What are the challenges that you experienced as the family of a child living with autism
- What do you think should be done to overcome the challenges?
- What are your needs as the family to be fruitful in taking care of this autistic child?

- How is the support at home and in the community?
- Can you describe your level of knowledge concerning ASD?
- What is your present coping mechanism as the caregiver of the autistic child?

The school was excluded from the main study and the results of the pilot study were not included in the study.

3.8 Data collection

The data collection process involves the generation of a large amount of data required to address the research problem (Sutton & Austin, 2015). The purpose of data collection was to obtain information to keep on record, to make a decision about important issues, and to pass that information to others.

3.8.1 Preparation for data collection

The researcher first visited the selected special schools to request permission from the principals of the schools, and to explain the outline of the study and its purpose. The school principals organised parents and teachers on a set date respectively for the researcher to inform them regarding the study. The researcher outlined the purpose, objectives and importance of the study and invited them to participate in the study. The date and time for the interviews were set for those who gave consent. Other family members were recruited telephonically through the principals permission as they did not managed to come to the meeting on the set date due to social problems. Before being interviewed participants completed a brief demographic information form.

3.8.2 Data collection procedures

In this study, before the semi-structured and focus group interviews were conducted, the researcher informed the participants that the audio recording equipment would be used. Participants were assured of confidentiality and offered to allow withdrawal if uncomfortable with being recorded. Participants were informed about the study details and given assurance about ethical principles, such as anonymity and the informed consent form that was signed. This was done to give participants some idea of what to expect from the interview.

Interviews were conducted in areas free from distractions in class at the special schools and locations that were most suitable for participants.

Both groups of participants participated in semi-structured and focus group interviews. Two focus group interviews were conducted with the primary caregivers and teachers respectively. A total of fifteen (15) semi-structured interviews were conducted with the primary caregivers and fourteen (14) with the teachers (see Table 3.2). Nine primary caregiver’s semi-structured interviews took place at their own homes in the Limpopo province as they could not travel to the school due to social problems. One telephonically interview was conducted in Gauteng province with the primary caregiver who did not managed to be at the special school due to work. Familiar surroundings helped the participants to relax and resulted in a more productive interview.

The researcher familiarised herself with the interview guide before the interview to avoid rehearsal. The central question (Annexure P) asked to the primary caregivers was: “please tell me in detail, all experiences you have with your ASD child concerning care and support”? The central question (Annexure P) asked of the teachers was: “could you kindly describe in detail your experiences when training the ASD children concerning care and support”.

During the interview, the researcher listened attentively to what was being said, so that participants were able to recount their experiences as fully as possible, without unnecessary interruptions. The researcher adopted open and emotionally neutral body language, nodding, smiling, and looking interested and making encouraging noises (e.g. ‘Mmmm’ “Okay”) during the interview. At the end of the interview, participants were thanked for their time and asked if there was anything that they would like to add. This allowed time to deal with issues that the participant had thought about, or thought was important but had not been dealt with during the interview. This lead to the discovery of new, unanticipated information.

The researcher debriefed the participants about the study after the interview had finished, by summarising the aspects that had been discussed. All semi-structured and focus group interviews were voice recorded and transcribed verbatim afterwards, as this would prevent bias and provide a permanent record of what was and was not said. Field notes about observations, thoughts, and ideas about the interview were taken during and immediately after each interview, as it would help in the data analysis process. Semi-structured interviews lasted for 30 to 60 minutes while the focus group lasted for one hour to one hour and 30 minutes. The data were collected for a period of three months. Data saturation was reached with all themes and sub-themes. Saturation is based on the verbatim excerpts from the transcriptions and voice recordings provided.

- *Qualitative research methods used in this study*

As already mentioned, qualitative research instruments used for data collection in this study were semi-structured and focus group interviews. The semi-structured interview was the technique used to gather research information in this study as it provided a 'deeper' understanding of the phenomenon under study (Creswell, 2014).

- *The reason for using semi-structured and focus group interviews*

Semi-structured and focus group interviews were appropriate in this study to gain information on the perspectives, understandings, and meanings constructed by participants regarding their experiences with children with ASD.

- *Semi-structured interview*

The semi-structured interview is more commonly used in healthcare-related qualitative research. Such an interview is characteristically based on a flexible topic guide (Annexure P) that provides a loose structure of open-ended questions to explore experiences and attitudes (Van Teijlingen, 2014). Semi-structured interviews consisted of central and follow-up questions that helped the researcher to define the areas to be explored. It also allowed the researcher or participants to diverge to pursue an idea or response in more detail. Ingham-Broomfield (2011) states that it provides participants with some guidance on what to talk about which many find helpful.

  - *Advantages of the semi-structured interview in this study*

The semi-structured interview has great flexibility. In this study, the researcher asked loose-structured or open-ended questions and follow-up questions to explore the experiences of the participants, which allowed the elaboration of information that was important to participants but were not anticipated by the researcher (Van Teijlingen, 2014).

It helps the researcher to develop a rapport with the participants. The researcher extended the time spent during the face-to-face semi-structured and focus group interviews in the field to improve the trust of the participants. The researcher started the interview with the central questions that participants answered and then proceeded to more difficult questions.

- *The disadvantage of using semi-structured interviews*

It takes a long time to conduct the interviews and to analyse the results, in addition to the difficulties of the analysis process (Creswell, 2014).

- *Focus group interviews*

As already mentioned, another qualitative research instrument used in this study was the focus group interviews. According to Dilshad and Latif (2013), a focus group is a group discussion on a particular topic organised for research purposes. The focus group interviews conducted comprised of four participants. It is advisable to use fewer participants in a focus group discussion when the matter for discussion is sensitive (Tynan, & Drayton, 2007). In this study describing experiences with regards to ASD children was sensitive as it triggers some emotions for both group of participants. The number of focus group interviews were determined by data saturation.

- *The advantage of using a focus group interview in this study*

It has the advantage of being more time-efficient as more participants were interviewed for the same amount of time. Participants provided a richer source of data. It allowed group members to talk to one another, argue and ask questions, and was especially useful for finding out about shared experiences (Ingham-Broomfield, 2011).

- *The disadvantage of using a focus group interview*

It tends to document the public rather than the private views of the individuals. In addition, some people do not interview well in in-group situations (Creswell, 2014). Table 3.2 summarises the number of semi-structured and focus group interviews (FGIs) conducted per special school.

- *Field notes*

Field notes are the written accounts of what the researcher has experienced, heard and felt during the process of collecting and reflecting on the data (Creswell, 2014). Thus, during interviews it is vital to make full and accurate notes of what goes on. In this study, field notes were taken down during, and after each semi-structured and focus group interview. These included the seating arrangements, the order in which people speak, striking themes, nonverbal behaviour, such as eye contact, posture, and crying. Participants verbalised their thoughts, ideas, and feelings and this was summarised to clarify what the participants were saying (Polit & Beck, 2010). Field notes enhance the richness of the data gathered by creating a detailed record of all the occurrences during the interview. These interpretative notes assisted in developing classification in initial concepts synthesis (Walker & Avant, 2011). The researcher also kept a reflective journal in which insights, thoughts, and experiences were written down after every interview to prevent bias and prejudice as the researcher has been a mental health practitioner for 12 years and a mental health educator for the last four years.

3.8 Data analysis

Analysis could be described as interpretation, making sense of data, or transforming data. The analysis is sometimes presented to indicate different procedures based on language, theory or what is described as interpretive and, or descriptive analysis. Data analysis relies on systematic and rigorous searching of text for categories and themes (Creswell, 2014). Qualitative data uses the process of inductive reasoning. Inductive reasoning moves from concrete observation to a general theoretical explanation (Chinn & Kramer, 2008).

Eight steps of Tesch’s (cited in Creswell, 2014) inductive, descriptive open coding technique was used by following the steps below:

- Step 1 – Reading through the data

The researcher got a sense of the whole by reading all the verbatim transcripts carefully. This gave ideas about the data segments and what they looked like and, or meant. The meaning emerged during reading and was written down as well as all ideas as they came to mind. The researcher carefully and repeatedly read the transcripts of all the participants until she understood them.

An uninterrupted period to digest and think about the data in totality was created. The researcher engaged in data analysis and wrote notes and impressions as they came to mind.

- Step 2 – Reduction of the collected data

The researcher scaled-down the data collected to codes based on the existence or frequency of concepts used in the verbatim transcriptions. The researcher then listed all topics that emerged during the scaling down. The researcher grouped similar topics, and those that did not have association were clustered separately. Notes were written on the margins and the researcher started recording thoughts about the data in the margins of the pages on which the verbatim transcripts appeared.

Table 3.2: Comparison of semi-structured and focus group interviews per special school

Province	**District or metropolitan**	**Name of the special school**	**No of semi-structured interviews** (Primary caregivers**)**	**No of FGIs (**Primary caregivers)	**No of semi-structured interviews** (Teachers)	**No of FGIs** (Teachers)
Limpopo	Capricorn	Special school A	02	0	02	0
Limpopo	Capricorn	Special school B	01	0	02	0
Limpopo	Capricorn	Special school C	0	01	02	0
Limpopo	Capricorn	Special school D	02	0	01	0
Limpopo	Waterberg	Special school E	0	01	02	0
Limpopo	Waterberg	Special school F	04	0	01	0
Limpopo	Sekhukhune	Special school G	03	0	01	0
Limpopo	Mopani	Special school H	01	0	0	01
Gauteng	Tshwane	Special school I	01	0	0	01
Gauteng	Tshwane	Special school J	01	0	01	0
Gauteng	Tshwane	Special school K	0	0	02	0
Total			**15**	**02**	**14**	**02**

- Step 3 – Asking questions about the meaning of the collected data

The researcher read through the transcriptions again and analysed them. This time the researcher asked herself questions about the transcriptions of the interviews, based on the codes (mental picture codes when reading through them) which were assigned to the frequency of the concepts. The questions were “Which words describe it?” “What is this about?” and “What is the underlying meaning?”

- Step 4 – Abbreviation of topics to codes

The researcher started to abbreviate the topics that emerged as codes. These codes had to be written next to the appropriate segments of the transcription. Differentiation of the codes by including all meaningful instances of a specific code’s data was done. All these codes were written in the margins of the paper against the data they represented with a different pen colour from the colour used for the codes in Step 3.

- Step 5 – Development of themes and sub-themes

The researcher developed themes and sub-themes from coded data and the associated texts and reduced the total list by grouping topics that relate to one another to create meaning applicable to the themes and sub-themes.

- Step 6 – Comparison of the codes, topics, and themes for duplication

In this step, the researcher worked through the data again from the beginning to check the work for duplication and to refine codes, topics and themes where necessary. Using the list of all codes she checked for duplication. The researcher grouped similar codes and recoded others that were necessary so that they fitted into the description.

- Step 7 – Initial grouping of all themes and sub-themes

The data belonging to each theme were assembled in one column and preliminary analysis was applied.

- Step 8 – Validating the accuracy of the information

The information was validated during the meeting between the researcher and co-coder to reach consensus on the themes and sub-themes that each one had come up with independently.

The findings which emerged from step 1: (concept identification) were utilised in step 2: (concepts description and definitions), and subsequently step 3 which comprised the model description and guidelines to operationalise the model.

3.10 ETHICAL CONSIDERATIONS

Important ethical concerns that were taken into account while carrying out the present research study were confidentiality and anonymity, informed consent, the principle of no harm and justice:

3.10.1 Permission

Ethical clearance (Annexure A) was obtained from the Turfloop Research Ethics Committee (TREC) (TREC/232/2016: PG). Permission to conduct the study was obtained from the Department of Education in the Gauteng and Limpopo provinces (Annexure C) and the principals of selected special schools in these provinces because teachers were employed at the study site and caregivers' children were admitted at the study site.

3.10.2 Confidentiality and anonymity

Confidentiality according to Sanjari, Bahramnezhad, Fomani, Shoghi, and Cheraghi (2014) means that no personal information is passed on except in certain situations. Researchers protect the participant's identity and hold the information strictly confidential. In this study, the selected special schools were identify using a unique codes. Furthermore, no names were used in transcripts, and each participant was allocated a code number rather than using their names to ensure that research data could not be linked to the individual's identity or institution. Transcripts and voice recorders were stored in a secure place.

3.10.3 Informed consent

Informed consent has been recognized as an integral part of ethics in research carried out in different fields (Sanjari et al., 2014). Prior to being interviewed the participants were informed about the nature of the study, and their potential role, the identity of the researcher, the objectives of the research, the types of questions which were likely to be asked, the method of anonymity, and how the results would be published and used were clarified. Thereafter, written consent (Annexure Q) was obtained. Permission to use a voice recorder and field notes during data collection was obtained from the participants. Participants were also informed about the benefit of carrying out the research and that it could contribute to the improvement of health policies.

3.10.4 The principle of no harm

Beneficence refers to the obligation on the part of the researcher to minimise the risk of harm to the participants while maximising benefits for the individual participant (Polit & Beck, 2010). In this study, emotional distress was experienced by three caregivers during data collection. The primary caregivers became emotional as they discussed their children’s behaviour and cried during the interview. Various strategies to deal with emotional distress were implemented. The researcher provided a break and offered a therapeutic touch, water, support and counselling because the researcher is trained to handle psychological distress. Furthermore, there was consistent monitoring of participants' emotional reactions, and information on available psychological or social services was provided. Those participants who were not in severe emotional distress were also encouraged to go to the psychologist for further counselling to assist them with the acceptance and management of their child.

3.10.5 Justice

This principle requires the researchers to be fair to the participants in their research and that the needs of research participants should always come before the objectives of the study (Polit & Beck, 2010). Participants who meet the inclusion criteria were selected purposively. Those who were excluded were excluded according to the exclusion criteria, and not simply by language, culture, religion or issues unrelated to the research. All participants were treated equally. The researcher provided copies of research reports to the special schools at which data were collected.

3.11 MEASURES TO ENSURE TRUSTWORTHINESS

Any inquiry irrespective of its approach is usually evaluated by peers, readers, and sponsors. The evaluator of research projects or findings usually adopts some trustworthiness criteria that have been agreed on in the literature about a particular research approach. Trustworthiness was achieved in this study by adopting Lincoln and Guba’s (1979) criteria of credibility, transferability, dependability, and confirmability.

3.11.1 Credibility

Credibility is defined as the confidence that can be placed in the truth of the research findings (Anney, 2014). It is seen as one of the key aspects of establishing trustworthiness. This is because credibility essentially asks the researcher to link the research study's findings to reality to demonstrate the truth of the research study's findings. Credibility establishes whether or not the research findings represent acceptable information drawn from the participants' original data and is a correct interpretation of the original views of participants. In this study, the rigour of the inquiry was established by adopting the following credibility strategies: prolonged and varied field experience, triangulation, member checking, time sampling, reflexivity (field journal), peer examination, the interview technique, establishing the authority of the researcher and structural coherence (Anney, 2014). Each strategy is discussed in detail in the sub-sections below.

Prolonged engagement in the research site: Before the first data collection took place, the researcher arranged a preliminary visit to the selected special schools. The aim was to immerse herself in the participant' worlds, to gain an adequate understanding of the institutions, and to establish a relationship of trust between the participants and the researcher. The researcher's extended time in the special schools improved the trust of the participants and provided a greater understanding of participants' culture and context (Anney, 2014). The researcher visited each special school three times. The first time was to ask for permission to collect data, and then in respect of the second visit the aim was to conduct interviews with the teachers, and on the third occasion the aim was to conduct interviews with the caregivers. Data collection was done over a period of three months. Prolonged engagement in the special schools helped the researcher to understand the core issues that could affect the quality of the data because it helped to develop trust with the study participants.

Use of peer debriefing: Peer debriefing provides inquirers with the opportunity to test their growing insights and to expose themselves to searching questions (Houghton, Lasey, Shaw & Murphy, 2013). During the research process, a qualitative researcher is required to seek support from other professionals willing to provide scholarly guidance, such as members of the academic staff at the university, the postgraduate dissertation committee, and the relevant department (Anney, 2014). The research project was supervised by two experts in qualitative research. A continuous discussion of the research with the study supervisor and co-promoter was done to ensure peer examination. The research proposal and report were presented to the Department of Nursing Science, School of Health Care Sciences, Faculty of Health Science and Turfloop Research Ethics Committees of the University of Limpopo to receive their comments. Feedback from peers, research committees and supervisors helped the researcher to improve the quality of the research findings. An expert in qualitative research was asked to code interview transcripts and subsequently asked to review the coding conducted in this research for comparison. The coding carried out by the expert corresponded to that of the researcher in that the same main themes and sub-themes for discussion arose.

Triangulation: Triangulation involves the use of several and different methods, investigators, sources and theories to obtain corroborating evidence (Anney, 2014). Triangulation helped the researcher to reduce bias and it cross-examines the integrity of participants' responses. The present research study used two different research instruments, namely, semi-structured and focus group interviews to enhance the quality of the data from a different source. Two different groups of participants were interviewed, that is, the primary caregivers on the one hand, and the teachers of children with ASD, on the other. Data collected through semi-structured and focus group interviews were found to be consistent.

Member Checks: Member checks refer to the fact that data and interpretations are continuously tested as they are derived from members of various groups from whom the data are solicited (Anney, 2014). The researcher in this study summarised what was discussed at the end of the interview. The researcher included each participants' words in the analysis and interpretation of the data. The purpose of doing member checks is to eliminate researcher bias when analysing and interpreting the results.

3.11.2 Transferability

Transferability is concerned with the extent to which the results of qualitative research of one study can be applied to other situations (Houghton, Lasey, Shaw, & Murphy, 2013). The researcher facilitated the transferability judgment by a potential user through the 'thick' or in-depth description and purposeful sampling.

This means that when the researcher provides a detailed description of the inquiry and participants were selected purposively, it facilitates the transferability of the inquiry.

Provide thick description: thick description helps other researchers to determine how well the research context fits other contexts (Houghton et al., 2013). In the final report, detailed and appropriate descriptions of the research methodology are offered so that readers can make informed decisions about the applicability of the findings to specific contexts.

Purposive Sampling: participants who were particularly knowledgeable of the issues under investigation were selected purposively in this study and it provided greater in-depth findings.

3.11.3 Dependability

Dependability refers to the stability of findings over time (Anney, 2014). If the research study was to be repeated, in the same context with the same methods and with the same participants, similar results would be obtained (Houghton, et al., 2013). To address the criteria of dependability, the techniques used in the data collection, the findings of the study, and the interpretations and recommendations within the study were reported in detail, thereby enabling a future researcher to repeat the study, if not necessarily to gain the same results. In this study, dependability is ensured because the following criteria have been applied: an audit trail, a code-recode strategy, triangulation, and peer examination or iterator comparisons (Anney, 2014).

An Audit Trail: An audit trail consisting of the written field notes and verbatim capturing of the interviews on a voice recorder, raw data, interviews, and observation notes collected from the field were kept to cross-check the inquiry process in this research.

Stepwise Replication: Stepwise replication is a qualitative research data evaluation procedure in which two or more researchers analyse the same data separately and compare the results (Anney, 2014). Data were analysed by the independent co-coder and the researcher. Meetings were held between the two and consensus was reached on the themes and sub-themes that emerged from the data.

Code-Recode Strategy: The code-recode strategy involves the researcher coding the same data twice, allowing a period of one or two weeks between each coding (Anney, 2014). The results from the two coding's were compared to determine whether the results were the same or differed.

Peer Examination: Peer examination in principle is no different from the member checks strategy employed to enhance the credibility of the inquiry. During peer examination, the researcher discussed the research process and findings with the supervisor and co-supervisor, who are experts in qualitative research. They helped to identify the categories not covered by the research questions.

3.11.4 Confirmability

Confirmability refers to the degree to which the results of an inquiry could be confirmed by other researchers (Houghton et al., 2013). Steps were taken to ensure that the research findings were the result of the experiences and ideas of the participants, rather than the preferences or imagination of the researcher. Confirmability was achieved through an audit trail, reflexive journal, and triangulation. A reflexive journal or practice is described as reflexive documents kept by the researcher to reflect on, tentatively interpret, and plan data collection (Anney, 2014). Maintaining field notes can be an important expression of reflexivity (Houghton et al., 2013). The researcher kept field notes, for all events that happened in the field and personal reflections concerning the study.

3.11.5 Authenticity

Authenticity means something that is genuine or that represents the essence of an idea (Amin, Nørgaard, Cavaco, Witry, Hillman, Cernasev, & Desselle, 2020). It takes the influence of context into consideration by addressing additional intrinsic naturalistic criteria. Certain initial conditions are prerequisite to achieve authenticity sub-criteria, including fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity (Amin, et al., 2020). In this study both groups of participants were sampled from the target population.

Caring and trusting relationship was developed during the prolonged engagement. All participants consented for participation. Data collection procedures, significance, objectives and purpose of the study were outlined to all participants. Participant's inquirer collaboration was built into every step, with full agreement on the guidelines to oversee the research and with information completely shared. Besides, the research report is to be available to all participants. What follows is a brief discussion and application of authenticity sub-criteria. *Fairness* is defined as "the extent to which all competing constructions of reality, as well as their underlying value structures, have been accessed, exposed, deconstructed, and taken into account in shaping the research findings, that is, the emergent reconstruction" (Amin, et al., 2020) . Of all criteria of authenticity, fairness is considered to be most important. The fairness criterion was addressed in the study in several ways. All interviews were guided by the same detailed interview guide. This gave all participants the chance to make their opinion heard on different aspects of the issue. 8 steps of Tesch was used to analyse all interviews. Most importantly, the findings identified in the study were not labelled as "truths", but as social constructions true for the specific relevant group that was interviewed.

Ontological authenticity is defined as "the extent to which individual participant' (and the inquirer's) early constructions are improved, matured, expanded, and elaborated, so that all parties possess more information, become more sophisticated in its use, and get their consciousness raised" (Amin, et al., 2020). Ontological authenticity was applied by analysing findings of each province separate to identify the differences and similarities regarding caring/teaching ASD children. Then introduced alternatives to solve challenges through the guidelines. Comparing Limpopo and Gauteng provinces findings and draw a conclusion.

Educative authenticity is defined as "the extent to which individual participants (and the inquirer) possess enhanced understanding of, appreciation for, and tolerance of the constructions of others outside their own stakeholding group" " (Amin, et al., 2020). One of the developed guideline is to provide information to the community, and all participants involved through trainings, media and awareness.

Catalytic authenticity is defined as “the extent to which action (clarifying the focus at issue, moving to eliminate the problem, and/or sharpening values) is stimulated and facilitated by the research being carried out” ” (Amin, et al., 2020). The social support model developed in this study and the guidelines are sufficient to deal with the different issues that participants raise during the research process.

Tactical authenticity is defined as “the degree to which all participants are empowered to take the action(s) that the inquiry implies or proposes” (Amin, et al., 2020). The following Useful procedures/techniques applicable when striving towards tactical authenticity were described in detailed in this study include ethical principles, data collection procedure and data analysis.

3.12 BIAS

Bias is defined as any tendency that prevents the unprejudiced consideration of a question (Pannuci & Wilkins, 2010). Noble and Smith (2014) identified five types of bias in research, namely, design bias which occurs when there is incongruence between aims and methods and poor study design. Selection or participant bias is related to both the process of recruiting participants and study inclusion criteria. It occurs when a sample does not adequately represent the entire population. Data collection bias and measurement bias can occur when a researcher’s personal beliefs influence the way data is collected. It is related to how questions are asked in an interview which can influence the information obtained. Analysis bias occurs when analysing data the researcher may naturally look for data that confirms his or her hypotheses or personal experience, overlooking data inconsistent with personal beliefs. Publication bias tends to occur when there is a lack of depth when describing study methodologies and findings are not clearly presented.

Bias was minimised in this study as follows:

Nonprobability purposive criterion sampling was used to sample primary caregivers and teachers of children with ASD. The information obtained and recorded from the participants in semi-structured and focus groups interviews were similar in some way as interviews were guided by the interview guide. No leading questions were asked during data collection. Field notes for reflection on the research process and verbatim reports from the participants were written down. During data analysis, transcripts were carefully read and coded using themes and subthemes, and an independent coder verified the themes and subthemes that emerged from the data.

3.13 CONCLUSION

This chapter described in detail the qualitative, phenomenological, descriptive, explorative, and contextual research design. Qualitative research instruments used in this study were semi-structured and focus group interviews with an interview guide to collect information until data saturation was reached. Field notes and a voice recorder were used during data collection. The content analysis method was used for data analyses as outlined by Bengtsson (2016).

CHAPTER 4

PRESENTATION AND DISCUSSION OF THE FINDINGS

4.1 INTRODUCTION

The previous chapter described the research methodology used in this study. This chapter presents the findings of the research and discusses the analysed data of the participant groups in the Limpopo and Gauteng provinces, the data gleaned from the semi-structured and focus group interviews. The findings are discussed in conjunction with the literature control that reinforces the study results.

The data which were collected during individual semi-structured in-depth interviews were analysed using eight steps of Tesch's open coding qualitative data analysis method as described by Creswell (2014) and outlined in chapter 3 on research methodology. Data was also submitted to an independent coder who also used the eight steps of Tesch's open coding method of qualitative data analysis as cited by Creswell (2014). A consensus meeting was set up between the researcher and the independent coder to discuss and agree on final themes and sub-themes based on the themes which emerged when the data was analysed independently.

Tables 4.3, 4.4, 4.5, and 4.6 depict the final themes and sub-themes which were agreed upon by the researcher and the independent coder and serve as the findings of the study. As a final check, the researcher considered how the findings of the current study correspond to theories and earlier findings reported in the literature with the purpose of determining the experiences and support needs of families of children with ASD.

This chapter is arranged into two sections. The first section presents and discusses the demographic data of the participants of the two groups.

The second section presents and discusses the results from semi-structured and focus group interviews conducted with the primary caregivers and teachers of children with ASD in the Gauteng and Limpopo provinces. The researcher conducted a literature search to find information. The information obtained in the literature has been integrated into the results and responses of the participants.

The presented demographic data, the responses from the semi-structured interviews and the findings from the focus group interviews with all the participants addressed objective 1:

To explore and describe the experiences of families and teachers regarding the support of families with ASD children in the Gauteng and Limpopo provinces of South Africa.

4.2 SECTION ONE: DEMOGRAPHIC DATA

The first part of the data analysis is composed of demographic data. This data contains extraneous information about the participants that may influence the model. The purpose of including demographical data about the participants is that the study investigated their views of the kinds of support services that are required for the families of children with ASD. Based on their demographic data their needs would differ according to the kinds of support services that they require. Table 4.1 summarises the characteristics of the primary caregivers and Table 4.2 summarises the characteristics of the teachers of children with ASD.

Table 4.1: Primary caregivers' characteristics

Characteristics	No of primary caregivers	Percentage
Gender:		
Male	2	9%
Female	21	91%
Age:		
18-29	2	9%
30-49	12	52%
50-64	8	35%
65 years and over	1	4%

Educational level		
Primary school	6	26%
High school	10	44%
College/university	7	30%
Marital status		
Single	8	35%
Married	13	56%
Widowed	2	9%
Relationship to the child		
Mother	17	74%
Sibling	1	4%
Grandparent	3	13%
Aunt/Uncle	2	9%
Race		
Black	22	96%
Coloured	1	4%
White	0	0%
Employment status		
Employed	7	30%
Not employed	9	39%
Pensioner	3	13%
Temporary	4	17%
Number of people in the household	3-10	
Number of ASD children in the family	22 families had one ASD child	96%
	1 family had 3 ASD children	4%
Gender of the ASD child		
Male	15	65%
Female	8	35%

Age of the ASD child		
1-12	11	49%
13-21	8	35%
22-33	4	17%
Social grant for ASD child		
Yes	22	96%
No	1	4%
ASD child staying in hostel/day scholar		
Hostel	3	13%
Day scholar	20	87%

Percentages and frequencies in respect of the participants' characteristics are presented below:

The findings reveal that most (91%) of the primary caregivers were females and only 9% were males. The reason for this could be that women were the primary caregivers because they provide physical care for their children. The results correspond to that of a study conducted by Russa, et al. (2015) which reported that men were found to be less involved with the physical care of ASD children and domestic tasks than women.

More than half (52%) of the participants comprised the middle age group and over one-third (35%) comprised the senior age group. Only 9% were of a young age and 4% were over 65 years of age. The participants had been involved with the care of a child with ASD for several years. Most (96%) of the primary caregivers were black which reflected the composition of the South African population and only 4% were coloured. The characteristics of families of children with ASD with regard to their genetic and ethnic origins were of importance in this study as the various groups do not share the same culture or language. The most dominant ethnic group in South Africa is black according to Statistics South Africa.

Mothers of children with ASD were the most dominant group in this study with 74% who participated followed by grandparents (13%), aunts and, or uncles (9%) and siblings (4%). Mothers are the most important resource for any child, given the fact that children spend the early years of their lives under their mothers' supervision. The results correspond to the findings of a study conducted by Karst and Van Hecke (2012) which indicated that mothers are viewed as critically important in providing intervention and lifelong care for ASD children.

Regarding the marital status of the participants, 56% of the primary caregivers were married, 35% were living without a spouse (single) and only 9% were widowed. The burden of caring for the child with ASD has been shown to fall predominantly upon the parents, which may result in them experiencing less marital satisfaction as indicated by Sitimin, Fikry, Ismail, and Hussein (2017). Therefore, it was important to assess the marital status of the families of children with ASD, as both partners need the support of each other in managing and caring for the child.

The highest educational level of the primary caregivers in this study was high school in the case of 44%, followed by college and, or university education (30%) and primary school education (26%). The educational levels of the families of children with ASD is important as the support model should be directed at the level of education of the participants for proper utilisation and application.

Findings revealed that 39% of the primary caregivers were unemployed, 30% were employed, 17% were doing temporary jobs as they had to look after their ASD children and only 13% were pensioners. Finding a reliable person to look after the ASD child may be difficult. The results correspond to the results of the study conducted by Gona, Newton, Rimba, Mapenzi, Kihara et al (2016) which indicated that having a child with ASD has a significant effect on the careers of their parents, particularly their mothers. The percentage of unemployment amongst this group should be seen against the background of unemployment in South Africa as a whole. Thus, the other reason for unemployment among the participants could be sought in the jobless rate in South Africa which is the highest since the first quarter of 2004 as unemployment rose faster than employment.

Regarding the number of children with ASD in their family, most (96%) of the families had only one child with ASD, and only 4% of the families had more than one child with ASD. Grasu (2015) indicated that between 2% and 4 % of the siblings of autistic children also had autistic disorders. ASD appears to be more common among males than females. The gender of ASD children in this study were males (65%) and females (35%). The results correspond with the results of the study conducted by Chiang (2014) which indicated that seven families of children with ASD who participated in his study were all boys. Statistics from the Centres for Disease Control and Prevention in South Africa also indicated that ASD is about 4.5 times more common amongst boys than girls.

The age of children with ASD appears to be increasingly younger. In this study, half (49%) of the ASD children were in the younger age groups, that is, between one and 12 years of age, 35% were between 13 and 21 years of age and only 17% of the children were over 21 years of age. Most (96%) of the ASD children receive a Care Dependency Grant and only 4% did not qualify as their parents did not meet the criteria for the grant. Many (87%) of the ASD children were reported as being day scholars while 13% reported that their children were staying in school hostels.

Primary caregivers indicated that they do not want their children to stay in a hostel as the care in a special school hostel is below standard. The White Paper no 6 on Inclusive Education (Department of Basic Education indicates that when learners stay in a special school hostel it has an impact on their quality of life in more than one respect. The results are in agreement with a newspaper article by Haper (2015) in Kwazulu Natal, South Africa which indicated that boarding facilities in special schools were reported to have a critical shortage of supplies. Children with disabilities in some of the hostels were living in appalling conditions, with insufficient food to feed the children.

Table 4.2: Teachers' characteristics

Characteristics	No of teachers	Percentage
Gender		
Male	0	0%
female	23 (17 Limpopo & 6 Gauteng)	100%
Age		
18-29	3	13%
30-49	12	52%
50-64	8	35%
Race		
Black	18	78%
Coloured	0	0%
White	5	22%
Experience in teaching ASD children	1	4%
0-2	5	22%
3-5	7	30%
5-10	10	44%
>10 years		
Number of ASD children in the class	1	26%
	3	35%
	5	9%
	6	4%
	9	17%
	11	9%

The findings revealed that all teachers who participated in this study were females (100%). The majority of them were in the middle (52%) to senior (35%) age group, and only 13% were young adults. The majority (78%) of the teachers were black and 22% were whites. Regarding experience in teaching ASD children, the findings revealed that 44% of the teachers had been involved in the teaching of ASD children for several years (more than ten years), 30% had five to10 years' experience, 22% had three to five years' experience and only 4% had no experience or two years' experience. Matters regarding the number of ASD children in a class and a school was determined by the type of special school. Some (21%) of the teachers had one child with ASD in their class, 35% had only three children with ASD in their class, 9% had five ASD children, and 4% had six children with ASD, 17% had nine and 9% had eleven children with ASD. The total number of children with ASD in one of the autism schools in Pretoria was 116. The total number of children with ASD in a special school with autism classes was between 23 and 31, and in special schools with no autism classes, the total number of children with ASD ranged between three and 19.

4.3 SECTION TWO: FINDINGS OF SEMI-STRUCTURED AND FOCUS GROUP INTERVIEWS WITH PRIMARY CAREGIVERS AND TEACHERS

This section captures the experiences of primary caregivers and teachers in the Gauteng and Limpopo provinces regarding the caring and teaching of ASD children. The findings of the semi-structured and focus group interviews resulted in themes and subthemes. The themes are grouped according to the province and according to the category of participants. This section is divided into four groups, namely: Group A is the Limpopo Province Primary Caregivers (LPPC), Group B is the Limpopo Province Teachers (LPT), Group C is the Gauteng Province Primary Caregivers (GPPC) and Group D is Gauteng Province Teachers (GPT). These designations are given by the researcher to distinguish between the groups, it is not officially recognised names of official groups. The themes and subthemes are supported by a literature control that reinforces the study results and participants' verbatim statements which are presented in italics.

4.4 GROUP A: LIMPOPO PROVINCE PRIMARY CAREGIVERS: RESULTS

This section captures primary caregivers' experience of caring for children with ASD in Limpopo Province, their challenges, existing support systems, identified support needs, knowledge regarding ASD and their coping strategies.

The following research questions were asked to attain the aforementioned objectives:

4 Describe in detail your experiences regarding caring for a child with ASD?
5 What challenges do you experience when caring for an ASD child?
6 What existing support services are in place to support ASD children?
7 What are the support needs of the family of children with ASD?
8 What are the coping strategies utilised by primary caregivers of children with ASD?
9 What is your knowledge regarding ASD?

The same set of questions was posed to primary caregivers in both the Limpopo and Gauteng provinces as described in Annexure P. The results are presented separately for each group to capture the similarities and differences in the perceptions of each group.

Six themes and 22 related sub-themes emerged from the findings of the study as depicted in Table 4.3. These themes and sub-themes are discussed below:

Table 4.3: Themes and Sub-themes for Limpopo Province Primary Caregivers

THEMES	**SUB-THEMES**
THEME 1A: Experiences of primary caregivers when caring for ASD children	**Sub-theme 1.1A:** Family perceptions of ASD child's pattern of behavior
	Sub-theme 1.2A: ASD children's communication skills: problematic to improve
	Sub-theme 1.3A: Existence of different conditions within ASD child described
	Sub-theme 1.4A: Effects of ASD child on the family
THEME 2A: Existing support for ASD children and family	**Sub-theme 2.1A:** Parents' and relatives' support
	Sub-theme 2.2A: School support
	Sub-theme 2.3A: Neighbours'/community's support
	Sub-theme 2.4A: Government support for ASD children and families

THEME 3A: Challenges experienced by caregivers regarding caring for ASD children	**Sub-theme 3.1A:** Financial constraints blamed for lack of consistent care for ASD children
	Sub-theme 3.2A: Lack of transport interferes with educational programmes
	Sub-theme 3.3A: Constant care required by ASD children exerts pressure on primary caregivers
THEME 4A: Knowledge of families related to caring for ASD children	**Sub-theme 4.1A:** Lack of, versus deficient knowledge regarding ASD
	Sub-theme 4.2A: Deficient knowledge regarding the causes of ASD
	Sub-theme 4.3A: Limited knowledge regarding the management of behavioural problems
	Sub-theme 4.4A: Adequate knowledge on how to take medication as influenced by health education given by nurses
THEME 5A: Identified needs for families with ASD children	**Sub-theme 5.1A:** The need for relevant community services and resources for ASD children described
	Sub-theme 5.2A: Community, parental training and awareness needs for ASD described
	Sub-theme 5.3A: The need for a multidisciplinary team for continuous monitoring described
THEME 6A: Coping strategies for families with ASD children	**Subtheme 6.1A:** An explanation that religion is used as a coping strategy for families of ASD children
	Subtheme 6.2A: Existing parents support group helps in coping
	Subtheme 6.3A: Supportive environment: a coping strategy for families of ASD children outlined
	***Subtheme* 6.4A:** Positive emotions: acceptance of the child

The semi-structured and focus group interviews conducted with primary caregivers of ASD children and teachers in Gauteng and Limpopo provinces established similarities and differences in the findings. The findings were integrated to maximise important information and the strengths of the study.

4.4.1 Theme 1A: Experiences of primary caregivers when caring for ASD children

The question asked of the primary caregivers was: “Please tell me in detail, all the experiences you have with your ASD child concerning care?” Primary caregivers of children with ASD indicated a variety of symptoms, behavioural problems, and skills associated with ASD children. Four sub-themes emerged from the analysis as discussed below.

4.4.1.1 Sub-theme 1.1A: Family perceptions of an ASD child’s patterns of behaviour

A major feature of ASD is the variety of symptoms that ASD children display. Primary caregivers of ASD children shared their experiences on the symptoms, and, or kinds of behaviour that are associated with their ASD children.

“*He doesn’t have a speech but follows the instructions, he is hyperactive, he jumps up and down the tables, interaction with other children is poor, he plays alone, and he eats too much, he does not want surprises, and he became anxious, angry and throw tantrums.* (P4, LPPC)

The families also shared that, as the children grew, their behaviour became more difficult to manage. They discussed a range of significant ASD-related behaviour that they encountered each day which included eating unusual things, aggression, and disruptive behaviour:

“She eats everything, she eats even her clothes, all of her clothes have holes and when it has holes she will tear it off. She even tears her blankets. When she eats she never gets satisfied” She smells everything before she can eat. She is 17 years but acts like a baby” (P21, LPPC)

The aggressive and disruptive behaviour reported by families include fighting with others, and damaging the house. As one mother said:

"He is verbally aggressive, he breaks everything at home e.g. TV, windows, microwave, etc. He even breaks a car windscreen for our neighbor with rocks. When he is angry he fights with everyone at home and throws items into others" (P17, LPPC).

"His friends are afraid of him because he hits and kicks them, sometimes he runs away from home" (P21, LPPC)

Families reported how they dealt with the escape of their children. Several families had installed a fence to prevent the child from escaping and running away. Some their children under lock and key.

"I installed a fence around the yard and when we are at home we lock all the doors because his behaviors destroyed our neighbor's homes" (P21, LPPC).

4.4.1.2 Sub-theme 1.2A: ASD children's communication skills problematic to improve

In addition to behavioural challenges, families also raised their concerns about the lack of communication skills of their ASD children. The child's patterns of behaviour also included the abrupt changes that occurred day-to-day and over time, such as the child suddenly losing the ability to talk, typically at about 18 months of age. One mother said,

"As time went on, he used to say mama but all of a sudden he said Nana and from there he never talked again". (P11, LPPC)

"He started talking while he was two years but unfortunately he stopped while he was three years old" (P16, LPPC)

In this study, the absence of adequate language development was most stressful for the families. Families seek medical assistance in the first instance after their children failed to develop normal speech. As two mothers stated:

"By the age of two, I realize that there is something that is not right with him, as his speech was delayed. Then I decided to take him to the doctor for assessment" (P10, LPPC)

A mother of an ASD child from Limpopo province verbalises her concern and wishes with regard to her son’s speech:

“I wish he can have speech, I wish God can answer my prayers and one day be able to speak, I will be very happy if one day I can be able to speak to him” (P13, LPPC)

Due to stress associated with the absence of adequate language development, four of the mothers had the habit of putting their child on a couch in front of the television so that they would not cry. These actions resulted in their children learning how to speak but using the English language only. As evidenced by:

“When I was busy with the house chores I used to put him on a couch, switch on cartoon channel on television for him not to cry. Then he taught himself English by watching television, from there he started talking, his first words that he said was “mom”, I was so surprised. The problem is that he does not speak any other language except English” (P10, LPPC).

However, for some parents in this study, their child's language deficiency is still a source of stress long after the child's diagnosis. As one primary caregiver commented when asked about her son's most difficult symptoms:

“The communication for me is the hardest... he gets angry if he wants something and I don’t understand for instance he will bring a cup, not knowing he wants either water or juice, so I had to show him both so that he will choose by himself.. . . I think that is the hardest and most frustrating (P10, LPPC).

4.4.1.3 Sub-theme 1.3A: Existence of different conditions within the ASD child outlined

The next essential sub-theme described ASD children's patterns of development and the presence of different conditions in ASD children. The families shared that the development of behavioural milestones in ASD children was delayed when compared to children without developmental disorders. As two mothers said:

“*All her milestones were delayed, sitting, standing, walking and speech never developed”* (P21, LPPC).

Despite the delay in developmental milestones, ASD was also found to be associated with other conditions, such as epilepsy and behavioural problems. Some of the families reported that these children experience seizures at home and school and are on epileptic treatment. This is evidenced by the following statement:

“…he is having uncontrolled epilepsy he always experiences seizures although he is on treatment.” (P9, LPPC)

4.4.1.4 Sub-theme 1.4A: Effects of ASD child on the family

The study found that many families of ASD children are particularly vulnerable to stress because of the child's severe behavioural issues and impaired communication. This was evident both in the interviews and the family lifelines. A good illustration of stress in this study was when four of the mothers and one grandmother became emotional and cried during the interviews. The experiences described below upset and frustrated most of the families.

Many families were found to be concerned about who would look after their children in the future when they passed on.

“I asked myself this question every day that, what if I die who is going to take care of him”. (P20, LPPC)

Lack of rest due to the need to maintain vigilance watching the child throughout the day because of his or her hyperactivity and destructive behaviour also frustrated the families.

When there is a serious need that I must attend a gathering, I make sure that he is next to me always, and I will inform them that I cannot participate in the preparation for the function such as cooking because I must watch over him. If I left him at home with his aunt I made sure that I told them that they must watch over him so that he does not destroy a lot of things while I am away. If he can enter into my bedroom he will put things upside down if we don’t put an eye over him. (P17, LPPC)

Families also shared the constant need to reinforce good behaviour all day, every day to model self-care and positive social skills. This involved constantly reminding the child and patterning behaviour for the child. As one mother stated:

"Every day I supervised her on self-care, undressing, bathing, dressing, applying lotion and roll on and combing of hair. Sometimes I bathed at the same time with her so that she can imitate me. If I don't supervise her she will bath without undressing". (P19, LPPC)

A mother of a severe ASD child also shared the frustrations of caring for an older child who acted like an infant because of his delayed development.

"Every month I buy four packets of nappies two for him and two for his six months old younger brother". (P9, LPPC)

Families also narrated their experiences when visiting the hospital for follow-up consultations. For these families, one trip to a hospital could be exhausting because of the child's behaviour and the need to hold the child down to help keep the child calm. As one mother said,

"When I took her for follow up I need to hire a private transport as she will touch everyone in the taxi and other people they don't like it". (P20, LPPC)

In addition, the families discussed their unique experiences that affect their personal and emotional well-being, such as denial, disbelief, feelings of hopelessness, feeling of being overburdened and a tendency to be overprotective. As a primary caregiver commented:

My husband and I are not in good terms since the birth of this child. He doesn't involve himself in the care, treatment or follow-ups of the child. Financially he does not support us he is there at home doing some piece jobs but he doesn't support us, some of the time he does not sleep at home (P14, LPPC)

Mothers of children with ASD voiced their uncertainties and asked themselves many questions about their children's condition. The majority of the participants reported that they experienced feelings of disbelief and refused to believe that their children had ASD. As evidenced by the following statement:

"…at the beginning I couldn't believe it, I used to wake up at night and ask myself why God gave me this child, and I couldn't accept him. I used to lock myself in the house and ask myself too many questions". (P13, LPPC)

"It is heart-breaking to me to have a child with ASD more especially when I start talking about her. Even if it's long that she has been there but the situation is not simple to accept, this is just like losing a loved one or death to me is sorrowful". (P21, LPPC)

Families with severe ASD children shared their experiences with regard to ASD-related services which were not beneficial because their children's condition did not improve and this left them feeling powerless and helpless. As these primary caregivers commented:

"I have given up on speech therapy and physiotherapy because his behavior does not change (P5, LPPC),

I do not go and collect treatment anymore because it does not assist her, and the condition remains the same. I do not know what to do anymore". (P21, LPPC)

"I used to take him for speech therapy before, but I did not see any improvement, I think is better if we teach him different things by ourselves because since he was five years he was attending speech and physiotherapy but it was useless" (P8, LPPC)

Many families in this study showed that they do not feel comfortable about other people taking care of their autistic children. As one primary caregiver commented:

"I don't feel comfortable living him with other people … I do not even prefer him to stay in school hostel" (P3, LPPC)

It was found that the families of children with ASD experience a lack of money. It became evident in this study since most of the primary caregivers reported that they did not work and were less educated because they had to take care of their ASD children. Most of them depend on a social grant to support themselves and their children. As one mother commented:

“I’m not working… I depend on social grant and pension from my parents, I am unable to meet the needs of my child and family” (P11, LPPC)

4.4.2 Theme 2A: existing support for ASD children and family

The study found that there is a lack of support for families of children with ASD. Four sub-themes emerged from the analysis, namely, support at home for parents, relatives and friends, support at special schools, support of neighbours, and, or communities for families of children with ASD and government support for ASD children.

4.4.2.1 Sub-theme 2.1A: Parents, relatives, and friends’ support

There were negative as well as positive feelings with regard to the support shown by fathers and, or /partners as evidenced by the following statement:

“He blames me every day for having a child with ASD. He does not involve himself concerning the caring of the child. When the child experiences some cramps during the night he does not assist, he rather moves and sleeps in the spare room. He feels annoyed, irritated and intolerant to the child. Financially he does not support the child. He even refuses to accompany us for a follow-up visit to the hospital. If I asked him that on such a date we will be going to the hospital for a check-up, a day before check-update he would not sleep at home”. (P14, LPPC)

Few fathers were reported to be providing the necessary support to their partners with regard to taking care of an ASD child. However, the following statement is evidence of a caring father:

“This Friday is he follow update at the hospital and his father will go with him as I will be at work. Everyone at home takes part in accompanying him to the hospital”. (P12, LPPC)

One mother reported that they did not receive any counselling after the diagnosis of their child, as is shown in the following statement:

"We never received any counseling and I have never disclosed the situation between myself and my husband to anyone you are the first person to know about this". (P13, LPPC)

The study found that the relationship with, and support of siblings of the ASD child has been extremely varied due to behavioural problems, reflecting the fact that no two families or situations are the same. However, the majority of brothers and sisters of children with ASD reported supporting each other well. The positive feelings are evidenced by:

"I'm happy the way he and his brother are relating to each other at home, his brother always supports him, he is not ashamed of him, he took him everywhere he goes and he listened to his brother very well". (P11, LPPC)

However, there is evidence of some sibling relationships which have been affected by the behavioural problems of the ASD child. It was also reported that ASD children ruin the relationships between the siblings and their friends due to their disruptive behaviour. These negative feelings are shown in the following statement:

"He has got a younger sister ….. She cried …… pause …….. They play together at home, but they can't get along because of his behavioral problem. When they went out to play with others, the other children do not want to play with them because of his brother's behavioral problem, this affects her a lot. She decided not to go out and play with him anymore because the other children will chase her and they would not allow her to play with them. The younger sister used to say her brother is ruining her relationship with her friends, therefore she cannot go out to play with him anymore. When she went out to play she make sure that he does not see her otherwise he will follow her". (P17, LPPC)

In their reports on their relatives' support, some families in this study referred to their rejection by relatives, and other participants reported that their relatives are not involved much in the care and management of the child's behaviour. This is evidenced by the following statement:

"*Our relatives are afraid of him, due to uncontrolled epilepsy, they even refuse him to visit their homes during schools holidays"* (P9, LPPC)

4.4.2.2 Sub-theme 2.2A: School support

Families expressed positive as well as negative feelings in regard to the special schools' support. Regarding the positive feelings expressed by participants, ASD children were reported to benefit from vocational skills training and language development as evidenced by the following statement:

School support is good, the teachers are supportive, every year we go out to celebrate with our children for a family day, or a casual day. Since he started schooling he has improved a lot nowadays he can make noodles for himself using a microwave, spreading of butter on the bread, tying off his shoes and he even makes juice for himself". (P10, LPPC)

"We are satisfied with the support provided by the school as his speech has improved he even prayed for us before we eat at home he will say God bless our food before we eat amen". (P9, LPPC)

Other primary caregivers expressed the opinion that special schools seem to delay the progress of their children rather than the home environment. Other negative feelings expressed were that ASD children did not benefit from anything offered by the special school as evidenced by the following statement:

"With school support, there is only one kind of a problem when we take him from school during school holidays it seems to be a bit of a change like his progress is going backward, and we are not satisfied as to the family. There is no progress with him like now he seemed traumatized, disturbed, upset, noiseless, inaudible and low. but if he goes home you will find him being active, hyperactive, trying to talk or talking using hands, and he becomes better and better. We were even thinking of changing him the school but not yet confirmed". (P1, LPPC)

"When this school opened some years ago children were not many in this school, so my child was able to get the proper care that she needs, when time goes on the school admitted more children and she could not receive the same

management and she was problematic. Then I asked my mother to take care of her at home because she needs more care than others". (P20, LPPC)

4.4.2.3 Sub-theme 2.3A: Neighbours and community support

Families with ASD children experience a lack of support from the community as a primary caregiver commented:

"Our neighbors treat him like they are treating a dog which will bite their children". (P13, LPPC)

"When he plays with the neighbor's children, they don't understand that he is not clashing with them but playing with them. When he moves they thought he is running after them they don't understand that he is playing with them. Even their parents they misunderstood his behaviour as they become furious with him as they thought he is wrestling with their kids, they end up punishing him things like that". (P8, LPPC)

One parent of a child with ASD and epilepsy reported that there is no support from the community leaders or indunas as they are not even aware that the family has a child with a disability, as evident in the following statement:

"We are not receiving any support from the community leaders because he is not even aware that we have a disabled child at home (P8, LPPC)"

ASD children in this study were found to be stigmatised as shown in a caregiver's comments:

"They gave him a name, they said he is "Siyandlane" because I'm always holding him by his hand". (P13, LPPC)

"They called him "le Greysana" because he is attending school at Grace and Hope special school". (P9, LPPC)

"*I am struggling to get school transport for my child because he is still messing himself, so private transport refuses to transport him because of that. I feel like they are discriminating against him".* (P8, LPPC)

A mother of a 17 years old ASD child voiced her experiences with regard to the sexual abuse of her child in the community:

“People from our community took advantage of her because of communication challenges. One day after school while she was on her way home, someone took her to his house and raped her. I took her to the hospital for confirmation, and they confirmed that she was raped. I also opened a raped case but nothing has been done so far”. (P6, LPPC)

The disruptive behaviour of a child with ASD causes serious difficulties in a family’s participation in community activities. In this study, families with ASD children were forced to keep their children under lock and key due to behaviour that was misunderstood by the public and to avoid rejection by the community as one caregiver commented:

“We keep him under lock and key during school holidays as people are afraid of him”. (P13, LPPC)

Families expressed how they coped with the rejection and stigmatisation from the community

Community support is not that good, some they are surprised by his behavior, but I took initiation to explain to my neighbors what kind of a child he is, for an example: I told them that if you gave him food he will smell it first before he eats, and sometimes he won’t eat it. Since then their support has improved. (P10, LPPC)

Lack of support groups

All participants revealed that there are no support groups in their communities, schools or health facilities for families of children with ASD. As evidenced by:

“There are no support groups in our community” (All participants)

Some participants acknowledged that they do not know what a support group is, and that they have never heard of such a group. As one caregiver commented:

“I don’t even know what a support group is” (P5, LPPC)

One parent in Limpopo Province expressed her concerns with regard to the support group which was established in Polokwane but is no longer active. As evidenced by her statement below:

“It was three years back when we were having the support group, we were having a support group where we were to meet once a month, but you know people outside becomes discouraged, we were meeting with one of the doctors here in Polokwane we were meeting there every month and then discussing with everyone. The parents were given the inputs, sometimes we make awareness in town at the park the one next to SABC but that was three years back. Last year and two years back those groups never existed they didn’t even call us”. (P7, LPPC)

4.4.2.4 Sub-theme 2.4A: Government support for ASD children and families

The families explained that the government is providing some support to assist with the caring of their ASD children. Services, such as care dependency grants or disability or social grants are provided every month as evidenced by:

“The child is getting a social grant”. (P10, LPPC)

The participants reported that the care dependency, and, or disability and social grant is not enough to meet their needs, as they are not able to work due to the burden of caring for their ASD children. As evidenced by:

“The child is getting a social grant, but is not enough for our needs as I am not working because I must take care of him”. (P16, LPPC)

Free basic medical service

Participants reported that their children are receiving their medication free of charge at the hospital as one caregiver commented:

“…he is getting his treatment at the hospital for free of charged”. (P12, LPPC)

Feeding scheme

The government provide food for the children at school (P1, LPPC)

School and hostel fees

Most of the families reported having paid school fees per quarter at the special schools.

“We are paying school fees every quarterly” (P3, LPPC)

4.4.3 Theme 3A: Challenges experienced by primary caregivers regarding caring for ASD children

Families of children with ASD in Limpopo Province reported a variety of challenges related to caring for, and supporting children with ASD.

4.4.3.1 Sub-theme 3.1A: Financial constraints blamed for lack of consistent care for ASD children

One of the major concerns expressed by those families with ASD children in Limpopo Province was lack of money due to unemployment and the burden of caring. The mother of a child with ASD described how she struggles financially with the hostel fee, transportation of the child and other basic needs at home, by sharing that:

“He is staying in the school hostel, but he comes home once every month, there are not suitable for me because I don’t even have money to go and fetch him monthly as the school is 50km away from home. When I hired a car to take him to and from school it needs R800.00 which I cannot afford. I am not affording to pay the hostel fee as currently, I owe R9000.00. At the moment we don’t have food and electricity in the house and he is coming home for the school holidays this Friday”. (P13, LPPC)

Another mother voiced her concern on lack of money to buy a device that would assist her child with computer skills and technology

“Her teacher told me that he is good with a computer, she further indicated that if I have money I was supposed to buy him a computer at home so that he can practice more. But unfortunately, I don’t have money”. (P11, LPPC)

Another caregiver expressed her concern with regard to a lack of money for access to services relating to interventions for the child’s condition:

“The doctor indicated to us that he needs a CT scan which will cost around R8000, to assist him with the interventions, but we cannot afford such an amount”. (P5, LPPC)

Another caregiver expressed her concern in regard to the financial burden of having to regularly buy and replace a damaged school uniform which they could not afford, as evidenced by the following statement:

“The other thing is that our kids troubled each other at school as some will take other children’s shoes or socks, sometimes because of the behavioral problems they tear/damage their uniform. So they end up not complying with school uniform because we cannot keep on buying a new uniform now and then as we don’t have money”. (P18, LPPC)

The mother of a child with ASD shared her experiences of the reasons for the lack of money and poverty in her family. These included her own unemployment and the deaths of the father of her child and a grandmother. She shared the following:

“I am unemployed as I cannot manage to work with the burden of caring for the child” (P16, LPPC)

“His father committed suicide last year, he was the one who supports us financially even though we were not staying together. From then on we depended on my mother pension fund, lately, she passed on in December, now we only depend on social grant” (P10, LPPC)

4.4.3.2 Sub-theme 3.2A: Lack of transport interferes with educational programmes

The study showed that often children with ASD in the Limpopo Province did not to go to school every day because of the inadequate school transport facilities. There are too many children with special needs who reside in different villages, and, therefore, they alternate the days that they travel to school. Sometimes the bus is full and some learners have to remain behind. Those children that reside far from the school use public and private transport. The buses and motor cars from these special schools cannot accommodate all the children to transport them to school. As two primary caregivers commented:

“Our grandchild is not attending school daily due to the school transport issues, the school transport comes only on alternate days if this week comes on Tuesday and Thursday. Next week it will come on Monday, Wednesday, and Friday. These have an impact on their learning progress” (P4, LPPC)

“….at the moment there is no available transport as the department is not repairing the buses those that were broken. Most of the children from other villages are no longer attending school due to lack of transport” (P1, LPPC)

4.4.3.3 Sub-theme 3.3A: Constant care required by ASD children exerts pressure on primary caregivers

The findings reveal that at home children with ASD always need caregivers to assist them with self-care and to safeguard them from danger. As a result, caregivers live in strict isolation. Thus, families of children with ASD were found to be isolated because of the children’s behavioural and communication problems. As one primary caregiver commented:

“We are unable to attend funerals or any community social events as one of us needs to remain to look after the child”. (P4, LPPC)

One family reported that they were not given the necessary support at church. This contributed to the severe isolation of the family as they stopped attending the church as evidenced by the following statement:

“I quitted attending the church because some of the church members including the Sunday school teachers misunderstood his behavior”. (P5, LPPC)

4.4.4 Theme 4A: Knowledge of families related to caring of ASD children

The findings revealed that primary caregivers had poor to limited knowledge with regard to ASD, its causes and management. Primary caregivers need accurate knowledge regarding ASD as they play a vital role in caring for children with ASD.

4.4.4.1 Sub-theme 4.1A: Lack versus deficient knowledge regarding ASD

Most of the primary caregivers were found to have no knowledge about autism although they had indicated that their children were disabled, but that they did not know the specific diagnosis in respect of their children. This is evidenced by the following statements:

"I don't know anything about autism, what I can say is that my child is uncontrollable". (P8, LPPC)

"I don't want to lie, I don't know anything about autism, as she was born being normal but unable to talk". (P5, LPPC)

A few of the primary caregivers acknowledged that they were aware that their children were suffering from ASD, but that they had little information about the condition. As evidenced by the following statement:

"*They said he is having autism, but most of the information was explained to his late mother, I don't have enough knowledge regarding his condition".* (P3, LPPC)

Television and magazines were reported to be the source of little information about autism for some of the primary caregivers. As evidenced by:

"I have seen some of the things about autism on television". Wwhen he was young we didn't know. Even the Occupational therapist and psychologist I don't remember them telling me anything". (P6, LPPC)

"I am someone who likes to read magazines, one day while I was reading I realized that the things that I was reading about is what my child is doing and they said is autism" (P10, LPPC)

Community knowledge about ASD

It is apparent from this study that there is a general lack of knowledge and awareness of ASD in the community. It was shown that children with ASD and their families are rejected and stigmatised by the community. This study showed that these children were called by different abusive names and that fellow church members misunderstood their behaviour.

4.4.4.2 Sub-theme 4.2A: Deficient knowledge regarding the causes of ASD

Families expressed a lack of knowledge concerning the causes of ASD as a result of not being informed by the health care practitioners. Some indicated that ASD is caused by delivery complications, family history, message not interpreted on the brain and a cut on a tongue. As evidenced by:

"At the hospital, they said it was caused by delivery complications, there were some blood vessels which were ruptured during delivery and bleeding due to poor bearing down". (P9, LPPC).

"What I heard is like he lacked oxygen maybe during birth, but I am not sure". (P1, LPPC)

One participant, whose child is 17 years old with lack of speech expressed the following with regards to the causes of ASD:

"I heard that it is caused by a cut on the tongue, but my child does not have a cut, so I am wondering what causes it". (P3, LPPC)

A mother, whose child had difficulty in swallowing and lacked the ability to speak stated that:

"They said the message is not interpreted on the brain that is the cause of him to be unable to talk and swallow something like that" (P7, LPPC).

One participant maintained that ASD is caused by a family history of the condition because their family had three children with the same condition at home. This is evidenced by the following statement:

"I think is family history because we have three of them with the same condition at home". (P19, LPPC)

4.4.4.3 Sub-theme 4.3A: Limited knowledge regarding the management of behavioural problems

Families seem to have limited knowledge concerning the management of the behavioural problems of their ASD children. Some participants indicated that they were never informed about the management of their children but that they had learned some of the strategies that assist them. As evidenced by:

"haaaa… about that one I don't remember anyone telling us how to handle him. …. but our mother makes sure that he is always safe and there is nothing that can harm him for an example all electrical appliances are always switched off". (P1, LPPC)

Other participants discussed the little information that they were given by the health care practitioners with regard to the management of behavioural problems, as evidenced by the following statements:

"They said at home we must teach them the daily activities". (P3, LPPC)

"They told me that the child needs to be taken care of but they did tell me how". (P18, LPPC)

"They said I must not shout at him, I must be patient with him". (P17, LPPC)

"They said we must give him support, we need to understand him, for hyperactive we must avoid food with a lot of sugar". (P10, LPPC)

"We must give him medication as prescribed always collect the treatment at the clinic, go for 6 months follow up visit at the hospital, and the child should always be clean and take treatment all the time". (P8, LPPC)

4.4.4.4 Sub-theme 4.4A: Adequate knowledge on how the child should take medication as influenced by health education given by nurses

Most of the participants maintained that their children were on medication and that they had adequate knowledge with regard to the administration of the medication and the dosage as a result of the health education given by nurses. As evidenced by the following statements:

"He on Risperdal and Ritalin. Ritalin we give him twice a day, in the morning and evening, Risperdal is 5mls daily". (P17, LPPC)

"He is on Ritalin 20mg, we give him one tablet per day, the other one is Epilim, and they also reemphasized the issue of taking them at the same time". (P11, LPPC)

4.4.5 Theme 5A: Suggested needs of families of children with ASD

Primary caregivers revealed their needs in regard to caring for children with ASD. Their priorities in respect of their needs differed from one primary caregiver to another. These needs related to schools for autistic children, guidance, daily management, relational support, emotional support, and the transmission of knowledge and skills.

4.4.5.1 Sub-theme 5.1A: The need for relevant community services and resources for ASD children outlined

The most important form of support that was identified by the participants was an ‘autism school’ specialising in the education of children with ASD.

Mothers in Limpopo Province voiced their needs with regard to autism schools, as expressed in the following statement:

“We want the government to build at least an autism school in the Limpopo province because we don’t have any in our province”. (P4, LPPC)

“…..we are requesting the government to build at least an Adult Autism Centre in our area next to the special school so that after 21 years they will move to the Adult Autism Centre where they will be safe”. (P2, LPPC)

“I wish the government can build more special schools to accommodate them, as they are schooling very far away from home” (P13, LPPC)

Limpopo Province primary caregivers show intense needs for guidance and information about the reason for the difficult and unusual behaviour of their ASD child and want to be shown what to do when a child acts unusually. As one mother from Limpopo province commented:

“… Health care providers must give us more information regard to our children’s condition, as most of us we don’t know” (P14, LPPC)

School transport was a serious concern to the participants in Limpopo Province. Therefore, participants suggested that the government should provide adequate transport for special needs learners. This was expressed as follows:

“The department of education should provide with the transport of these children to school because at the moment there is no available transport as the department is not repairing the buses those that were broken”. (P2, LPPC)

“The government should provide transport that will transport the children to school daily not alternative days”. (P4, LPPC)

“The government should provide transport because private transport is expensive for us” (P8, LPPC)

In terms of the future of children with ASD, many primary caregivers were concerned about their children’s level of independence and their ability to maintain relationships. Primary caregivers were also worried about what would happen to their children when they die and could no longer take care of them. Families from both provinces voiced their needs with regard to the future of their children, as evidenced by:

“My needs are that the child should attend school gets assisted to be better so that he can have a better life everyone wishes to have”. (P4, LPPC)

One of the participants in Limpopo Province voiced her concern with regard to the support group that no longer exists in their area. Furthermore, she suggested ways to be used to re-establish it as follows:

“We use to have autism Limpopo group in Polokwane for the parent's support group but the parents do not attend the meetings anymore. We tried to send them messages but they don’t avail themselves. Last year at the meeting we were thinking of re-establishing it by going to radio Thobela and Capricorn FM to give them the message through the radio. Maybe if the messages it is through the radio they will respond”. (P5, LPPC)

4.4.5.2 Sub-theme 5.2A: Community, parental training and awareness needs for ASD described

Primary caregivers expressed the need for understanding by family, relatives, neighbours and the community. They also stressed the need for community awareness to prevent the stigmatisation and rejection of children with ASD as evidenced by:

“I think the community needs to be aware of autism because they see it as the cursed. The community needs to be aware of maybe through the awareness in the community. Even the parents of the kids must be called to be work-shopped to have accepted and love their children, as some may have rejected them. Some parents have divorced because of the couple blaming each other”. (P1, LPT)

One participant indicated the importance of the education of parents to prevent the hiding of children with ASD, as evidenced by:

“Parental education is important because I have got a neighbor who has got the child who is intellectually disabled like mine, this child is getting a social grant but the mother hides him”. (P10, LPPC)

One of the teachers from Gauteng Province also supported the idea of community awareness as evidenced by the following statement:

“So if churches can get on board, and the schools get on board you know HIV & AIDS are discussed in the normal mainstream syllabus why isn’t disabilities being addressed in the mainstream schools, why isn’t that part of life orientation program”. (P5, GPT)

4.4.5.3 Sub-theme 5.3A: The need for a multidisciplinary team for continuous monitoring outlined

Families maintained that a child with ASD needs someone with knowledge about ASD, such as a health care professional or a home-based carer to continuously monitor the child at home to reduce the burden of caring.

Two grandparents of a child with ASD expressed the wish to have someone who would assist them with the care of their grandchild because they are getting old and isolated as follows:

“I wish that the government can provide us with someone who will assist us to take care of her daily, because as you can see that we are getting old and we are unable to attend funerals”. (P4, LPPC)

A mother of a 17-year old child with ASD voiced her needs with regard to continuous monitoring as follows:

"I wish I can have someone to assist me with taking care of her while I'm still at work P4, LPPT)".

A brother to a 9-year old child with ASD also indicated the need for monthly continuous monitoring by specialists:

"I think he needs maybe continuous monthly monitoring from a specialist so that when there is a chance someone can notice, rather than six months follow up visit at the hospital (P1, LPPC)".

Moreover, families expressed their concerns about the need for more health care professionals who specialise in ASD in both provinces.

One participant in Limpopo Province expressed her concerns with regard to the lack of specialists in the field of ASD as follows:

"In South Africa, we are having a few doctors who are knowledgeable or specialized in ASD. With me no one told me that my child is autistic, they just treated epilepsy. Her teacher at school, she is the one who told me that my child is presenting with autism signs and symptoms, I was so frustrated because she was under a specialist and that specialist never told me that my child is having autism that is why I'm saying we are looking forward to South Africa to have doctors who will study more about ASD, not only doctors but including dieticians and nurses". (P7, LPPC)

"We are looking forward to the Department of Health to provide us with Dieticians those with expertise concerning the diet of ASD children". (P6, LPPC)

This was supported by one of the teachers in Gauteng Province as follows:

We need health professional's people that work with autistic children because there is a difference between knowing about autism and working with autism. (P5, GPT)

4.4.6 Theme 6A: Coping strategies for families of children with ASD

The findings revealed that primary caregivers have coping strategies that assist them in managing stressful situations related to caring for these children. It was further indicated that the parents and families start employing coping strategies soon after the diagnosis of the child with ASD.

4.4.6.1 Subtheme 6.1A: An explanation that religion is used as a coping strategy for families of ASD children

The study revealed that the most useful coping strategy for both groups of participants (primary caregivers and teachers) of children with ASD is religion. Most of the participants even if they are not strongly religious have adopted this method in coping with the ASD situation.

A mother of a child with ASD who is also a teacher of children with ASD, explained how religion assisted her to cope:

"With God, everything is possible because I'm the believer in God, every strength I ask God to give me strength and wisdom to can tackle this as a mother and as a teacher of child/children *with ASD. You see is so difficult because at home my child is there, at the class my learners are there but I just see the glory every day and I don't even have stress for them. I just see myself coping".* (P6, LPT)

"Eish… sometimes it feels so stressful but I end up saying that is the will of God". (P18, LPPC)

Participants reported focussing on prayer and the reading of the Holy Book, as evidenced by:

"With God, I can face my challenges" (P19, LPPC)

"I pray every day and ask God to give me strength" (P21, LPPC)

A caregiver of two ASD children believed that she was chosen by God to be a caregiver of children with ASD, and this is what motivates her to cope with the caring burden. As evidenced by the following statement:

"I have accepted because this is what God chose to give it to me, out of all these people I was chosen to be the one to take care of them, and I will continue to take care of them until death P5, LPPC)"

One participant with dual role of being a mother and a teacher of child/children with ASD believe that ASD children are gifts from God, and that is what motivates her to cope with the situation, as evidenced by:

I cope very well because this is a gift from God that has been given to us so that we might help them, it seems as if we are caregivers for them, I feel happy when I'm with them, and there is no learner at school that I will take him/her as nothing. (P10, LPT)

4.4.6.2 Subtheme 6.2A: Living grandparents support group helps in coping

The study reveals that the present support that the primary caregivers receive from the grandparents, in particular the grandmothers, helps them to cope with their ASD children. As evidenced by:

My mother is the one who assists me with the caring of the child, she is the one who monitors her while I'm at work and the siblings are at school". (P18, LPPC).

4.4.6.3 Subtheme 6.3A: Supportive environment: a coping strategy for families of ASD children outlined

The findings revealed that a supportive home environment is one of the coping strategies used by primary caregivers, as evidenced by:

"The support that we provide to each other as the family keeps me going". Her siblings understood her condition. (P2, LPPC)

The partner's support was reported to be one of the strategies that helps a primary caregiver to cope with the caring of a child. This was shown in the following statements:

"The support that I got from his father motivated me to cope with the situation, he was his only child, and he loved him so much, even though we were not staying together". (P12, LPPC)

All family members love her so much including the father, they treat her like any other child in the family. (P19, LPPC)

"I cope because, I stay with my husband and children, they support me, they don't have a problem, my firstborn was born is 22 years old and the second born is 17, so if I arrived home late, they will have bathed her and give her some food". (P20, LPPC).

4.4.6.4 Subtheme 6.4A: Positive emotions: acceptance of the child

Most of the participating families reported having had a high level of dissatisfaction, frustration, and difficulty accepting their autistic children immediately after the diagnosis of their children. In this study, it was found that as time went on they gradually accepted their children's condition. As one primary caregiver commented:

"I don't have problems anymore because I'm used to the situation, I have accepted him". (P1, LPPC)

*"I don't see any problem anymore, I have accepted her condition as she was born with this condition, this is God's will and I love her more than anyone else." (P*2, *LPPC)*

The following section discusses the results of the semi-structured interviews with the primary caregivers in Gauteng Province.

4.5 DISCUSSION OF THE LIMPOPO PROVINCE PRIMARY CAREGIVER'S FINDINGS

4.5.1 Theme 1A: Experiences of primary caregivers when caring for ASD children

A major feature of ASD is the variety of symptoms that ASD children display. Primary caregivers of children with ASD shared their experiences on the symptoms and kinds of behaviour that are associated with their ASD children.

4.5.1.1 Sub-theme 1.1A: Family perceptions of ASD child's patterns of behaviour

The families reported that as the children grew, their behaviour became more difficult to manage. They discussed a range of significant ASD-related kinds of behaviour that they encountered each day which included:

- Impaired speech but with the ability to follow instructions, abrupt changes in speech, speaking English and the humming of a tune,
- Hyperactivity,
- Poor interactions, playing alone or with favourite toys,
- Eating too much but never being satisfied, eating unusual things and smelling food before eating,
- Upset by surprises and anxiety when exposed to an unfamiliar environment,
- Aggressive behaviour, throwing tantrums, hitting and kicking others, destroying property,
- Escaping from home,

- Delayed milestones, epilepsy in some children.

As the primary investigator, the researcher observed ASD-related behaviour and property destruction when visiting the participants to collect data. This behaviour was documented in field notes. The researcher was able to meet several of the children with ASD at home and school during data collection. Particular note was made of one child who used only groaning sounds for communication and was very hyperactive. During the interview with his parents, the child wanted to take the audio recorder by force, and he even tore some pages from the field notebook. He was constantly moving. He pinched his little sister's face very hard. All of the doors and gates were locked, as his parents were afraid that he would escape. The researcher also observed several homes in which the television screens had been cracked caused by the child with ASD throwing toys or other objects at it.

4.5.1.2 Sub-theme 1.2A: ASD children's communication skills most problematic to improve

In addition to behavioural challenges, families also raised their concerns about the communication skills of their ASD children. Most of the children in this study were reported to be nonverbal although a few could use simple sentences. The findings are similar to the results of a study conducted by Gorlin, et al. (2016), which found that most of the children had severe communication deficits. A few children were nonverbal and a few could use simple sentences, but the majority had only a few words in their vocabulary and very few children could carry on a meaningful reciprocal conversation.

It was found that the patterns of behaviour of a child with ASD also included abrupt changes that occurred from day to day and over time, such as the child suddenly losing the ability to talk, typically at about 18 months of age. In this study, the absence of adequate language development was most stressful for the families. Families seek medical assistance in the first instance after their child failed to develop normal speech. Due to the stress associated with the absence of adequate language development, four of the mothers who participated in the study used to put their children on a couch in front of the television so that they would not cry. These actions resulted in their children learning how to speak using the English language only.

4.5.1.3 Sub-theme 1.3A: Existence of different conditions in the child with ASD described

Children reach developmental milestones at their own pace. Minor, temporary delays are usually no cause for alarm, but an ongoing delay in reaching milestones can lead to issues later in life (Krucik, 2016). Most children follow typical patterns of development from birth through adolescence. However, children with ASD, do not. A limited intellect in ASD children impairs normal development (Uys & Middleton, 2014). Differences are often detected early and become clearer as a child with ASD begins to drop behind the development of his peers (Landa, 2013). However, in some cases, an infant appears to develop normally until the age of one to three years. Then, sudden changes may occur that indicate the presence of ASD, according to the National Institute of Mental Health in the US. Landa, (2013) found that children with ASD exhibit disruption in developmental domains in the first year of life in their motor development attention span and temperament.

The families shared their views that the development of milestones among children with ASD was more delayed than among children without developmental disorders.

Some of the families reported that these children experience seizures at home and school and are on epileptic treatment. Epilepsy occurs in around 20 to 30% of children with autism and the age of onset tends to be in late childhood or adolescence (Kirk & Sharma, 2017). The basis for the association is, however, poorly understood. There is evidence that epilepsy and ASD are correlated, however, the picture may be different in a group with early-onset epilepsy.

4.5.1.4 Sub-theme 1.4A: Effects of ASD child on the family

Many families were found to be concerned about who would look after their children in the future when they passed on. Lack of rest due to the need to maintain vigilance watching the child throughout the day because of the hyperactivity and destructive behaviour associated with the condition also frustrated the families. Families also shared the constant need to reinforce good behaviour all day and every day and to model self-care and positive social skills. This involved constantly reminding the child about good behaviour and patterning good behaviour for the child. A mother of a severe ASD child also shared the frustrations of caring for an older child who acted like an infant because of her delayed development. Families also reported their disappointment about the shortage of special schools, particularly in the rural areas and the lack of autism schools in Limpopo Province.

Furthermore, families in Limpopo Province also reported their frustration about the shortage of health care professionals in special schools, such as social workers, physiotherapists (PT), occupational therapists (OT), speech therapists and professional nurses. Families also narrated their experiences when visiting the hospital for follow-up consultations. For these families, one trip to a hospital could be exhausting because of the long waiting times, the child’s behaviour, and the need to hold the child down so that he or she could be kept calm. In addition, the families discussed the unique experiences that affected their personal and emotional well-being, such as denial, disbelief, feelings of hopelessness, feelings of being overburdened and overprotectiveness.

An experience of denial was found to be common in parents of children with ASD in this study because they struggle to come to terms with their child’s diagnosis. These feelings affected their marriages and often resulted in separation or divorce. Mothers of children with ASD constantly wonder and ask themselves many questions about whether they deserved to have a child with this condition. The majority of the participants reported that they harboured feelings of refusal to believe that their children had ASD.

Other factors causing severe stress were the ASD-related services which did not seem to be beneficial as they tended not to bring about any improvement in the condition of their children, and this left the parents feeling powerless and helpless. Lack of funds was a problem because most of the primary caregivers reported that they were no working and were less educated since they had to take care of their ASD children. Thus, most of the families depend on the social grants of their children.

The causes of stress to primary caregivers in this study are similar to those found in the study conducted by Dababnah and Parish (2013) in Palestine with 24 parents. Their findings indicate that parents struggled with financial stressors, child behavioural and medical challenges, and depression. In the current study, families were worried because their children had not yet accomplished self-care tasks, such as toileting, personal hygiene, feeding themselves, and educational targets (Madiba, Kgole, & Lekhuleni, 2015). According to Bashir, et al. (2014) mothers of children with ASD in Cape Town were reported to worry about the future of their children, about their marital relationships, childbearing, social relationships and their occupations. The presence of stress and burnout were also reported. The sources of stress to the mothers of ASD children in the study conducted by Koydemir and Tosun (2009) were reported to be exhaustion, being the only person taking care of the child, financial constraints and the negative attitudes of people towards the child.

Caregivers living in Bangkok were found to experience depression and caregiver burdens related to the number of problems related to their children and the number of hours spent with their children, communication problems and the inappropriately repetitive behaviour of their children (Sukmak & Sangsuk, 2018).

The participants in this study reported that the diagnosis and the prognosis of ASD make it difficult for them to accept their children's condition. The findings are supported by Bitsika, et al., (2013) who indicated that the extent of the impact of ASD on the family varies according to its severity. Furthermore, families experience feelings of disbelief, anxiety, and confusion as their child’s problems become noticeable and they find it difficult to understand the child’s milestones. The early phase before a diagnosis could be stressful for the families as a manifestation of the disorder is often unclear.

ASD is one of the developmental disorders which present parents with ongoing grief. Thus, autism is unique in several ways. First, this disorder has no clear biological marker, unlike many other developmental disabilities. Second, because it is characterised by problems of social interaction, such as forming attachments and showing affection, parents of children with ASD are often denied some of the fundamental rewards of parenthood. Consequently, ASD has been considered as one of the most complex and intractable developmental disorders with which families may have to cope (Bashir, Lone, & Ahmad, 2014).

The feeling of helplessness is consistent with the findings of a study conducted by Matenge (2013) who reported that health practitioners were not supportive but rather contributed to the family’s feelings of hopelessness and uncertainty. Some of the caregivers’ decisions to give up on therapies and prescribed treatment are potentially dangerous to the child's health. This indicates that these caregivers lack information regarding their children’s condition. Diekema (2014) states that parental decisions that are not in a child's best interest should be challenged by health practitioners.

Parents were reported to feel overworked due to the disturbing behaviour of their ASD children (Madiba, et al., 2015). Parents of children with ASD were reported to feel uncertain as they doubt their competence because their child does not respond as expected (Pottas & Pedro, 2016). Participants in this study reported that these children require supervision, strict monitoring and special attention in each and everything that they do. It was found that some of these caregivers did not know what to do about their children's behavioural problems. These results show that caregivers of autistic children experience high levels of chronic stress. Both of the parents of ASD children were reported to be exhausted (Pattern, Baranek, Watson, & Schultz, 2013). These reactions may result from limited knowledge about the management of disruptive behaviour in ASD children.

Families indicated that they do not want their children to stay in school hostels and that they do not feel comfortable leaving their children with other people. The caregivers feel that no one else can take care of their child with the same love and care that they have done (Madiba, et al., 2015). It was found that caregivers tend to become overprotective of their ASD children because they are often labeled as being disabled. Excessive overprotection of young adult ASD children can ruin and destroy their lives especially if they function at a high level. Families should let these young people explore and learn about the world on their own.

Puberty and the adolescent stage was also a disturbing thought as participants realised that their children would not cope with this developmental stage. Russa et al. (2015) indicated that both parents of ASD children were reported to have doubts about their future. Another form of disturbing thought was that learners with intellectual disabilities would leave school at 21 years without any qualification which, in turn, would seriously limit their chances of successfully progressing into the labour market (Department of Education, 2015). There are limited sheltered employment and adult centres available in South Africa for ASD children. The Department of Education (DoE) (2015) indicates that there is a serious shortage of rehabilitation centres in the field of ASD.

4.5.2 Theme 2A: Existing support for ASD children and family

The study found that there is a lack of support for families of children with ASD. Families of children with ASD face a host of difficulties in obtaining appropriate care and support including obstacles, such as the rejection of the ASD child by community members and relatives, discrimination and poor support from the fathers of children with ASD. There is also a lack of support groups in the communities, and the parents of children with ASD do not have opportunities to socialise due to the burden of caring.

Van Biljon, et al. (2015) found that 35% of children with autism had difficulty in obtaining needed medical services. It was further indicated that parents had difficulty in accessing specialised services when they suspect that their child’s development is delayed, obtaining an appropriate diagnosis, and accessing care after the diagnosis has been made. The lack of an effective, coordinated care system for children with autism that provides accurate information combined with the diagnosis of the symptoms of the disorder itself, can lead to high levels of stress for families, social isolation, negative health outcomes, and marital dissatisfaction. Four Sub-themes emerged from the analysis namely, support at home for parents by relatives and friends, support at special schools, support by neighbours and the community for families of children with ASD and government support for families of children with ASD.

4.5.2.1 Sub-theme 2.1A: The support of parents, relatives and friends

There were negative as well as positive feelings with regard to the support of fathers and partners. The study found that most of the fathers of children with ASD did not provide the necessary support because they blamed their partners for having a child with ASD. It was found that it was the mother who was blamed for having a child with ASD. This meant that mothers experienced a lack of support from their partners. Another effect of having a child with ASD was that it caused relationship problems for primary caregivers. Placing the blame on each other led to divorce. A study conducted by Koydemir and Tosun, (2009) found that mothers lack a social life which was a frequent concern and their relationship with their husbands was of a low quality and was followed by divorce.

Other worrying factors for primary caregivers was the lack of counselling by health care practitioners after the initial diagnosis of their children. This is similar to the finidng of the study conducted by Koydemir and Tosun (2009) which found that most of the mothers reported that they were not well informed about autism. Only a few fathers were reported to provide the necessary support to their partners with regard to care.

The study found that the relationship with, and support of siblings of the ASD child are extremely varied due to the child’s behavioural problems, reflecting the fact that no two families or situations are the same. However, the majority of brothers and sisters of children with ASD reported supporting each other well. Nevertheless, there is evidence of some sibling relationships that were affected by the behavioural problems of the ASD child. It was also reported that children with ASD ruin the relationship between the siblings and their friends due to their disruptive behaviour.

A total of eight South African fathers who cared for at least one child with ASD each shared the view that caring for their children with ASD was both stimulating and enriching and that, with time, they were able to adapt and better respond to the specific needs of their child (Pottas & Pedro, 2016). Fathers in the study conducted by Russa et al. (2015) reported experiencing stress due to continually having their sleep disturbed, and the need to take time off work to support their partner in managing the child’s behaviour.

Kovshoff, Cebula, Tsai, and Hastings (2017) maintain that children between the ages of six and fifteen rate their relationships with their siblings positively. Other families reported having poor relationships with their peers, showing anger towards the sibling with ASD, particularly if that sibling is aggressive. On measures of behaviour problems and relating to others, the parents/caregivers of children with ASD reported more negative behaviour than the parent with normal children.

The relationships between children with ASD and their siblings were characterised by less intimacy, prosocial behaviour, and nurturing. Such non-intimate relationships have also been found among the siblings of children with developmental disabilities in general according to Kovshoff et al. (2017) and may result from the atypical quality and quantity of social interactions. Children with autism and their siblings reportedly spend less time together. In addition, the time they do spend together is not qualitatively comparable to interactions between typical siblings. Children with ASD frequently fail to respond to social interactions, or they may respond in an atypical manner that is difficult for a sibling to interpret. In his study sample, Simelane (2015) also found that the response of children with autism to their siblings was less positive than the response of children without autism to their siblings.

Rejection of the ASD child by the sibling and other children can result in a feeling of loneliness. Having a sibling with ASD may exact varying effects on different children. The ability of a child to successfully adjust may be moderated by his or her access to social support and by the severity of the sibling's autism (Simelane, 2015).

Participants revealed that there is little support for families of ASD children from relatives and friends. Poor support from relatives and friends results in the isolation of the family as the primary caregivers reported that they do not attend family social functions because of the way in which the family treats their ASD children. Nevertheless, the caregivers of children with ASD rate family and relatives as one of their main sources of support. Friends was also a source of support to some caregivers. People who constitute the family's informal support network will probably respond in different ways to the ASD child's behaviour or characteristics (Anderson, 2016).

Some members of a family may be quick to adapt to the behaviour of the child with ASD and be ready to support the parents immediately. Others may need a bit longer to get used to the child's condition. Hartley, Dawalt and Schultz (2015) indicated that some family and friends would find it difficult to offer support. It was suggested that families with ASD children should let their family, relatives, and friends know which comments and reactions are helpful and supportive and which ones are not. Anderson (2016) suggests that caregivers should be patient and that generally, the situation would improve as people begin to understand more about the condition.

4.5.2.2 Sub-theme 2.2A: School support

Families expressed positive as well as negative feelings regarding the support given by special schools. The positive feelings about the support provided by the special schools were found to be related to vocational skills training and language development. The negative feelings about the support by the special school were found to be poor progress due to the intake of children with different conditions and the lack of resources.

Regarding the positive feelings about school support, ASD children were reported to benefit from the vocational skills training and language development. Families reported that children learn different vocational skills, such as washing dishes, cleaning, doing their own washing, sewing, gardening, and welding. Some children were reported to have gained improved communication skills.

The results are consistent with the study conducted by Tsiopela and Jimoyiannis (2014) on the use of information and communication technologies (ICT) in educating a child with ASD. The student achieved proficiency in almost all tasks after six sessions and he improved his performance in terms of speed and accuracy. The use of ICT in educating children to adapt to the environment can also help children with autism to acquire pre-vocational skills.

Other families of children with ASD, however, reported that the special schools seemed to delay the progress of their children other than the home environment which helped them, and that their children did not benefit from the special school at all.

Adequate support to ASD children through peer group support systems

It was found in this study that children with ASD in Gauteng Province support each other at school through peer support groups. Senior learners who understand and know safety rules, help other children with severe or profound intellectual disabilities. They hold their hands and make sure that they get to, and from the playground. This is called a peer buddy system. Another peer support system used is called the ‘wheelchair pushers’ whereby senior learners push those children who are in wheelchairs to the assembly point in the morning and when the school is out they accompany them to the school buses.

This finding was supported by the study conducted by Foster (2011) which states that students with disabilities could increase their interaction with typical peers by participating in a peer buddy programme. Peer group mentors could encourage and motivate them to become more active socially.

4.5.2.3 Sub-theme 2.3A: Neighbours and community support

In this study, families with ASD children experienced a lack of support from the community and neighbours. This was shown because individual participants reported that community members teased their child who has ASD, prevented their children from playing with an ASD child, and were afraid of the child. Thus, these children with ASD were stigmatized in public situations. This may be because of limited awareness, a lack of knowledge, and limited services in their communities in regard to ASD and other developmental disorders. One parent of a child with ASD and epilepsy reported that there is no support from the community leaders or indunas as they are not even aware that they have children with disabilities in their communities.

ASD children in this study were found to be treated differently by other people, as they were called by abusive names, labeled according to their school uniform and were denied the use of private school transport. One of the female ASD children was reported as having been forced into sexual intercourse. In this study, it would appear that children with ASD are kept under lock and key due to their disruptive behaviour that is misunderstood by the public and to avoid rejection. Also, families maintained that there are no support groups in the community, clinics or special schools.

As already mentioned, families with ASD children experience feelings of being rejected by the community and their neighbours. It was found that community members tend to tease children with ASD, isolating a child by preventing their children from playing with a child with ASD, are fearful of the ASD child and stigmatise the child in public situations. It is difficult for families of children with ASD to obtain understanding and support from the community due to the disruptive behaviour displayed by their children (Lam, Wong, Leung, Ho, & Au-Yeung, 2010).

Children with intellectual disabilities in the Moletsi area, Limpopo Province were also denied the opportunity to play with other children in the street (Kgole & Molepo, 2014). It was found that communities and neighbours were not able to understand the behavioural characteristics of children with ASD (Lam, et al., 2010). A family level of adjustment is associated with the extent to which families find support in their neighbourhoods and community (Greeff & Van der Walt, 2010).

Children with ASD and their families were found to experience a high level of stigmatisation within the community. The possible explanation for stigmatisation in this study could be a lack of knowledge because communities are not made aware of the ASD condition.

These findings were supported by Russa, et al., (2015) who maintained that there are a lack of programmes designed to teach communities about developmental disorders. The negative beliefs about ASD and lack of understanding of a child's behaviour results in societal stigmatisation. Stigma is one of the most difficult aspects of public encounters experienced by parents of children with disabilities. Stigma is a social construct defined as a mark of shame or discredit, characterised by guilt or disgrace. Components of stigma include labelling, stereotyping, separation, status loss, and discrimination. Parents of children with autism often experience stereotyping and negative public reactions (Gona, Newton, Rimba, Mapenzi, Kihara, Vijver & Abubakar, 2016).

Families of children with ASD experience isolation as a result of difficulties in finding a reliable person to look after the child and the feeling of tiredness due to the constant physical care (Greeff & Van der Walt, 2010). Russa, et al., (2015) stated that many families of children with ASD have limited leisure skills, community, and recreational experiences.

In this study, participants indicated that they are unable to attend funerals, churches, parties, and family functions. These families were reported to have lower rates of social participation than families without a disabled child (Madiba, Kgole, & Lekhuleni, 2015). It is apparent from the quotes above that the physical care of children with ASD left some of the caregivers isolated from the public.

Isolation was found to be mainly the results of society's lack of understanding which is an external source. However, for other parents isolation is mainly the result of internal sources, such as a feeling of incompetence, and, therefore, they choose isolation over the frustrations of taking their child out in public (Russa, et al., 2015).

All participants revealed that there are no support groups in their communities, schools or health facilities for families of children with ASD. Some participants responded that they do not even know what a support group is, and that they have never heard of such a group. Support groups and social support have been associated with positive family and child outcomes. They are important resources to relieve stressors associated with having an ASD child at home (Greeff & van der Walt, 2010). Support groups brings together people facing similar issues because members of support groups often share experiences, acquire information, advice, and emotional support and make friends. It can be helpful for families of children with ASD to simply talk to other people who are in the same situation.

Parents of children with ASD have been identified as experiencing higher levels of stress than parents who have children with other disabilities (Kissel & Nelson III, 2014). Parents of ASD children with behavioural problems and severe language deficiencies were more likely to bond with other parents after being referred to a support group (Pattern, Baranek, Watson, & Schultz, 2013). Public awareness of ASD may be increased through support groups. Families who cope well have a higher level of social support from friends, family, professionals and other parents of children with ASD (Dorsett, 2015). Lower-income families were also found to be at a disadvantage in terms of both information and support as they are less likely to attend workshops, conferences and autism support groups.

4.5.2.4 Sub-theme 2.4A: Government support for ASD children and families

In South Africa, the primary caregivers of children with a disability receive a Care Dependency Grant from the South African Social Security Agency (SASSA) for their children as they need permanent care due to the disability. The child must be younger than 18 years. Primary caregivers must submit a medical or assessment report confirming that the child is severely disabled and receiving permanent care and support services. The primary caregiver should not earn more than R73 800 per year if single or R147 600 if married (SASSA, 2015). The results reflected that all primary caregivers who meet the criteria were reported to be receiving a Care Dependency Grant for their children. An adult with ASD who is older than 18 years receives a disability grant.

The participants reported that the care dependency, disability and social grant is not enough to meet their needs as they are not working due to the burden of caring for their ASD children. This corresponds to the reports by social grants recipients who engage in formal and informal borrowing which indicates that sometimes families borrow groceries from local spaza shops as their grants are inadequate (Neves, Samson, Van Niekerk, Hlatshwayo & Du Toit, 2009)

Free basic medical service

Basic medical care is free in South Africa which has a sophisticated public healthcare system in major towns and cities. Participants reported that their children are receiving free medication at local hospitals. Children's right to health care is expressed in two sections of the South African Constitution. Section 27 accords "the right to have access to health care services for all South Africans". Section 28 (1) (c), which is that portion of the Bill of Rights dealing specifically with children's rights, states that children have "the right to basic health care services".

The government seems to be providing support to the families and children with ASD through a free basic medical care. According to the Mental Health Care Act 17 of 2002 (Department of Health, 2004) assisted care, treatment and rehabilitation should be provided to a person if there is a reasonable belief that the person is suffering from a mental illness or a severe or profound mental disability. Furthermore, the person requires care, treatment and rehabilitation services for his or her health or safety, or for the health and safety of other people, and is incapable of making an informed decision about the need for care, treatment and rehabilitation services.

Feeding scheme

Children with ASD were reported to receive free meals at special schools. In South Africa, the National School Nutrition Programme (NSNP) currently provides meals to over 9 million learners. “The NSNP is a poverty alleviation strategy introduced in 1994 by the government as part of the reconstruction and development programme of the newly founded democratic Republic of South Africa. To contribute to the improvement of the quality of education by enhancing primary school learners’ active learning capacity as well as their school attendance and punctuality through the temporary alleviation of hunger” (Circular 24.2004. National school nutrition programme).

School and hostel fees

There seems to be an inconsistency concerning the payment of school fees in special schools. The majority of the families reported that they have been paying school fees per quarter at the special schools. However, some reported that the government is paying for them. Affordability was found to be a challenge for most families.

According to the Department of Basic Education (2014) it is “working tirelessly to improve the chances of every South African child to access a quality education”. The Department of Education is committed to ensuring that no child is prevented from accessing a public school based on poverty or is in any way discriminated against or has to face punitive measures imposed by a school in the case of non-payment of fees.

If learners meet certain criteria, they should not have to pay school fees in any public school and the Department has several initiatives and programmes in place to make it easier for learners to access quality education. These include schools that are designated as no fee schools, partial fee exemptions and automatic fee exemptions institutions (Department of Education, 2014).

4.5.3 Theme 3A: Challenges experienced by caregivers regarding caring for ASD children

Challenges experienced by primary caregivers in Limpopo Province include poverty, unemployment, lack of school transport and the burden of caring.

4.5.3.1 Sub-theme 3.1A: Financial constraints blamed for lack of consistent care for ASD children

A child with ASD is particularly demanding for families in poverty who may not have the appropriate knowledge or access to resources to care for their child’s needs. Many families with ASD children in the Limpopo Province are severely financially and socially disadvantaged because the expenses of their ASD child are overwhelming. The expenses include the cost of care, traveling, school transport, food, hostel fees, devices, the frequent buying of uniforms as clothes do not last because of the child’s behavioural problems. The causes of a lack of funds and poverty in families include unemployment and the death of partners and grandparents.

Financial difficulties have significant impact on families who are raising a child with ASD as it is physically, emotionally and financially costly (Simelane, 2015). Bitsika, Shapley, and Bell (2013) indicated that high therapy and educational costs are other challenges faced by families of children with ASD. Disadvantaged families simply do not have the financial resources to give their children the therapies most likely to improve their quality of life (Dorsett, 2015). The primary caregivers may not be able to advocate for services due to low educational status. The families of caregivers with a low level of education find it difficult to advocate on behalf of their children. Their children may fall behind both academically and socially. The more educated the primary caregiver, the more likely the family is to receive care, as an educated caregiver understands a child’s legal rights in respect of care, how to actively engage the community in seeking that care and has the personal resources to continue fighting for the child’s rights (Dorsett, 2015).

4.5.3.2 Sub-theme 3.2A: Lack of transport interferes with educational programmes

Transport is generally inaccessible to children with special needs, preventing them from accessing special schools. ASD children spend an unreasonable amount of time on the road because they do not have transport. The study found that children with ASD in Limpopo Province do not go to school every day because of inadequate school transport. Therefore their caregivers alternate the days that they attend school, because sometimes the school bus becomes filled to capacity and some learners have to remain behind. Those children that live far from the school use public transport. The number of school buses or cars from special schools were found not to be sufficient to accommodate all of the learners.

Inadequate school transport affects the children's training progress as some attend school twice a week. When the bus has been damaged children stay at home until such time as the bus is repaired. These results correspond with the findings of the study conducted by Van Biljon, Kritzinger and Geertsema (2015) which indicates that transport is generally inaccessible to children with special needs preventing them from accessing special schools.

The DoE (2015) indicated that children with special needs are unable to enroll in full-service schools that have been upgraded and they spend an unreasonable amount of time on the roads because they do not have transport. Furthermore, the costs for special schools to provide transport is one of the most serious challenges. Therefore, a school transport policy is currently being developed and will take an integrated approach which does not separate transport for special schools from that of the transport of ordinary schools.

In conclusion, participants suggested that the government should provide adequate transport for special needs learners as stated in White Paper no 6 on inclusive education (Department of Basic Education, 2015)

4.5.3.3 Sub-theme 3.3A: Constant care required by ASD children exerts pressure on primary caregivers

The constant care required by children with ASD exerts pressure on primary caregivers as they must assist the child with self-care and guard him or her against danger. This results in primary caregivers living in strict isolation.

Families of children with ASD were found to be severely isolated because of the child's behavioural and communication challenges. Families feel uncomfortable taking their children to social events due to the community's stigmatisation of the child. They were found to be spending their time at home taking care of their ASD child as they need their caregivers' attention. Church members were also reported as not providing the necessary support to one of the families of an ASD child, and this attitude contributed to the severe isolation of the family as they stopped attending church. This finding is similar to the findings of a study conducted by Gorlin, et al. (2016) which reports that families described not being able to physically leave home or not having the ability to meet with friends because of the child's needs.

Risk factors for the caregiver burdened in this way include a higher number of hours spent caregiving, depression, social isolation, financial stress, and lack of choice in being a caregiver, low educational attainment, and sharing a residence with the care recipient (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). Therefore, psychosocial interventions include support groups or other psycho-educational interventions that are essential for caregivers.

Primary caregivers raising a child with autism face extreme difficulties in dealing with problematic kinds of behaviour, teaching their child to communicate, teaching basic life skills, guarding their child against danger, and preparing their child for adult life (Bashir, et al., 2014).

4.5.4 Theme 4A: Knowledge of families related to caring for ASD children

The findings revealed that in Limpopo Province primary caregivers of children with ASD had a poor knowledge of ASD, its causes and management. However, participants seemed to know how their children should take their medication.

4.5.4.1 Sub-theme 4.1A: Lack of knowledge versus deficient knowledge regarding ASD

Most of the families indicated that their children are disabled, and they do not know the specific diagnosis of their children. A few of the primary caregivers stated that they are aware of the fact that their children are suffering from ASD, but they have little information about the condition.

Knowledge about ASD is important for caregiving. Primary caregivers with little knowledge about their child's disorder is a significant predictor of caregiver stress (Johnson & Simpson, 2013). One study conducted by Lindsey and Barry (2018) found that knowledge of ASD did not significantly correlate with caregiver distress although it was expected that caregivers with higher levels of knowledge about ASD would also report lower levels of distress. To date, little research has investigated caregiver knowledge of ASD, but limited studies have speculated that increasing caregiver knowledge about the behaviour of children with ASD leads to decreased caregiver stress. Derguy, Bouvard, Michel and M'Bailara (2014) conducted a study about the knowledge of caregivers and their beliefs about the causes of ASD. Almost half of the sample had inconsistent knowledge and beliefs about ASD, and participants with this inconsistency reported significantly higher levels of anxiety than participants with consistent knowledge and beliefs.

Television and magazines were reported to be the source of limited information about autism for some of the primary caregivers. It was found that health care providers did not provide any information to caregivers about the condition of their children.

Primary caregivers and teachers of children with ASD can provide significant data on the effects of a wide variety of treatments (Wetherston, Gangat, Shange, Wheeler, Sayed Karrim, & Pähl, 2017). Primary caregivers and teachers need accurate knowledge regarding ASD as they play a vital role in caring for and teaching ASD children. This should be done by the health professionals who provide counseling and information to the parents and teachers about the condition and its management.

4.5.4.2 Sub-theme 4.2A: Deficient knowledge regarding the causes of ASD

Based on the results the Mental Health Care Act no 17 of 2002 (*Government Gazette*, 2002) states that every mental health provider before administering any care, treatment and rehabilitation services should properly inform the mental health care user and family with regard to the condition and their rights. Knowledge and awareness of ASD are still low in sub-Saharan Africa (Bakare & Munir, 2011). The period of the first diagnosis is noted as an important time when families have a critical need for information (Russa, et al., 2015).

4.5.4.3 Sub-theme 4.3A: Limited knowledge regarding the management of behavioural problems

Behavioural problems, such as impaired social communication, interaction and limited repetitive patterns of behaviour can be a source of stress for families of children with ASD. Doctors, psychologists, and other health care practitioners in this study were found not to give accurate information and explanations to the families regarding ASD and the management of related behavioural problems. The aforementioned result corresponds to the findings of this study because the families reported that the relevant health care providers did not inform them about their children’s condition. Lack of access to proper information about the diagnosis is a barrier to the management of the ASD child for the families, particularly as the child grows older (Russa, et al., 2015).

Providing families with quality information regarding the diagnosis, available services, and support services is essential to the families of children with ASD during the entire life span of the child. Knowledge and skills of ASD enable families to take positive steps towards learning how to help their child (Greeff & Van der Walt, 2010).

4.5.4.4 Sub-theme 4.4A: Adequate knowledge on how to take medication as influenced by health education given by nurses

The only information that is reported to be given by nurses during health education is how to administer medication. Caregivers seem to know how to take medication as this was also demonstrated to the researcher during data collection. Providing medical information about the causes of ASD is the first step in helping parents understand the child's disorder and to cope with it (Derguy, et al., 2014).

4.5.5 Theme 5A: Identified needs of families with ASD children

In this study, the participants revealed their needs in caring for and teaching children with ASD. Some needs were identified by primary caregivers as priorities and have already been discussed. These include the need for autism schools and adult autism centres with hostels, additional school transport, and a curriculum for learners with ASD, and free school and hostel fees. Participants also identified other needs, such as access to quality information, sheltered employment for ASD children, the establishment of support groups, parental training and community awareness on ASD, continuous monitoring of ASD children by a specialist, home visits by health care providers, emotional and debriefing support, senior management support and the recruitment of more specialists in ASD.

4.5.5.1 Sub-theme 5.1A: The need for relevant community services and resources for ASD children described

Participants suggested that the government should provide autism schools and adult autism centres in Limpopo Province to improve the education of their ASD children. School transport was another need identified by caregivers in Limpopo Province. The need for an autism support group in the province was also identified by parents so that they could share their experiences without being judged.

Lack of access to proper information on diagnosis and as the child grows older is a barrier to the management of the ASD child for the families. Quality information regarding the diagnosis, available services, and support services are important to the families of children with ASD over the whole life span of the child. Other most commonly reported needs were related to services, professionals, and quality information about their child's unusual behaviour. Limpopo Province primary caregivers have critical needs for guidance and information about the reason for the difficult and unusual behaviour of their ASD child and wanted to be shown what to do when a child is acting unusually.

Primary caregivers and teachers reported having significant information and education needs before, during and after the diagnosis as supported by Matenge (2013). Indeed, education was a high information priority for all the participants in this study. Therefore, professionals and service providers need to be aware of the potential variability in parents’ information coping styles if they are to meet the information and education needs of primary caregivers effectively.

4.5.5.2 Sub-theme 5.2A: Community, parental training and awareness needs for ASD described

Families and teachers suggested that the public must be educated about ASD through autism awareness campaigns because the community at large lacks the knowledge. It was suggested that the World Autism Awareness Day (2 April) and World Autism Awareness Month (April) can be utilised to educate the public about ASD. In the UK and US, educating the public about ASD and, hence, raising autism awareness has been the focus of large-scale initiatives. Millions of dollars, pounds and euros have been reported to be spent on autism awareness campaigns (Dillenburger, Jordan, McKerr, Devine & Keenan, 2013).

A study conducted in Northern Ireland assessed autism awareness and knowledge about autism with a sample of 1204 people. It found high levels of autism awareness. In fact, over 80% of the sample were aware of ASD and over 60% of these respondents knew someone with ASD in their own family, the circle of friends or work colleagues. Furthermore, results show that local and international autism awareness campaigns have largely been successful (Dillenburger, et al., 2013).

4.5.5.3 Sub-theme 5.3A: The need for a multidisciplinary team for continuous monitoring described

People diagnosed with autism not only have greater medical needs than the general population, but also have particular characteristics that are often not accommodated by medical services (Boada & Parellada, 2017). Therefore, the families in this study suggested that their children require continuous monitoring by the health care practitioners.

Home visit vulnerability and medical paternalism are replaced with more equal relationships in which decisions can be made collaboratively regarding the most important aspects of the client's life and health. The main indications for a home visit include a general assessment of the functioning of the ASD child, meeting with a patient's family to discuss his or her condition and to make ethical decisions. However, at times, the home visit is simply a meeting between two individuals who just happen to be a doctor and a patient, one that transpires outside of the strict and determined framework of the clinic. This encounter requires time, and enables a conceptual shift coming closer to the patient's world, family and community (Kannaia & Alonb, 2018)

Specialists in ASD

The study also found that there was a lack of doctors who specialise in ASD in both Provinces. The caregivers indicated that in South Africa there are a few doctors who are knowledgeable about, or have specialised in ASD. South Africa requires doctors who will make a study of ASD, and not only doctors but dieticians and nurses.

4.5.6 Theme 6A: Coping strategies for families with ASD children

The findings revealed that primary caregivers have coping strategies that assist them in managing stressful situations related to caring for these children. Caregivers of children with ASD experience significant stress and challenges in caregiving (Lai & Oei, 2014). The word ‘coping’ implies the process of managing stressful circumstances (Mahmood, Saleemi, Riaz, Hassan, & Khan 2015). It was further indicated that the parents and family start employing coping strategies soon after the diagnosis of a child with ASD.

4.5.6.1 Subtheme 6.1A: An explanation that religion is used as a coping strategy for families of ASD children

In this study religion was found to be the most useful coping method for both primary caregivers and teachers. According to the study conducted by Mahmood, et al. (2015) positive coping strategies for the mothers of children with ASD were integration, networking, and religion. Spiritual and religious faith assisted with acceptance and stress reduction. Participants in the study conducted by Reddy, Fewster and Gurayah (2019) reported praying all the time and asking God to give them patience and to help their child. This instilled hope, thereby enabling coping and acceptance.

4.5.6.2 Subtheme 6.2A: Living grandparents support group helps in coping

Support from living grandparents and significant others were reported to be the coping strategies for the primary caregivers in this study. Grandparents are reported as being the most important people who could provide support to the caregivers as they assisted with the caring burden. Five ASD children were found to be staying with their grandparents as their mothers are single and working.

This finding agrees with the results of a study conducted by Gorlin, et al. (2016) which states that physical and emotional support systems stem from nuclear, extended families and friends who seemed to help the families of a child with ASD as they navigate through the difficulties associated with severe autism.

4.5.6.3 Subtheme 6.3A: Supportive environment a coping strategy for families of ASD children described

The study found that an environment that provides physical, emotional, social and spiritual support assist families in coping with the multiple challenges of parenting a child with ASD. Emotional support from a partner and friends seems to help primary caregivers through stressful events. Caregivers in this study reported coping well with the assistance of siblings. The sharing of experiences with friends was also reported and assisted primary caregivers to cope well with the burden of caring. Families facilitated coping in discussions about crises and alternate solutions. Preparation for alterations in routines and social outings are necessary to prevent outbursts and anxiety according to Reddy, et al. (2019).

Coping strategies like problem-focused and emotion-focused coping strategies are used by parents and primary caregivers. Support groups, the role of the pastor's wife, and raising awareness and educating others were identified as the coping mechanisms utilised by caregivers in dealing with the stigma attached to ASD in the study conducted by Timothy, Philip and Marshall (2011). Taking appropriate breaks and seeking out available support were other coping strategies utilised by the parents of ASD children to strive for balance within the family according to Hoogsteen and Woodgate (2013)

The problem-focused strategy is mostly adopted by fathers or male members of a family. It involves cognitive and behavioural strategies to change the situation. These coping efforts are based on the stressful situation itself. Emotion-focused strategies are adopted mostly by mothers or female members of a family and it involves social support, the expression of emotions and communication of feeling as a reaction to stressful situations which is the key to these coping strategies (Mahmood, et al., 2015). General stress coping is a transitional process whereby coping methods vary across time and contexts to match the changing demands of stressful events (Lai & Oei, 2014).

The results of the study conducted by Lai and Oei (2014) reveal that the two most useful coping resources for primary caregivers are problem-focused coping and social support. Primary caregivers' coping strategies are also reported to be influenced by the following factors:

- Demographical characteristics (i.e., gender, age, education, income, language)
- Psychological attributes (i.e., personality, cultural values, optimism, sense of coherence, benefit-finding and sense-making abilities, emotional health, coping styles),
- Child characteristics (i.e., age, gender, medical conditions, cognitive and adaptive functioning abilities, language difficulties, and behavioural problems) and
- Situational factors (I., treatment availability, family function, and clinician referrals to support resources) (Lai & Oei, 2014).

4.5.6.4 Subtheme 6.4A: Positive emotions: acceptance of the child

Most of the participating families in this study reported that they utilised the acceptance of the child's condition as a means of coping because families generally experience a high level of dissatisfaction, frustration, and difficulty accepting their autistic children immediately after the diagnosis of the condition. As time goes on participants in this study gradually accept their children's condition. One caregiver in this study indicated that acceptance was influenced by other parents of children with ASD during follow-up consultations at the hospital. This finding was supported by the findings of a study conducted by Gardiner and Larocci (2014) which found that previous experience in contacts with parents of ASD children is associated with greater acceptance of autism in parents. Furthermore, those individuals with a family member on the autism spectrum tend to be more accepting and open towards autism.

‘Autism acceptance’ can be defined as an individual who feels accepted or appreciated as an autistic person with his or her autism positively recognised and accepted by others and the self as an integral part of that individual (Cage, Di Monaco, & Newell, 2018). It was also indicated that autism acceptance by others could be important for autistic individuals’ mental health for various reasons.

4.6 GROUP B: LIMPOPO PROVINCE TEACHERS’ RESULTS

This section captures teachers’ experiences in Limpopo Province of teaching children with ASD, their challenges, existing support systems, identified support needs, knowledge regarding ASD and the different coping strategies. Six themes and sixteen subthemes emerged from the results as illustrated in Table 4.4.

The following research questions were asked to attain the aforementioned objectives:

- Describe in detail your experiences regarding teaching children with ASD?
- What challenges do you experience when teaching ASD children?
- What existing support services are in place to support ASD children?
- What are the support needs of the teachers of children with ASD?
- What are the coping strategies utilised by teachers of children with ASD?
- What is your knowledge regarding ASD?

The same set of questions was posed to teachers in both the Limpopo and Gauteng provinces. The results are presented separately, for each group to capture the similarities and differences of the perceptions of each group.

The following section discusses the results of the semi-structured interviews with the teachers in Limpopo Province.

Table 4.4: Themes and Sub-themes for Limpopo Province Teachers (LPT)

THEMES	SUB-THEMES
THEME 1B: Experiences regarding teaching children with ASD	**Sub-theme 1.1B:** ASD child's pattern of behavior
	Sub-theme 1.2B: An explanation of teaching methods for ASD children
	Sub-theme 1.3B: Teaching children with ASD described as frustrating
THEME 2B: Challenges experienced by teachers of children with ASD	**Sub-theme 2.1B:** Lack of human and material resources in the special schools: a challenge towards achieving objectives
	Sub-theme 2.2B: Poor parental, school management and government support problematic
THEME 3B: Knowledge about ASD	**Subtheme 3.1B:** Insufficient knowledge of teachers in regard to teaching ASD children blamed on lack of on-the-job training
	Subtheme 3.2B: Insufficient knowledge of diagnosing ASD children by health professionals blamed on medical reports
THEME 4B: Learning needs of ASD children and special schools	**Sub-theme 4.1B:** The need for a human and material resource for teaching and learning in the special schools identified
	Sub-theme 4.2B: The need for formal and on- the-job training for teachers of ASD children described
	Subtheme 4.3B: The need for a formal curriculum for ASD children described
	Sub-theme 4.4B: The need for debriefing and emotional support for teachers of ASD children described

	Subtheme 4.5B: The need for family involvement in teaching for consistency in managing the ASD child outlined
	Subtheme 4.6B: The need for balance in the teacher-learner ratio described
THEME 5B: Coping skills for teachers of ASD children	**Sub-theme 5.1B:** Dual role of being a parent and a teacher of a child/children with ASD a coping strategy
	Subtheme 5.2B: An explanation of the various coping strategies outlined. Passion, religion, and hobbies

4.6.1 Theme 1B: Experiences with regard to teaching children with ASD in Limpopo Province

The study reveals that there were some similarities in the experiences of teachers and in the experiences of primary caregivers with regard to caring for, and teaching ASD children.

4.6.1.1 Sub-theme 1.1B: ASD child's patterns of behaviour

Most of the symptoms that the children present at home were also presented at school. The most common symptoms that were experienced by both groups of participants are lack of speech, poor social interaction, playing with one toy, temper tantrums, anger, and hyperactivity, eating problems and fighting.

However, teachers had additional experiences that they observed when teaching children with ASD. One teacher voiced her experiences concerning the behaviour of the children with ASD in the class. The teacher indicated that when ASD children without speech are angry they interrupt the class. They learn through repetition and reinforcement and once they have learned something it becomes a habit or routine. As evidenced by:

"When they are angry, they will do certain behaviors that will disturb the whole class for you to be aware that something is not going well with them because they cannot speak or express themselves. What I have experienced also is that when you teach him/her something for a long period he get into that particular thing and

becomes a habit. It can take time to grasp whatever they are being taught but when it is in their heart it rests for a long time" (P1, LPT).

The above statement was supported by the example of hand washing which was shared by another teacher:

"I taught them that always when they get into the class they must first wash their hands. So I put a bucket of water and soap outside next to the door. For them to comply with hand wash, I just put the same bucket every day. If they don't find it they will rub their hands as if the bucket and water are there. Even when the bucket is there but there is no water they still rub their hand without water? Through repetition, gradually they realize that there is water in the bucket, so nowadays if there is no water in the bucket they will show me by a sign that you must put water". (P9, LPT)

Another teacher shared her experience with regard to ASD learners who do not talk when they are in class but talk when they are alone, reciting what the teacher has said in class, as evidenced by the following statement:

There is this child in my class he does not talk at all when he is in class, but when he is alone somewhere outside during break he would say aloud those things that I told them in class. He just does a repetition like he is doing a recitation, for example, body parts, but in class, he does not talk. Sometimes he just sleeps you might think he does not hear anything, but later when he is alone maybe after school he will repeat everything that I have said, he will say "what is your name", he can even repeat what the other learners were communicating during the class. When you move towards him while busy reciting what we did in class, he keeps quiet and just looks at you as if nothing was happening. If you asked him to repeat it, "bolela oreng" when you go out he will say "bolela oreng". That is the interesting part" (P8, LPT)

Another teacher added her experiences with regard to the repetition of words, that is, echolalia, as evidenced by the following:

“They repeat what you said when you said John they will say John too, they also followed the instructions if you tell them to sit down they do. Some will spend the whole day staring at the roof, and they avoid eye contact”. (P5, LPT)

A teacher in one of the special schools in Polokwane, Limpopo Province shared her experiences with regard to ASD children from rural areas:

“My experience in teaching autistic children is especially in the junior phase, I experience a lot because most of them they never went to school before and when they first come to my class they find it difficult for them to acquit with the school routine. In the first place, you find that they are not toilet trained, and some of them are not used to a flushing toilet because they are from rural areas. When it comes to flushing the toilet the child begins to run away”. (P6, LPT)

Another teacher indicated that ASD children do not like noises made by other people. This was also observed by the researcher during data collection where five learners in one of the special schools always blocked their ears with their fingers. The noise was reported to frustrate them, as evidenced by the following statement:

“They don’t like noises that are made by other people, but theirs themselves they are making noises but they don’t want you to make noise for them because if you make noise to them they became frustrated. If he was sitting down he will stand up quickly and run from corner to corner blocking his ears yes, doing the head like this at the same time he is making noise himself but he is blocking the ears”. (P7, LPT)

ASD children were reported to injure themselves when they are angry as evidenced by:

“The other thing is that when they get angry they injure themselves, if something or someone bothers them after crying instead of going after that person they injure themselves. For them it feels as if they are doing revenge, unaware that they are injuring themselves, some they beat themselves, some they threw themselves on

the ground, some they scratch themselves with their nails, some they bump into objects". (P8, LPT)

Other children were reported to bully or act violently towards each other as evidenced by:

"I have one child that is always bullying others so other learners are always afraid of him, if he comes near them they run around as they are afraid of him". (P7, LPPT)

In addition, teachers also shared the strategies that they have used in managing the behavioural problems of children with ADS as evidenced by the following strategy:

"Those that keep on humming a tune I distract the behavior by allocating tasks to the child to keep him busy. Sometimes I give the child favorite toys because their behavior interrupts the whole class". (P2, LPT)

"I gave him the water and the utensils to wash, the other one like to play with the toys so I gave him the toys, the other one likes to stay next to me so I just put his chair next to me and then I gave him a paper or book or pen something that can keep him busy. That's how I'm managing them". (P7, LPT)

"I put them in front so that I can see whatever movement they do whatever ever slight changes I see I record it down". (P10, LPT)

"Those that are unable to talk I use sign if I want him to sit down I just put a chair next to him and he will sit down if I want him to pray before eating I just go to him and fold his arms then he will wait for amen". (P9, LPT)

"During break time two educators and support staff are outside to look after the learners, even after school there are educators who are doing supervision". (P5, LPT)

A teacher of ASD children in the junior phase class shared the strategies that she used for those children who are not toilet trained and are afraid of the flushing sound.

As a teacher, I am forced to do everything that they can do at the toilet, for example, I'm supposed to take off my pants, sit on the toilet, pass urine/stools and then flushing to show them what he is expected to do in the toilet". (P6, LPT)

4.6.1.2. Sub-theme 1.2B: An explanation of teaching methods for ASD children

The study revealed that teachers utilise different methods to train, stimulate and teach ASD children. ASD symptoms differ in severity, and, therefore, different methods are used to meet the learning needs of the child. The results also revealed that teachers from the Gauteng and Limpopo provinces utilise the same teaching methods. Therefore, the results of both provinces are discussed under this subtheme.

I'm using Makaton, Applied Behavioural Analysis, Sunrise, Augmentative and Alternative Communication (ACC) and Teach methods because they are different in their disorders, one method cannot fit all children, so I look at the child, then I called the parents in the first place to do individual educational plan guide according to how the child is, the parents will give me the strengths of the child and I'm going to emphasize the strengths of the weaknesses. In most cases when I start the new thing with the child I use strength. Again I'm having the individual support program for every child in the class". (P5, LPT)

Most of the time I use lip reading so that they can see what I mean and through gestures". (P2, LPT)

"When you teach then you must have many teaching aids that are when they understand, you must also use the signs, you must use concrete examples, don't just talk if you said this is a spoon you must have it, they must see it. (P2, LPT)

"Most of my teaching methods is individual teaching because those learners are all differed, every individual has got his different ideas of taking things" (P8, LPT)

4.6.1.3 Sub-theme 1.3B: Teaching children with ASD described as frustrating

The study revealed that most of the teachers believe that teaching ASD children is frustrating but, particularly in the case of those children who lack speech.

"Firstly at first when I come across these children I was so frustrated because I didn't know what to do with them, I didn't know how to communicate with them because some of their behaviours are so destructive. When you are with them let's say he does not have a speech at all, when he comes to you looking for something you don't know because he will be making a lot of sounds "aaaaaaa", then you don't know if he is looking for something or does something hurt him or is he having pain somewhere for what, even in case of the child is so frustrating because he does not get what he wants because we don't understand him or her what he wanted". (P7, LPT)

"It is so frustrating if you don't know how to assist this child. You think of your child at home or another school because there are people there who are assisting my child but here I am I'm failing to assist this innocent child". (P9, LPT)

"After appointed in the special school I was always getting frustrated, I started not to like my work anymore because of these children, when I think of coming to work I was demotivated". (P10, LPT)

4.6.2 Theme 2B: Challenges experienced by teachers of children with ASD in Limpopo Province special schools

Teachers in Limpopo Province special schools experienced various challenges that contribute to the poor provision of education for children with ASD. The challenges range from deficient infrastructure and a lack of human and material teaching resources.

4.6.2.1 Sub-theme 2.1B: Lack of human and material resources in the special schools: a challenge towards achieving objectives

The study found that the major challenge experienced by teachers in the special schools of Limpopo Province is the lack of material and human resources. As evidenced by the following statements:

"The challenges are that we don't have a proper classroom, the classroom is the crucial one. Number two the classroom is not autism-friendly, as you can see that we are in a mobile class, in another way we can say infrastructure is not good for

us. When the learners move around the floor shakes. Even the learners are suffering from the noise caused by other children who run around in the mobile class. You see the whole day that poor child closes his ears with fingers because he is afraid of the noise made by the mobile class. Also, we don't have resources like water that is running in the classroom. We go outside as you come here you saw a learner carrying water with a bucket, this is some of the challenges that I'm facing. I am teaching them life skills such as how to wash dishes, I should have running water in the classroom". (P6, LPT)

"We don't have enough teaching materials as I have indicated that their differences in their disorders one teaching aid cannot fit them all". (P7, LPT)

"We do not have teaching resources the aided and unaided once. unaided resources are the once that are to show that sit down and we adopt some of the sign like please sit down those are adopted, please bring the water by showing the bucket, please go to the toilet showing the picture that is unaided, is the one that you are not going to buy but to apply. With the aided once is the resources that may be bought that eee… in AAC we should use apron as one of our resources, I must wear an apron here with pockets to put words when I teach so that I will be able to move around with an apron showing them what is this, or match this with this like when I'm teaching colors, I can put different colors and words on this site so that the child can match, those are the aided once". (P6, LPT)

"Another thing is that the school is unable to afford the equipment that autistic children are supposed to use. They are expensive, like a computer toy with sounds". (P4, LPT)

"I don't even have sponge where they can rest a little bit when they are tired so that when they woke up they will be energetic with the lesson". (P10, LPT)

"In my class, I have a picture communication board is a device that works with batteries the ASD children enjoyed it, unfortunately, we have got only one device. When the child is unable to talk he just presses on the picture and it will say the

things that the child wants, it talks on behalf of the child, like I want to go to the toilet". (P11, LPT)

"Our main challenge is the physical infrastructure and lack of devices. Two groups of learners ten on each group use one class, meaning we are running two classes under one roof" (P9, LPT)

"We don't have space where the child can rest in my class after the seizure, we just put the mat and put him there to rest because after a seizure is difficult to wake up". (P5, LPT)

In addition to material resources, teachers expressed their concern with regard to the lack of health care professionals in the special schools, which delays the progress of the child as follows:

We don't have health care professionals in our school. Specialists like speech therapists, the one that is coming are the one that the parents paid for themselves. We also don't have the Occupational Therapy (OT) for fine motor and gross motor development. We don't even have a psychologist. Even our nurse she passed away in 2014, the one that is here now is a voluntary nurse. She worked here before then she resigned, then the one that passed on she was replacing her. Then because of the pity, she just comes on a voluntary base because we cannot be diagnosed or buy medication without her. We need her to recommend the medication. You see it is so difficult for us to even the individual education plan we cannot do without those people. (P6, LPT)

The lack of health care professionals in the special schools affects the teachers because they have to manage epileptic seizures and give treatment on their own, but while they are doing so they have to leave the other children unattended. This state of affairs is evident in the following statement:

"When I'm busy with the children another one can have an epileptic attack and then I'm going to leave the whole group and attend to the epileptic one, so you find that it is so difficult because it will depend on the seizure, how long is going to last and then I'm supposed to have a record of that seizures and we take it to

the clinic. Sometimes you find that the nurse is not there you have to do what is needed". (P5, LPT)

Furthermore, teachers reported that each autism class should have a teacher and class assistant, but in special schools in Limpopo Province most of the classes do not have a teacher's assistant. As evident in the following statement:

"In our school, we only have four teacher assistant for the whole school, while each class was supposed to have one teacher and one class assistant" (P6, LPT)

The study also found that one teacher teaches a large number of learners with ASD in one class. This is shown in the following statement:

"……the ratio for ASD learners in class must be 1 teacher is to 6 children with a teacher assistant, with my class one teacher is to 12 children. One child with ASD is equaled to six children in the mainstream and then if the child is having epilepsy, the government rate epilepsy as three children. Which means that a child with ASD plus epilepsy is equaled to 9 children". (P7, LPT)

The teacher-learner ratio is a challenge for me because I am alone in my class with 09 learners. I'm not doing the work according to my expertise because of lack of class assistance." (P12, LPT)

One teacher in Mopani district stated that their school is overcrowded because they are the only special school with a hostel in their district, as evidenced by:

"Our school is the only school with a hostel in our district, therefore, learners from far are brought in here, and we have overcrowded classes". (P8, LPT).

4.6.2.2 Sub-theme 2.2B: Poor parental, school management and government support problematic

Parents of children with ASD were found to be less involved with their children's education. The study showed a parental lack of involvement in attending school meetings and children's school activities. This is evident in the following statements:

"When we sent letters they don't attend the meetings". (P4, LPT)

“Only two parents in my class of the 9 children they sign the message book every day so they read it, so the other parents they don’t care, and we have letters staying here for the whole term so I must say the support from parents we struggle a lot”. (P4, GPT)

One parent of a child with ASD confessed that she did not attend school meetings due to a lack of money as evidenced by her statement:

“*Let me tell you the truth, I don’t attend school meetings, but they called us but is rare that I attend it, the reason for not attending is because I don’t have enough money for the transport”* (P17, LPPC)

Teachers from Mopani and Capricorn districts indicated that parents do not provide support with regard to the continuity of learning at home. As evident in the following statement:

“Parents don’t give us support once they brought the learner to us they expect us to do everything, they ignore the part on the learner they just leave them to you to do everything and sometimes some of the programmes they must continue at home but you could see that there is no continuation during school holidays because whenever the learner comes back from holidays you have to start once again”. (P7, LPT)

“The parents are not cooperative because when you call them to come they don’t come. Our meetings are usually scheduled when we are about to close when they are supposed to come and collect their children but they don’t come. They just send other people while important information we need it from them. They send other people like brothers, sisters those that when you ask background information they don’t know, because we want to know how are they behaving at home, about what we taught them”. (P6, LPT)

“If you meet a parent of a learner with ASD during school holidays they will ask you “when are you opening at school I’m so tired, how do you deal with these learners at school”. (P2, LPT)

Another teacher voiced her concerns with regards to parents that abandon their children at the special school, as evidenced by the following statement:

“If their children stay in a hostel for them is fine they don’t even come and pick them up during holidays, they just leave them there until school closes. And we expect them to take their children during holidays for them to know their parents more, for them, they feel relieved they won’t even come”. (P8, LPT)

One teacher in one of the autism schools in Gauteng Province also experienced the abandonment of these children in their school. As a teacher commented:

“….I’m just being honest, a lot of parents use this as a dumping area”. (P5, GPT)

Other teachers expressed their concerns with regard to parents who do not involve themselves in the development of an educational programme for their children, as evidenced by the following statement:

“When developing a program for these learners it needs parents. According to the educational program, we should sit together as a group sharing ideas, the parents, educators, class assistants, and caregivers at home as well. Sometimes we invite them maybe once a year some they turn up some they don’t turn up. What I’m teaching here it must be continuous as well at home if they are not part of us, what I taught them here it won’t even be practiced at home, it is of my concern that they should be part of us”. (P6, LPT)

Another teacher shared her concerns with regard to those parents who do not support school fundraising, as evidenced by:

In our school every Wednesday they are having a snoopy, the school is selling the snack, packet of chips, chocolate, sweets, some of the parents they don’t pay. It is the school program for funds raising but it is so painful to see other learners eating and others they don’t eat. Some parents pay some they don’t pay we keep on requesting money for snoopy some they don’t give support”. (P4, LPT)

Other families were found not to support their children when they are sick, as one teacher commented:

“Sometimes when the learner is sick and we call them they don’t answer the phone or they will tell you that they don’t have money to come to school. Meanwhile, this is a school if a child is sick must be separated and be provided

with the care that is needed when the child is sick at home, so with us we will do that here at school as they won't come". (P8, LPC)

Teachers of children with ASD in both provinces also reported a lack of a specific curriculum or syllabus for ASD children. Teachers from the Limpopo and Gauteng provinces raised the same concern with regard to the curriculum for special needs children, as teachers commented:

"The challenges that we experience is that we don't know how to assist them the reason being I don't know if I should blame the department but we don't have the programs designed for them. You as the educator you need to design for yourself to make sure that you can assist those learners" (P9, LPT)

"We still use the CAPS but is adapted to SANASE, so we use the SANASE curriculum they adapted from the CAPS, to get more basis to these children is specific for the special schools because I mean the CAPS curriculum has grades 1, 2, to grade 12. So we cannot use that because our classes are not according to grades, it is just a junior, middle and senior phase, so we can't use it that is why we use the adapted curriculum for them". (P4, GPT)

"…we don't have the formal syllabus curriculum for these learners. They have adapted the mainstream curriculum, but they don't write examination" (P6, LPPC)

Another teacher expressed her concerns with regard to the lack of development in their school. Limpopo Province does not have an autism school, but there are two classes of learners with ASD in one of the special schools in Polokwane and one class in the Waterberg district. This is evidenced by the following statement:

"Another addition is that when we start this school they said our sector is a small unit in a big unit. At first, they said they are going to turn this school into an autism school, but you know departmental issues, this is my 9th year being here nothing has happened. But because things are beyond our control we are a small unit in a big unit with only two classes for ASD". (P6, LPT)

One of the teachers voiced her concerns with regard to poor management support, as evidenced by the following:

"*The management keeps on admitting every year, but the staff members remain the same. They will admit because they are in the office and you are struggling alone here they cannot see".* (P6, LPT)

One teacher voiced her concern with regard to the government that has not been filling the teaching posts after resignations, retirements, and deaths, as evidenced by:

"Department of Education is not filling the posts for those lecturers who have left even when somebody has passed on. Other teachers are supposed to share the work of a retired teacher". (P6, LPPC)

Very few families were reported as not being supportive of their children. As one teacher commented:

"The support from their home I can say it is good because most of the time they come to see them, sometimes when they bring them back to school they will ask for my phone numbers, they do phone to wanted to know how is my child. When they visit they brought sweets or anything else to make them happy. Some buy new clothes for them, they are taken into consideration. Even when they brought them back you could see that they were being taken care of at home". (P9, LPT)

4.6.3 Theme 3B: Teacher's knowledge about ASD

The study revealed that teachers of children with ASD in Limpopo Province vary with regard to the level of their knowledge about ASD. Most of them expressed the fact that they have limited knowledge due to a lack of job training. Teachers need accurate knowledge regarding ASD as they play a vital role in teaching ASD children.

4.6.3.1 Subtheme 3.1B: Insufficient knowledge with regard to teaching ASD children blamed on lack of on-the-job training

Teachers of children with ASD in Limpopo Province were found to have limited information about the training or teaching of children with ASD. Overall, the teachers were varied in the level of knowledge that they had regarding the ASD.

Teaching experience and prior training were positively correlated to knowledge. This is evidenced by the following:

“So far I have not attended any ASD workshop, it was just feedback from those who attended the workshop. Sometimes I don’t even know whether I’m going forward or backward with my lessons in class” (P11, LPT)

“I have never attended a workshop for autism in our province but Gauteng province organizes a lot of workshops and I managed to attend once. But still some of the behaviours I don’t know how to handle them”. (P9, LPT)

It is long that we have been attended the workshop, it is about maybe between 2004 /2005 somewhere there. My knowledge needs to be updated. (P1, LPT)

The little knowledge that I have is through reading because I have not yet attended the course or training. (P10, LPT)

One teacher emphasised again that on-the-job training is very important when dealing with ASD children. This is evidenced by the following statement:

“If you don’t have that luck of attending the workshop you won’t even know where to start”. (P10, LPT)

One teacher voiced her concerns with regard to her knowledge about ASD:

The knowledge that I have acquired is not enough I still need to read more. Because sometimes I got frustrated with some of the things, we become the barriers to the progress of the learners due to lack of knowledge. (P8, LPT)

4.6.3.2 Subtheme 3.2B: Insufficient knowledge of diagnosing ASD children by health professionals blamed on medical reports

Teachers in Limpopo Province were also worried that the diagnoses of ASD children are not clearly stipulated in the medical reports. One teacher expressed her concerns with regard to the diagnoses of the children which affects the training of the learners. This is evidenced by:

“…the psychologist does not disclose the condition of the learner in the psychological report I think that’s what made us guess we don’t know exactly

what the learners are suffering from, we don't even know how to assist them may be in their report they should include something related to their condition or diagnosis, I think it will also help, so that when we admit the learner we will know what they are suffering from, we understand that it is confidential but we as teachers we need to know their types of conditions in order to assist them. We don't have colleges that offer a course for learners with special needs we just went to college and graduated as ordinary teachers'. (P8, LPT)

"Because the doctors and the psychologist reports do not give a specific diagnosis for these children, some of the signs and symptoms we discover them while the children are in class, then you will see that this one is autistic, this one is what-what". (P9, LPT)

"When it comes to allocation of classes for these learners is difficult because we don't know their diagnosis and we are not allowed to diagnose" (P8, LPT).

4.6.4 Theme 4B: Learning needs of ASD children and special schools

Teachers suggested particular teaching and learning needs that should be met in the special schools of Limpopo Province. The needs range from human and material resources, a formal curriculum, emotional support, the teacher-learner ratio, and the remuneration of teachers.

4.6.4.1 Sub-theme 4.1B: The need for a human and material resources for teaching and learning in the special schools described

Teachers voiced their needs with regard to human and material resources in the special schools of Limpopo Province. They commented as follows:

"Minister of basic education must visit the school to look at what is happening with regards to substandard infrastructure and overcrowding." (P11, LPT)

"Because ASD children do not have speech we need to have more teaching aids so that they can understand what we are saying to them better" (P1, LPT)

"Many teaching aids, and a lot of workshops, if we keep being updated and having a lot of teaching aids we can make". (P1, LPT)

"To have enough teaching aids or posters. Posters to be displayed everywhere". (P3, LPT)

"We need devices those that are of high and low technology, AAC, Micro edit system." If we can have resources our kids will benefit more so that their families will no longer reject them because they feel like they are useless. (P6, LPT)

"If we can have a special school for autism learners in the Limpopo province, just like in Gauteng province may be more workshops will do especially for Limpopo teachers. We really want to learn more about autism". (P2, LPT)

One teacher in Gauteng Province voiced similar suggestions with regard to autism schools in the townships. As the teacher commented:

"…for the children who traveled from far the best place for them should be at the autism school with the hostel where they can live in and cared for," (P3, GPT)

Furthermore, the teachers in Limpopo Province offered more suggestions on how to improve teaching conditions in the province as evidenced by the following comment:

"…..the government can give us the post of speech therapy so that we will be happy knowing that we are busy working with speech therapy that is of our own." (P4, LPT)

"A proper classroom that is having the toilet and the sink inside not mobile classes so that everything is accessible, and to reduce overcrowding. If we are having a proper classroom we are going to extend our support, teach them how to make up their beds, maybe it will be divided, the other side be the bed site and the other side to be the kitchen site so that we can teach them even simple things like making a juice, simple things as they are trainable. I'm looking forward to the department to build a center for autism as we have only two classes for ASD in Limpopo province". (P5, LPT)

Department of education in collaboration with the department of health should provide us with assistance teachers and health care practitioners in special *schools. So that when we develop a program for these learners parents, Occupational therapists, Head of Department, Physiotherapist, and Principal must sit together so that we can share ideas. If I get frustrated as the teacher I can go and ask for assistance from them, or maybe a learner develops something that I did not see on admission so I can go to them for assistance that my learner has changed". (P5, LPT).*

4.6.4.2 Sub-theme 4.2B: The need for formal and on-the-job training for teachers of ASD children described

Teachers in Limpopo Province expressed their needs with regard to job training as shown in the following teachers' comments:

"I need a workshop, where a presenter of the workshop can also be trying to demonstrate with these learners, because in most cases when we attend the workshop is just a lecture or watching video is not a practical thing for me is of little help. When they said we must teach this and that we must be demonstrated, not just a theory, it is always a theory. I just have to figure out what works for me or it can work to the child, they must do hands-on demonstrations, like when I was in training for education other times lecturers were bringing the kids in the classroom, they call it demonstration they teach and then we observed how the kids were responding from there even for us it was so easy also to go and do as lecture". (P5, LPT)

"ASD children need teachers who are well trained. I think maybe the Department of Education can make workshops and trained educators about special children, I think they will be better people". (P2, LPT)

"At the workshops, they gave us pamphlets, therefore we need to keep on reading to update ourselves. I also suggest that people like you researchers comes frequently to interview us in order to motivate us to read the information". (P3, LPT)

"About the training, it needs me to go for regular workshops as each year we are admitting different children with different behaviours. Regular workshops and

training, we cannot stay for 4 years without training. Even researchers like you discover new things so we need continuous development every year". (P4, LPT)

One of the teachers in the Capricorn district expressed her needs with regard to job training and formal education in the following comment:

"….because the ASD children are different, the group comes from home this year being like this and another group can come next year being like that. It needs me to come for in-service training and workshops because I cannot stick on one thing as the teacher is a lifelong learner. So I was looking for more knowledge even though the people who are researching will find new things every day because researchers are busy searching about autism so it needs even me to be on the same line with them. I am even now willing to do my master's degree because I'm having honours in management and special education". (P4, LPT)

In addition to on-the- job training, teachers also requested that the medical reports of the children should specify their diagnosis. As one teacher commented:

Doctors and psychologist need to indicate the specific diagnosis for the children rather than intellectual disability so that when we admit the learner we will know what they are suffering from, we understand that it is confidential but we as teachers we need to know their types of conditions in order to assist them). (P7, LPT)

4.6.4.3 Subtheme 4.3B: The need for a formal curriculum for ASD children described

Teachers expressed their suggestions with regard to a formal curriculum for ASD children, as one teacher commented:

"If ASD children can have their own center and the formal curriculum not to be forced on CAPS because is difficult for us as teachers and we delayed their progress". (P4, LPT)

Another teacher also suggested that ASD children must be separated from other learners with special needs because their needs are not the same. As the teacher commented:

These children need to be on their own because mixing them with a group of Down syndrome and Cerebral Palsy are suffering because they cannot communicate and those they are talking and this once always they are isolated. (P4, LPT).

4.6.4.4 Sub-theme 4.4B: The need for debriefing and emotional support for teachers of ASD children described

Teachers in Limpopo Province expressed their suggestions with regard to emotional support. They commented as follows:

"As teachers, we need counseling as we are working with different learners from different families really we are always frustrated, every day we are facing different challenges so we need counseling. There is no one even bothering coming to us and say are you coping what is it that we can do for you we need counseling, especially with overcrowdedness". (P5, LPT)

"It is discouraging because we don't have enough support from our department and our local place where we are working. I am alone without an assistant with 12 ASD children. Sometimes I have my own challenges at homecoming here also is a challenge how do you cope with those two things together. I really need counseling". (P5, LPT)

4.6.4.5 Subtheme 4.5B: The need for family involvement in teaching for consistency in managing the ASD child described

Teachers expressed their views on parent and family involvement in their child's schooling and or education.

"….. The parents must be called to be work-shopped in order to have accepted, love and participate in their children's education, as some may have rejected

them. Even the community needs to be aware of maybe through the awareness in the community”. (P1, LPT)

4.6.4.6 Subtheme 4.6B: The need for balance in teacher-learner ratio outlined

Teachers voiced their suggestions with regard to the teacher-learner ratio that is imbalanced and affects the management of the learners in the class. As the teachers commented:

“I think maybe we must not have more than 10 ASD learners in the class. The learners who have autism need a special time, you must attend to them individually so that they can understand what you say”. (P8, LPT)

“…some of the things are above us is for the department, because really if you have knowledge of this children you will see that we delay some of them, really for me is so hard because really you can see that this one can move forward, but because of another one who need more support, they delayed the progress of others because I’m one they are more. So my hands are always full. If it was a small group or if the class was autistic friendly also it will be better for me to work according to my knowledge and understanding of them”. (P4, LPT)

“Autistic children are not supposed to be mixed with other children with other conditions, they should be less and manageable”. (P6, LPT)

They need to be few in class in order to be manageable. (P3, LPT)

4.6.5 Theme 5B: Coping skills for teachers of ASD children

The findings revealed that teachers have coping strategies that assist them in managing stressful situations related to teaching ASD children.

4.6.5.1 Sub-theme 5.1B: Dual role of being a parent and a teacher of a child/children with ASD: a coping strategy

Teachers who are also parents of children with ASD explained how the dual role assisted them in dealing with the stress of having a child with ASD, as is shown in the following teachers’ comments:

The other thing that really assisted me a lot is that I was also having a learner with autism, my own blood daughter, she was also a part of this school, and she was here until the age of 21. Unfortunately, at the age of 22, she passed on because she was having epilepsy, she got sick when she was still very young at the age of 4 years. I think even with that thing encouraged I to help them because what I was doing to her I also do it in class, I'm a mother and a teacher and the same time". (P6, LPT)

I developed myself because I'm a teacher for ASD learners and a parent of a 'child' with autism. I google and look for the conferences for ASD in order to help my son. In 2010 I was in America Autistic Children Centre. I also went to UNICA for several workshops in Pretoria. I paid for myself so that I can accumulate knowledge. So that I can help because is so stressful to come to class and not knowing what to give to the children, just to look at them is so difficult for me more so because I'm a parent and a teacher whatever I'm thinking of my son I also think of my learners in the classroom". (P5, LPT)

A teacher with a dual role in the Waterberg district shared how the school is supporting her with regard to on-the-job training. She further indicated that the local clinic is using her to provide support to the other parents with ASD children. As the teacher commented:

"Support at school is good as I have already mentioned that they send me to different workshops for autism, I need a special book that I can read about autism, not pamphlets. I also want to specialize in autism. One day they called me at the clinic to come and talk to the mothers who have children with disability, I do home visits to encourage them on how to take care of their children, although some they don't want it, they chase me away". (P12, LPT)

4.6.5.2 Subtheme 5.2B: An explanation of the various coping strategies outlined: passion, religion, and hobbies

The study found that strong and controllable emotions are needed in teachers who are teaching ASD learners. This is evidenced by the following comments:

"*The first thing you need to have a passion, patience and you have to love these children"* (P2, LPC)

"You must be patient, you must be a parent, and you must have love". (P7. LPC)

"Kindness, love, patience, give time to learners, be prepared to teach them, to help them, assist them, guide them, to lead them". (P8, LPC)

The following section discusses the results of the semi-structured interviews with the teachers in Limpopo Province.

4.7 DISCUSSION OF THE LIMPOPO PROVINCE TEACHERS' FINDINGS

4.7.1 Theme 1B: Experiences regarding teaching children with ASD

Teachers in Limpopo Province experienced the different patterns of behaviour displayed by ASD children at school. Teaching ASD children was found to be frustrating for the teachers due to the different patterns of behaviour shown by learners with ASD.

4.7.1.1 Sub-theme 1.1B: ASD child's pattern of behaviour

Teachers of children with ASD in the special schools reported experiencing the following behavioural problems among ASD children:

- Disruption of the class
- Children must be given simple and clear instructions with continual repetition of activities
- Stereotyped repetitive behaviour, such as staring at the roof for the whole day
- Repetition of words
- Poor eye contact
- Aversion to too much noise, such as when a toilet is flushed, and blocking their ears with their fingers.
- Self-injurious behaviour, such as the throwing of himself or herself on the ground, scratching the body with their nails or bumping into objects
- Bullying each other and breaking windows.

These findings are similar to the findings of the study conducted by Boujut, et al. (2016) in which teachers mentioned the disruption of the class, unpredictable movements, or aggressive behaviour, awkward postures, and the need for a routine.

4.7.1.2 Sub-theme 1.2B: An explanation of teaching methods for ASD children

The findings showed that teachers use a variety of methods to teach and train ASD children. These include the Makaton method in which teachers and children with impaired communication, communicate directly using signs and symbols. Grove and Woll (2017) state that children with developmental disorders, such as ASD, have benefitted from the application of these techniques. Signing is reported to be one of the most widely used approaches in supporting the communication and language skills of children with ASD and those who have problems with communication in spoken language.

Applied Behaviour Analysis (ABA) is a method which teachers use to improve or change the specific patterns of behaviour of ASD children. ABA changes the environment to change the behaviour. Roane, Fisher, and Carr (2016) describe how the therapist can change the behaviour of the child using this method. The therapist delivers reinforcement of all verbal attempts, even those that are less accurate than those that the child has previously displayed. The therapist and the child take turns with toys during the treatment, thus allowing the therapist to model appropriate toy play and relevant speech in a structured context. The therapist uses a variety of examples to demonstrate the meaning of various words and activities. Finally, control of the therapeutic activities is shared between the therapist and the child by periodically allowing the child to select new toys and activities. Fennell and Dillenburger, (2018) state that Applied Behaviour Analysis has been applied successfully in a large variety of fields, such as classroom management, and across all age ranges and, therefore, is considered the basis for evidence-based autism interventions.

The Treatment and Education of Autistic and Related Communication of Handicapped Children (TEACCH) method was reported to be used by teachers to provide strategies and tools for teachers to use in the classroom. Virues-

Ortega, Julio, and Pastor-Barriusso (2013) state that TEACCH is an intervention programme that can be used with ASD learners and it is considered an emerging practice for ASD. It focuses on visual (or written) information to supplement verbal communication. Abou-Hatab, Zahran, and Abbas (2013) indicate that the TEACCH programme represents a model for the management of five major autistic behavioural problems: self-harm, aggression, disruptive behaviour, repetitive behaviour, and other behavioural deficits.

Augmentative and Alternative Communication (AAC) methods include gestures, facial expressions, vocalisations, speech, and sign language. Teachers in this study reported that those children who do not make any sound but just make the “gggg” and “mmmm” sounds will take a glass to show that they want water when they are thirsty. The Sunrise method is also used according to which the teacher joins the ASD child in his or her world and imitates what he or she is doing and then the child would understand that ‘this person is with me’. Zeina, Laila, and Bashir, (2015) state that children with ASD are candidates for AAC systems, either to supplement their existing speech or to act as their primary method of expressive communication. Various types of AAC modes have been taught to individuals with developmental disabilities. The modes used include the use of manual signs, picture-exchange, and electronic speech-generating devices.

Other teachers in this study reported using the lip-reading method which is a technique for understanding speech by visually interpreting the movements of the lips, face, and tongue when normal sound is not available. It has been demonstrated that most people use lip-reading cues to understand speech (Fernandez-Lopez & Sukno, 2018). However, these cues are often used unconsciously and to different degrees depending on aspects such as the hearing capability. Other teachers in this study reported using an individual teaching method, in which a teacher works with only one ASD child, and the child interacts only with the particular method or means of teaching used by the teacher. With this method, teachers reported that they identify children’s weaknesses and strengths. The trial and error method was also used by teachers in this study to experiment with various teaching methods until they find the most successful one.

4.7.1.3 Sub-theme 1.3B: Teaching children with ASD described as frustrating

Teachers of children with ASD in this study also reported the frustration related to teaching ASD children. The symptoms of ASD differ in intensity and can, therefore, be more or less difficult for teachers to manage. The most commonly encountered difficulties for teachers in special schools in dealing with children with ASD are having to teach too many ASD learners in a class, the limited attentional capacities and concentration of the children, and their lack of integration with other children. The discrepancy between expectations and reality brings about frustration amongst teachers and increases their emotional exhaustion. This explains why burn-out could be more common in the teaching profession than in others (Boujut, Dean, Grouselle, Cappe, 2016)

Job-related stress and burn-out have been identified amongst teachers of students with ASD. Challenging kinds of behaviour reported to be a source of stress for teachers include aggressive behaviour, in particular, as it is the most difficult for teachers to manage and is associated with high levels of stress (Nistor & Chilin 2013). Boujut, et al. (2016) found that 30 % of teachers present burn-out symptoms and this could be because teachers must work with a multitude of stressful factors, such as the learning difficulties of students, the incessant demands of parents, the non-recognition of the amount of work put into teaching and societal changes.

4.7.2 Theme 2B: Challenges experienced by teachers of children with ASD in Limpopo Province

As already mentioned, the study found that there is a lack of material and human resources in the special schools, more particularly in Limpopo Province. Teachers in Limpopo Province special schools were found to experience more challenges than teachers in Gauteng Province. The challenges range from a defective infrastructure, a lack of human and material teaching resources, the overcrowding of learners in classrooms and unequal teacher-learners ratio.

4.7.2.1 Sub-theme 2.1B: Lack of human and material resources in the special schools: a challenge towards achieving objectives

The study found that there was inadequate learning space, substandard infrastructure and poor infrastructural conditions, most of which are unfriendly to a person with ASD, including lack of adequate sanitary facilities and a lack of running water for hygienic purposes in Limpopo Province special schools.

- *Infrastructure*

It was found that the inadequate infrastructure leads to overcrowded classrooms, limits the number of admissions and could also affect quality education. The findings correspond with that of the Department of Education (2014) report which stated that special schools in rural areas are in the most deplorable condition. In this study, teachers in Limpopo Province also indicated that there are no private rooms where the child can rest and recover after a seizure if necessary. Some of the classrooms for autistic children are located in a mobile classroom and when the children move around the floor shakes noisily. This results in children blocking their ears with their fingers for the rest of the class period as they are sensitive to noise.

These findings are supported by the findings of a study conducted by Kim and Yoon (2019) which states that individuals with ASD require significant modifications to the environment due to problems related to noise. Because of sensitivities to the environment, the classrooms must be quiet and free of loud noises that may interrupt learning.

The lack of a physical infrastructure was also observed in Gauteng Province where one of the autism schools was reported to be renting a building from another school. This resulted in a limited number of children being admitted to that school. One of the standards for physical infrastructure according to the Department of Education (2014) is that the design of the physical infrastructure should take into consideration the programmes offered at the school, the anticipated learners who would be enrolled in the programmes and should ensure full accessibility to the whole school environment. This includes, but is not limited to the classroom, laboratories, and workshops where necessary, administration, library, computer room, ablution block, soundproof room for audiometric testing, hostel, therapy rooms, observation facilities, as well as pathways leading to these facilities.

- *Material resources*

Other challenges that contribute to the poor provision of education and support in special schools of Limpopo Province include a lack of learning and teaching support material and other material resources. This was reported by the participants but also acknowledged by the Department of Education (2014). In this study, teachers reported that there is a shortage of teaching materials suitable for ASD children, such as E-learning facilities; Personal devices for learners, such as Alternative and Augmentative Communication devices; devices and equipment required to support teaching and learning, such as CCTV cameras, scanners, interactive whiteboards, sound amplification systems, and other assistive technology. The findings correspond with the findings of a study conducted in Lesotho which indicates that there is evidence that there is a severe shortage of educational tools, and equipment to meet the needs of learners who need special care (Khoaeane, 2012).

One of the standards to ensure quality education and support in special schools and special school resource centres according to the White Paper no 6 on Inclusive Education (Department of Basic Education, 2014) is that special schools must be equipped with appropriate, up-to-date and well-maintained material resources. Schools should plan the sourcing of these material resources in such a way that teaching and learning are not affected (Department of Education, 2014). Despite this standard stipulation a lack of learning and teaching support material is still a challenge in the rural area.

However, the study also found that there were adequate learning and teaching support material and other material resources in the special schools in the Gauteng Province. It was reported that special schools need resources for the training of ASD children. Teachers reported that their schools do a considerable amount of fundraising and the Department of Education provides them with the necessary materials. A study conducted by Donohue and Bornman, (2014) in Gauteng Province revealed that most learners with disabilities received specialised support services as Gauteng Province is the richest and most resourced province of South Africa.

- *Teacher-Learner Ratio*

Overcrowding was found to affect the proper training of ASD children in this study. The findings revealed that one teacher teaches 11 or 12 children with ASD without a teacher assistant, particularly in Limpopo Province. The prescribed ratio for the number of ASD learners in a class should be one teacher to every six children together with a teacher assistant. One child with ASD is considered to be equal to six children in an ordinary school. If the learner has special needs plus epilepsy, then epilepsy alone is rated as being equal to three children. Therefore, if the child has ASD plus epilepsy that child is equated to nine children in an ordinary school (Department of Education, 2015).

Other teachers were found to teach 11 learners, five of whom were children with ASD without a teacher assistant. The progress of the children was reported to be delayed as some need more support and the quality of education was also compromised as one teacher cannot cope with the workload. The quality of education offered in many of these special schools is very limited and many learners enrolled in some of the schools never progress beyond Grade 1 (DoE, 2014).

- *Human resources*

As already mentioned, in addition to material resources, teachers expressed their concern with regard to the lack of health care professionals in the special schools which delays the progress of the child. Special schools should have professional teaching and professional specialist support personnel, non-teaching personnel and administrative support personnel according to the Department of Education (2014). The study revealed that in Limpopo Province there is a severe shortage of health care professionals and teachers' assistants in the special schools.

Health professional specialists, such as professional nurses, occupational therapists, speech therapists, psychologists, and social workers should be available in each special school for the provision of health, therapeutic, psychological and social support to enhance learners' capacity to achieve maximum benefit from learning experiences (White Paper no 6 on Inclusive Education, 2015). The study found that there is only one occupational therapist for the whole province of Limpopo in one of the special schools in the Waterberg district. Some of the special schools do not have any health care practitioner, while some have got only a professional nurse who assists with the ordering, the giving of medication and the treatment of minor ailments.

In the absence of health care practitioners, teachers were found to be responsible for giving the treatment, taking the learners to the clinic, managing epileptic seizures and developing the individual educational plan alone. Special schools do not have adequate specialist professional support staff and non-teaching staff according to the White Paper on Inclusive Education Department of Basic Education (2015).

In conclusion, teachers in Limpopo Province identified the needs of teachers for human and material resources for teaching ASD children. Insufficient human and material resources were found to affect teachers in performing their learning and teaching duties effectively. Those learners with ASD are also not able to acquire relevant skills due to a lack of resources in the special schools. Teaching and learning resources are imperative in developing the competencies of children with ASD in relevant vocational skills. Insufficient resources encourage teachers to practice the use of short-cut methods to complete their tasks quickly (Department of Education, 2015).

- *Shortage of Autism schools*

The study found that there is a lack of autism schools in Limpopo Province. The study showed evidence that there were only three autism classes in the whole province, two classes in the Capricorn district (New Horizon School) which caters for 23 learners and one class in the Waterberg district (Thusanang special school) which caters for 11 learners. The White Paper no 6 on Inclusive education, Department of Education (2015) states that the most serious shortage of special schools or specialised units is in the field of ASD in South Africa, especially in the rural areas. This result corresponds to similar findings reported by Aluri and

Karanth (2002), which states that there are very few rehabilitation centres for children with ASD in Bangalore city, India.

The enrolment for ASD children in 2014 in Limpopo Province was 245 (Department of Education, 2015). Only 23 of these children were accommodated in the classrooms for ASD learners and the rest were taught together with other children with developmental disabilities in other classes. Both educators and families in Limpopo Province indicated that the ASD learners must have an autism school so that they could be educated according to special ASD programmes.

The Report of the Human Rights Commission of 2004 in Department of Education (2015) showed that learners with special needs in rural areas experience the worst forms of educational exclusion. Not only are there very few special schools in rural areas, but they also do not exist in many deep rural areas.

- *Curriculum for special needs children*

Teachers of children with ASD in both provinces reported a lack of a specific curriculum or syllabus for ASD children. Teachers reported that the Department of Basic Education has adopted the ordinary school curriculum for learners with ASD but they are taught only the basics and they do not write examinations. They also indicated that the ordinary school curriculum is not applicable to moderate, severe and profound intellectually disabled children. The majority of learners with disabilities in special schools are following programmes with vocational or skills-orientated subjects.

The White Paper 6 on Inclusive education (Department of Education 2015) states that there is a need for a more structural-functional curriculum for learners who attend special schools that specialise in moderate and severe intellectual disabilities. In October 2013 the skills and vocational exit level qualification and learning programme was introduced for the development of learning programmes for learners with moderate, severe and profound intellectual disabilities (Department of Education, 2015). This programme is aimed at developing a vocational learning programme which can be followed in special and ordinary schools by learners with intellectual disabilities and also to register an exit level skills and vocational qualification at NQF level 1.

In conclusion, participants suggested the need for a curriculum specifically for ASD children. Because the current curriculum is inadequate and could not prepare a disabled person for independent living they are dependent on their families indefinitely (Ahmadi, Zalani, & Amrai, 2011).

4.7.2.2 Sub-theme 2.2B: Poor parental, school management and government support problematic

Families of children with ASD in Limpopo Province were found to be less involved with their children's education. Communication between the teachers and families were found to be poor. On the other hand, the special schools in Gauteng Province were found to have established a good communication system with the families of children with ASD. These were achieved through contact books which travel back and forth from home to school and vice versa, letters, and WhatsApp groups.

Families are essential partners in the education of children with autism (Azad & Mandell, 2016). Numerous conceptual articles encourage parents and teachers to openly communicate about their concerns regarding their children. It is of importance for parents to have consistent and reliable communication with teachers (Gabovitch & Curtin, 2009), especially because their child with disabilities may not be able to talk about the school day. According to Azad and Mandell, (2016) parents and teachers communicate to exchange information related to the child’s needs and performance, stay informed, and brainstorm strategies to resolve problems that arise at home or school. Parental involvement in their child’s educational programme is essential for all children to experience success. It is even more so in the case of a child who has ASD (McCulloch, 2015).

Oftentimes, children diagnosed with ASD are unable to communicate their needs and wants effectively. They rely on others to determine how best to educate them and help them with their daily functioning outside of the educational setting. Consistency and structure are important to those children with ASD. Thus, helpful strategies should be transferred across settings. Parental involvement and the use of these strategies at home during routine and daily activities are probably important ingredients of success and contribute to the outcomes in their child's progress.

Families were found to be less involved in the academic activities of their ASD children. These include a failure to attend school meetings, failure to take part in developing an individual educational plan for their children and poor communication between the families and teachers.

In terms of a child's specific individualised education plan, parents are encouraged to participate at all levels (McCulloch, 2015). At the beginning of each school year, parents should be invited to attend parent meetings with access to all of their child's providers, should the parent so wish. This meeting is held to review how their child began the year and the goals that are to be implemented as the year progresses. Parents' input is welcomed with written follow-ups for staff in terms of any changes, additions and, or concerns that a parent has regarding their child's programme. In this way, parents are empowered and reinforce their trust, which is essential in working successfully with their children (McCulloch, 2015).

In this study, a lack of family involvement during a child's illness was also reported. Some children were reported as coming to school without taking a bath and without food. Other children were reported as attending school only when it is time for the renewal of the social grant. The study also found that there is a delay in the academic progress of ASD children due to a lack of continuity at home during school holidays.

The reasons for a lack of parental involvement in this study were manifold. Some children are raised by their grandparents because their own parents have passed away or they are working on the farms, and may not be able to afford attending school meetings. Other parents could be alcoholics, while some are themselves intellectually disabled. Parental involvement is a critical aspect of a child's success. When a family receives early intervention services but fails to follow through consistently with the child's treatment plan, the prognosis for success drops (Azad & Mandell, 2016). Thus, it is the responsibility of both the school and the parents to maintain open communication regarding a learners' education plan. Schools, in particular, can step forward to assist parents in establishing and maintaining their involvement in their child’s educational plan.

McCulloch (2015) suggested a few techniques that have been found to be particularly effective in maintaining parents’ involvement in their child’s autism education plan. These include communication as the first and most important task to establish rapport with parents and gain their trust. Establishing open lines of communication from the start is extremely important. McCulloch (2015) suggested that daily communication, in the form of a written notebook that travels back and forth from home to school and vice versa is extremely helpful in ensuring that communication is consistent. When notes are written from home, each member of the educational team is aware of issues that are important regarding each child. Russa, et al., (2015) point out that parents of children with ASD are valuable members of their children's special education team. They should participate in the planning, evaluation, and development of their children’s school programmes. They are now considered to be the primary stakeholders together with the teachers, principal and the health care practitioners in developing plans for their children as decision- making and the responsibility for outcomes are shared.

This new important role has officially been recognised in legislation and policies, such as the South Africa Schools Act (1996) and the Education White Paper no 6. The benefits of the involvement of parents in the education of their children include improved behaviour, positive attitudes, and more successful programmes. In this study, another worrying factor for teachers was that after the school holidays children were found not to remember what they had done before the school closed. Teachers usually start from scratch as there is no continuity in training at home by the family. For successful academic programmes teachers have suggested full participation by the parents.

Many teachers maintained that the senior management of the special school does not provide the necessary support to deal with the multitude of stressful factors related to teaching children with ASD. Stressful factors include the lack of classroom resources, deficient physical infrastructure, unmanageable class sizes, inadequate support personnel, lack of emotional support, and insufficient training.

It was further suggested that senior management should visit classes to motivate teachers and check on how they are coping with the stress of teaching ASD children.

Lack of support from senior management is one of the stressors in the teaching profession (Boujut, et al., 2016). Management support practices are management practices aimed at creating a satisfactory working atmosphere for staff to effectively discharge their duties in a professional manner (Egboka, 2018). Many studies have demonstrated that teachers of children with ASD retire earlier than other professionals because they feel exhausted. This is particularly due to the harmful consequences of stress on performance, career decisions, physical and mental health, and global wellbeing (Boujut, et al., 2016). Provision of supervision, motivation, ensuring the professional development of staff and application of other supportive management functions to improve instructional delivery or the attainment of school goals and objectives, are highlighted as the management support practices in school (Egboka, 2018).

4.7.3 Theme 3B: Teachers Knowledge about ASD

Teachers in Limpopo Province reported having insufficient knowledge regarding the management of children with ASD in the classroom. Furthermore, other children are admitted to the special schools without a specific diagnosis and this could lead to teachers mistreating the children.

4.7.3.1 Subtheme 3.1B: Insufficient knowledge of teachers in regard to teaching ASD children blamed on lack of on-the-job training

Teachers of children with ASD in Limpopo Province were found to have little information about training or teaching children with ASD. Overall, the teachers were varied in the level of knowledge that they had regarding the ASD. Teaching experience and prior training were positively correlated to knowledge. Lack of adequate training and preparation for teachers was noted as a critical concern (Hendricks, 2011).

The study found that some of the teachers never attended any training related to ASD although they had autistic learners in their classes. This results in them getting frustrated as they lack the knowledge of how to manage behavioural problems. It was also found that teachers are not continuously engaged in relevant workshops specifically for ASD. Teachers with high levels of training with ASD learners are less burnt-out than others (Coman, Alessandri, Gutierrez, Novotny, Boyd, Hume, & Odom et al., 2013). Teachers of specialised classes must be specifically trained for their role, that is, they should have obtained a diploma preparing them for teaching children with special needs (Boujut, Dean, Grouselle, & Cappe, 2016). A high level of training promotes teacher commitment and this could be linked to preventing burn-out in teachers and improving the outcomes of all students with ASD.

Professional development is needed that provides teachers with the skills needed and quality in-service training to effectively serve these children (Hendricks, 2011). One of the standards for personnel capacity building in the special schools is that all personnel, especially teaching personnel, must engage in relevant ongoing professional development that will assist them in delivering the curriculum, support learners and keep them abreast of the latest developments in the education and support of learners who require a high level of specialised support (Department of Education, 2014).

Teachers also revealed that job training does not adequately match the needs of the teachers and children. It was indicated that in most cases when they attend ASD workshops it is just a lecture, not a practical session. They suggested that the workshops should be demonstrated practically on how to deal with the different kinds of behaviour of ASD learners in the class.

4.7.3.2 Subtheme 3.2B: Insufficient knowledge of the diagnosis of ASD children by health professionals blamed on medical reports Another worrying thought for the teachers in Limpopo Province was that the children's diagnoses were not indicated in the psychologists’ and doctors’ reports. This could lead to mistaken-diagnoses and the mistreatment of the learners with ASD. The reports only indicate whether the child is mildly, moderately, severely or profoundly intellectually disabled. The psychological reports were found not to disclose the specific condition of the learners. Participants reported that those without a specific diagnosis are placed according to their symptoms. They suggested that psychological reports should include information related to the condition or diagnosis for proper placement in the relevant classroom. The situation was worse in the Vhembe district special schools in Limpopo Province as the reports indicated that they do not have an ASD child as the psychological reports do not specify their diagnoses. As a result, the Vhembe district was excluded from this study. The pathophysiological basis of ASD is not yet well understood and, therefore, diagnosis at this point has to rely on behavioural criteria and the history of the child's development (Stephens, 2012). This finding is supported by a report from the University of Cape Town which states that there are no standardised screening and diagnostic tools that have been shown to work well in Africa (Boonzaier's, 2017). Developmental disability research has so far not been a priority in Africa, and very few funds are available for this kind of research on the continent. Very few researchers have the skills to do high-quality research on autism in Africa.

Special schools should be part of bigger medical and educational institutions according to Boujut, et al. (2016). These settings include specialised support, such as psychiatrists or other health professionals to allow for discussions with teachers about the child and his or her disability. There are many other institutionalised differences between these settings that may influence perceived social support, such as more frequent team meetings, student planning meetings, and the presence of a multidisciplinary team.

4.7.4 Theme 4B: Learning needs of ASD children and special schools

Teachers from the Limpopo Province suggested that there is a need for adequate human and material resources in the special schools and a need for parental involvement, reasonable teacher-learner ratios, and a specific curriculum for ASD children.

4.7.4.1 Sub-theme 4.1B: The need for a human and material resource for teaching and learning in the special schools outlined

One of the standards to ensure quality education and support in special schools and special school resource centres according to White Paper no 6 on inclusive education (Department of Education, 2014) is that special schools must be equipped with appropriate, up-to-date and well-maintained material resources. Schools should plan the sourcing of these material resources in such a way that teaching and learning are not affected (Department of Education, 2014). Despite this standard, the lack of learning and teaching support material is still a challenge in the rural area.

Participants suggested that Limpopo Province must be provided with autism schools and adult autism centres with hostels. Participants reported that autism schools would provide their children with specialised education and high-quality and well-resourced teaching and support. It was further indicated that an autism school is needed to provide professional caring and dedicated staff with autism qualifications. These requirements are supported in the study conducted by Chung, Chung, Edgar-Smith, Palmer, DeLambo and Huang (2015).

4.7.4.2 Sub-theme 4.2B: The need for formal and on-the-job training for teachers of ASD children outlined Professional development is needed that provides teachers with the skills needed and quality in-service training to effectively serve these children (Hendricks, 2011). One of the standards for personnel capacity building in the special schools is that all personnel, especially teaching personnel, must engage in relevant ongoing professional development that will assist them in delivering the curriculum, supporting learners and keeping them abreast of the latest developments in the education and support of learners who require a high level of specialised support (Department of Education, 2014).

Teachers also revealed that job training does not adequately match the needs of the teachers and children. It was indicated that in most cases when they attend ASD workshops it is just a lecture, not a practical session. They suggested that the workshops should be accompanied by practical demonstrations on how to deal with the different kinds of behaviour of ASD children in the class.

4.7.4.3 Subtheme 4.3B: The need for a formal curriculum for ASD children described

Participants in this study suggested the need for a curriculum specific to ASD children. Because the current curriculum is inadequate and it cannot prepare a disabled person for independent living learners would be dependent on their families indefinitely. The findings are similar to the study conducted by (Ahmadi, Zalani, & Amrai, 2011).

4.7.4.4 Sub-theme 4.4B: The need for debriefing and emotional support for teachers of ASD children described

Teachers suggested that they need emotional support for challenging behaviour which is particularly difficult for teachers to manage and is associated with high levels of stress. This finding is similar to that of the study conducted by Boujut, Dean, Grouselle and Cappe (2016) which states that teachers recommend increased social support for teachers to reduce the effects of stress and exhaustion linked to educating students with ASD.

4.7.4.5 Subtheme 4.5B: The need for family involvement in teaching for consistency in managing the ASD child described

In terms of a child's specific individualised education plan, parents are encouraged to participate at all levels (McCulloch, 2015). At the beginning of each school year, parents should be invited to attend parent meetings with access to all of their child's providers should the parent wish. This meeting is held to review the child's progress at the beginning of the year and the goals that are to be implemented as the year progresses. Parents' input is welcomed with written follow-ups for staff in terms of any changes, additions and, or concerns that a parent has regarding their child's programme. In this way, parents are empowered and reinforce their trust, which is essential to work successfully with their children (McCulloch, 2015).

4.7.4.6 Subtheme 4.6B: The need for balance in the teacher-learner ratio outlined

Teachers participated in this study, suggested that more teachers and teacher assistants must be hired to overcome the shortage of ASD teachers in Limpopo Province. As already mentioned, the ratio should be one teacher to every six ASD children and this should be applied in each ASD class. At least one teacher and one teacher assistant must be assigned to an ASD class. In Hong Kong, the class size of special schools ranges from eight to 15 per class, depending on the types of children served. The teacher-to-class ratio is 1.7 teachers per primary and junior secondary class, 1.9 teachers per senior secondary class for special schools for children with intellectual disabilities and two teachers per senior secondary class for special schools offering the ordinary curriculum.

4.7.5 Theme 5B: Coping skills for teachers of ASD children

Limpopo province teachers in this study described dual role, passion of being a teacher of children with special needs, love of the children and religious beliefs as their coping strategies.

4.7.5.1 Sub-theme 5.1B: Dual role of being a parent and a teacher of a child/children with ASD, a coping strategy

Sixteen percent of teachers of children with ASD in Limpopo Province were found to be performing a dual role of being a parent and a teacher of learners with ASD. At home, they full the day-to-day needs of their child with ASD as a parent, while at school they fulfil the teaching role of learners with ASD. Being a parent of a child with ASD motivated these teachers to move from ordinary schools to special schools to learn more about the condition of their children. The study found that teachers who performed both roles experienced less stress related to the behavioural challenges of ASD learners because of their experiences as parents of a child with ASD. Furthermore, these teachers were found to have adequate knowledge about ASD as a result of attending various national and international conferences and training courses on autism. Dual role participants found to educate themselves in regard to the different methods of managing ASD children and, in turn, conduct information searches, and read books and pamphlets.. Participants spent multiple research hours in attempting to understand and learn about various teaching methods and communication skills and how to apply these methods to their child.

Teachers with dual roles in this study were also found to have responsibilitiesin the community, as they were utilised by the local clinics as mentors and coaches for other parents with ASD children and to educate the community with regard to ASD. Furthermore, they participate in the establishment of support groups. Some reported doing a home visit as well.

The study found that the literature on the dual role of being a parent and a teacher of a child with ASD is limited. Parents of children with ASD take on multiple roles and responsibilities in their homes and communities, such as advocators, problem-solvers, organisers, coaches, tutors, disciplinarians, and primary caregivers (Hoogsteen & Woodgate, 2013). Also, it was reported that the key role that dominated the lives of these parents was that of the role of the teacher. Parents helped educate their children and assisted their children in relating to their external environment. Parents became teachers and spent many hours helping their children to deal with their autism.

4.7.5.2 Subtheme 5.2B: An explanation of the various coping strategies outlined: passion, religion, and hobbies

The study also found that strong and controllable emotions are needed in teachers who are teaching ASD learners. Teachers expressed a passion and love for children and learners with ASD and these emotions are part of their most important coping skills. Exercise as a hobby was also utilised. Physical coping strategies are comprised of such things as physical exercise and other recreational activities (Brackenreed, 2011).

Watson’s theory (2008) signifies that love is the most important source of care. Teachers in this study described that ASD children teachers has to be loving, accepting and tolerant of ASD children without being annoyed. A child with ASD usually takes longer to perform simple tasks, ASD teachers must give a child time to complete the tasks. Therefore, patience is a prerequisite in dealing with a child who has ASD as proven by Hendricks, (2011).

Most of the children with ASD are unable to communicate properly, while some function at low developmental levels, but no matter the issues, ASD teachers must accept all children and interact with dignity and respect. To relate to ASD children, the teacher must be able to love and accept them as they are. Department of

Education (2014) indicated that all personnel employed in special schools should have a positive attitude towards people with disabilities.

4.8. GROUP C: GAUTENG PROVINCE PRIMARY CAREGIVERS' RESULTS

This section captures the experiences of primary caregivers in Gauteng Province in caring for a child with ASD, its challenges, existing support systems, identified support needs, knowledge regarding ASD and their coping strategies. There were similarities with regard to the themes and subthemes identified for primary caregivers in the Gauteng and Limpopo provinces.

Table 4.5: Themes and Sub-themes for Gauteng Province Primary Caregivers

THEMES	**SUB-THEMES**
THEME 1C: Experiences of primary caregivers when caring for ASD children	**Sub-theme 1.1C:** Family perceptions of ASD child's pattern of behavior **(Analogous)**
	Sub-theme 1.2C: ASD children's communication skills: problematic to improve **(Analogous)**
	Sub-theme 1.3C: Existence of different conditions within ASD child outlined **(Analogous)**
	Sub-theme 1.4C: Effects of ASD child on the family **(Analogous)**
THEME 2C: Existing support for ASD children and family	**Sub-theme 2.1C:** Parents and relatives' support **(Analogous)**
	Sub-theme 2.2C: School support
	Sub-theme 2.3C: Neighbours/community support **(Analogous)**
	Sub-theme 2.3C: Government support for ASD children and family **(Analogous)**
THEME 3C: Challenges experienced by caregivers	**Sub-theme 3.1C:** Financial constraints blamed on expensive school fees
	Sub-theme 3.2C: Constant care required by ASD exerts pressure on primary caregivers

regarding caring for ASD children	**Sub-theme 3.3C:** Long waiting-list problematic towards timeous admission of ASD children into special schools
THEME 4C: Knowledge of families related to caring for ASD children	**Sub-theme 4.1C:** Lack of, versus deficient knowledge of ASD **(Analogous)**
	Sub-theme 4.2C: Deficient knowledge regarding the causes of ASD **(Analogous)**
	Sub-theme 4.3C: Limited knowledge regarding the management of behavioural problems **(Analogous)**
	Sub-theme 4.4C: Adequate knowledge on how to take medication due to health education given by nurses **(Analogous)**
THEME 5C: Identified needs of families with ASD children	**Sub-theme 5.1C:** The need for more autism schools outlined
	Sub-theme 5.2C: Needs for community, parental training and awareness about ASD outlined **(Analogous)**
	Sub-theme 5.3C: The need for specialists in ASD outlined **(Analogous)**
	Sub-theme 5.4C: The need for no fee school and subsidized hostel accommodation for ASD children
	Subtheme 5.5C: The need for the establishment of support groups
THEME 6C: Coping strategies for families with ASD children	**Subtheme 6.1C:** An explanation that religion is used as a coping strategy for families of ASD children **(Analogous)**
	Subtheme 6.2C: Grandparents support help in coping **(Analogous)**
	Subtheme 6.3C: Supportive environment: a coping strategy for families of ASD children outlined **(Analogous)**
	***Subtheme* 6.4C:** Positive emotions: acceptance of the child **(Analogous)**

4.8.1 Theme 1C: Experiences of primary caregivers when caring for ASD children

Primary caregivers of children with ASD indicated a variety of symptoms, behavioural problems, and skills associated with ASD children. Both groups in the Gauteng and Limpopo provinces highlighted similar behavioural symptoms experienced when caring for ASD children. Four sub-themes emerged from the analysis as discussed below.

4.8.1.1 Sub-theme 1.1C: Family perceptions of ASD child’s pattern of behaviour

A major feature of ASD is the variety of symptoms that ASD children display. Primary caregivers of ASD children shared their experiences about the symptoms and kinds of behaviour that are associated with their ASD children:

“*He was too hyperactive, and sleeps late at night, sometimes he does not sleep at all. He does not have friends, can’t speak or express himself, play with his favorite things like a stick and sits on the same couch every day, he likes humming a tune most of the time”* (P1, GPPC)

The families also shared that, as the children grew, their behaviour became more difficult to manage. They discussed a range of significant ASD-related behaviour that they encountered each day which included eating unusual things, aggression and disruptive behavior:

“He used to eat things that are not supposed to be eaten like bathing soap and potato peels” (P1, GPPC)

The aggressive and disruptive behaviour reported by families include fighting with others and destroying property, as summed up by one mother.

4.8.1.2 Sub-theme 1.2C: ASD children’s communication skills: problematic to improve

In this study, the absence of adequate language development was most stressful for the families. Families seek medical assistance, in the first instance, after their children failed to develop normal speech as the evidence from two mothers in both provinces showed:

“*I took him to the doctor at two years as he was unable to speak”.* (P2, GPPC)

Due to stress associated with the absence of adequate language development, one mother used to put her child on a couch in front of the television to prevent him from crying. As a result her child learned how to speak using the English language only.as shown in the following statement:

“He started to speak when he was 4 years, and he was speaking English only because he is someone who likes TV, so that is how he learns the language. Even now he speaks English only” (P1, GPPC)

4.8.1.3 Sub-theme 1.3C: Existence of different condition within ASD child outlined

The next essential sub-theme described ASD children's patterns of development and existence in different conditions. The families maintained that the milestone development of their ASD children was delayed when compared to children without developmental disorders. As two mothers said:

“He grew up with his cousin which was born the same year like his, they were like twins to me. He appears to develop normally until age 9 months. When I compared the two, sudden changes occurred to him, he was always behind with everything. He started talking when he was four years”. (P1, GPPC)

In addition to the delay in developmental milestones, ASD was also found to be associated with other illnesses, such as epilepsy and behavioural problems. Some of the families reported that their children experienced seizures at home and school and were on epileptic treatment as evidenced by one mother’s comment:

“…*my son was not born like this, he heard seizures while he was 9 months old and it affected all his milestones. He walked very late after 2years.” (P2, GPC)*

4.8.1.4 Sub-theme 1.4C: Effects of ASD child on the family

The study found that many families of ASD children are particularly vulnerable to stress because of the child's severe behavioural issues and impaired communication. This was evident both in the interviews and the family lifelines. A good illustration of stress in this study was when four mothers and one grandmother became emotional and cried during the interviews. The following experiences frustrated most of the families:

Many families were found to be concerned about who would look after their children in the future when they passed on.

"I asked myself this question every day that, what if I die who is going to take care of him". (P1, GPPC)

Families also shared the constant need to reinforce good behaviour all day and every day to model self-care and positive social skills. This involved constantly reminding the child and patterning acceptable behaviour for the child. As one mother stated:

"Every day I supervised her on self-care, undressing, bathing, dressing, applying lotion and roll on and combing of hair. Sometimes I bathed at the same time with her so that she can imitate me. If I don't supervise her she will bath without undressing". (P2, GPPC)

Families also narrated their experiences when visiting the hospital for follow-up. For these families, one trip to a hospital could be exhausting because of the long waiting periods, the children's behaviour, and the need to hold the child down to help keep the child calm. As one mother said,

"When we go to the hospital for treatment, there is a long wait time, they forgot that this child becomes irritated when we stayed in one place for a long time. They end up saying we must go and wait outside because of our children's disruptive behavior". (P1, GPPC)

In addition, the families discussed their unique experiences that affect their personal and emotional well-being, such as denial, disbelief, feelings of hopelessness, feelings of being over-burdened and over-protectiveness.

An experience of denial was found to be common in the parents of children with ASD in this study, because they struggle to come to terms with their child's diagnosis. These experiences affected their marriages and resulted in separation and, or divorce. As one primary caregiver commented:

“My husband and I, we had a house in Witbank where we lived together with our children. My husband struggles to come to terms with the child’s diagnosis and that affected our marriage. *He did not want anything to do with this child. He never accepted the child. We used to fight a lot because of this child, sometimes we go into battle in front of our children and they were so traumatized. So I decided that my happiness comes first. I was tired of crying in front of my children. So in July 2014, I decided to move to Pretoria to stay with my mother for the sake of my children.”* (P1, GPPC)

Mothers of children with ASD reported that they were wondering and asking themselves a lot of questions with regard to their children’s condition. The majority of the participants reported that they experienced a feeling of refusal to beleive that their children had ASD. As evidenced by:

“I used to asked myself why me, *why my child, I could not believe it”* (P2, GPPC)

Many families in this study showed that they do not feel comfortable with other people taking care of their autistic children. As one primary caregiver commented:

“I don’t feel comfortable living him with other people …I do not even prefer him to stay in school hostel” (P1, GPPC)

It was found that families of children with ASD experience a lack of money. It became clear in this study because most of the primary caregivers reported that they were not working and were less educated as they need to take care of their ASD children. Most of them depend on the social grants of their children. As one mother commented:

“I’m not working… I’m selling fruits on the street” (P1, GPPC)

4.8.2 Theme 2C: Support regarding caring for a child with ASD

The study found that there is a lack of support for families of children with ASD. Families of children with ASD face a host of difficulties in obtaining appropriate care and support, including obstacles, such as the rejection of the ASD child by community members and relatives, discrimination, and poor support from the fathers of children with ASD. The lack of support groups in the communities and severe isolation of the parents of children with ASD are other difficulties faced by the families.

Four sub-themes emerged from the analysis, namely, support at home for parents by relatives and friends, support at special schools, support by neighbours and the community for families of children with ASD and government support in regard to ASD children.

4.8.2.1 *Sub-theme 2.1C: Support at home by parents, relatives, and friends*

There were negative as well as positive feelings with regard to the father's or partner's support. In this study most of the fathers of children with ASD were found not to provide the necessary support as they placed blame on their partners for having a child with ASD in their homes. The study found that mothers experienced a lack of support from their partners as they were blamed for having a child with ASD. This lack of support includes not being involved in caring for the child, visiting the doctor, giving financial support and managing the child's behavioural problems. This is evidenced by:

"He used to blame me for the condition of this child and he told me that there is no history of ASD in his family. When we visit the hospital for a follow-up he refused to go with us for consultation he will drop us on the gate. I have asked him several times to go with us to the hospital so that he could observe other children with special needs but he refused. The child feels anxious, nervous and jittery to his father because he could see that he does not love him". (P1, GPPC)

The study found that the relationship and support by siblings of the ASD children have been extremely varied due to their behavioural problems. This reflects the fact that no two families or situations are the same. Yet, most of the brothers and sisters of children with ASD reported supporting each other well. The positive feelings are evidenced by:

"The child and her siblings are supporting each other very well" (P2, GPPC)

The families also described how their relatives support them. Some families referred to their rejection by relatives, and participants reported in this study that their relatives are not involved much with the care and management of the child's behaviour. This is evidenced by the following statement:

"*Support from our relatives is poor, they don't like him, maybe is because they don't understand his condition"* (P1, GPPC)

4.8.2.2 Sub-theme 2.2C: Support at special schools

Families expressed positive as well as negative feelings regarding the support at special schools. The positive feelings about the support by special schools was found to be related to vocational skills training and language development. The negative feelings about the special school support were found to be related to poor progress.

Regarding the positive feelings, ASD children were reported to benefit from the vocational skills training and language development as evidenced by the following statement:

"We are satisfied with the support provided by the school as his skills have improved. (P2, GPPC)

4.8.2.3 *Sub-theme 2.3C: Support by neighbours and the community for families of children with ASD*

Families with ASD children experience feelings of rejection by the community and neighbors, this was evidenced in this study because the community members were reported as teasing the ASD children, not allowing their children to play with an ASD child, harbouring fear of the child and stigmatisation in public situations. As the primary caregivers commented:

"…my neighbors are not supportive, they are calling our son with different names, and they are teasing him, everybody is afraid of him, they refused to play with him, they also laughing at him because he is attending a special school". (P2, GPPC)

The disruptive behaviour of the child with ASD causes serious difficulties with the caregiver's participation in community activities. Families with ASD children in this study were forced to keep their children under lock and key due to their behaviour which was misunderstood by the public and to avoid rejection by the community. As a caregiver commented:

“I do not allow him to go to our neighbors because they feel like he is spoiled or attention seeker”. (P1, GPPC)

All participants revealed that there are no support groups in their communities, schools or health facilities for families of children with ASD as evidenced by:

“There are no support groups in our community” (All participants)

4.8.2.4 Sub-theme 2.4C: Government support regarding ASD children

The families expressed the view that the government provides some support to assist them with caring for their ASD children. Services, such as care dependency, disability, or social grants are provided every month by the state as evidenced by the following comment:

> *“The child is getting a social grant”.* (P2, GPPC)

Participants reported that their children receive their medication at no cost at the hospital and, as some caregivers commented:

“…he is getting his treatment at the hospital for free of charged”. (P1, GPPC)

“Even parents who cannot afford food for their children have a feeding scheme in all the special schools to assist those children who really can’t afford it. (P1, GPPC)

There seems to be an inconsistency concerning the payment of school fees in special schools. The majority of the families reported having to pay school fees per quarter at the special schools. However, some reported that the government is paying for them.

“The government is paying for the school fees and I am paying for the hostel fees quarterly and transport monthly”. (P1, GPPC)

4.8.3 Theme 3C: Challenges experienced in caring for an ASD child

Families with ASD children were found to experience various challenges in caring for their ASD children. These include lack of money for the school fees, long waiting lists for admission and the burden of caring. These results are similar to the results in respect of caregivers in Limpopo Province.

4.8.3.1 Sub-theme 3.1C: Financial constraints blamed on expensive school fees

A mother of an ASD child shared how she struggles financially with the school, hostel fee, and transport as evidenced by the following statement:

"The fees in are expensive but it's a government school, for the school fees, the bus and hostel are about R6000 per month, and they cannot drop the prices because they said it is an autism school so they would not be able to provide what they providing to the children. Some of our learners are not staying here in Pretoria some are from Limpopo province and they stay in a hostel. Some they are here at school but they cannot afford, they need someone who can help". (P5, GPT).

4.8.3.2 Sub-theme 3.2B: Constant care required by ASD exerts pressure on caregivers

The findings revealed that at home ASD children always need a caregiver to assist them with self-care and to safeguard them from danger. This results in caregivers living in severe isolation. As one primary caregiver commented:

"I cannot visit neighbours or anyone because of him" (P2, GPPC)

Church members were also reported as not providing the necessary support to the families with ASD children. This contributed to the severe isolation of the family as they stopped attending the church as evidenced by the following comment:

> "….*he was up and about at the church, so I don't go with him anymore" (P1, GPPC)*

4.8.3.3. Sub-theme 3.4B: Long waiting list problematic in timeous admission of ASD children into special schools

The rights of children with ASD to education were found to be obstructed by the long waiting list for admission to special schools. Families also voiced their concern that autism schools in urban areas are always full and complained of the long waiting lists for admission in the special schools as shown in the following statement:

"When we arrived in Pretoria I could not find a school for him, so he stayed at home 2014 and 2015. He got admission in 2016. It is not simple to get a space in the special schools because most of them are always full and has got a long waiting list. I wanted him to go to an autism school. I applied to one of the autism schools while he was 5 years and even now they told me that they don't have space". (P1, GPPC)

4.8.4 Theme 4C: Knowledge of families related to caring for ASD children the findings revealed that primary caregivers had poor to limited knowledge with regard to ASD, its causes and management. Primary caregivers need accurate knowledge about ASD as they play a vital role in caring for ASD children.

4.8.4.1 Sub-theme 4.1C: Deficient knowledge regarding ASD

Primary caregivers stated that they are aware that their children are suffering from ASD, but they have little information about the condition. As evidenced by the following comment:

"…they said he is having autism and that children with autism are not the same as others, their milestones are delayed, they are hyperactive, some other things I have forgotten". (P1, GPPC)

4.8.4.2 Sub-theme 4.2C: Deficient knowledge regarding the causes of ASD

Families expressed a lack of knowledge concerning the causes of ASD as a result of not being informed by the health care practitioners.

One participant in Gauteng Province, whose child is 9 years old stated the following:

"At the hospital, they said they don't know what causes autism". (P1, GPPC)

4.8.4.3 Sub-theme 4.3C: Limited knowledge regarding the management of behavioural problems

Families seem to have limited knowledge concerning the management of the behavioural problems of their ASD children. Some participants indicated that they were never informed about the management of their children but they learned about some of the strategies that assist them on their own as evidenced by the following comment:

"...we must discover what he wants, we are not supposed to shout at him, he likes hug so we must give him a hug if we told him that we love him, he calms down" (P2, GPPC).

4.8.4.4 Sub-theme 4.4C: Adequate knowledge of how the child should take medication due to health education given by nurses

Most of the participants who said that their children are on medication had adequate knowledge with regard to the administration of medication and the dosage as a result of the health education given by nurses. As evidenced by:

"Whenever we go for follow up nurses teach us on how children should take their medication" (P1, GPPC)

4.8.5 Theme 5C: Identified needs for families with ASD children

Primary caregivers revealed their needs related to caring for their ASD children. Needs priorities were different from one primary caregiver to another. They included needs in respect of access to autism schools, guidance, daily management, relational and emotional support, and the transmission of knowledge and skills.

4.8.5.1 Sub-theme 5.1C: The need for more autism schools and autism adult centres

The most important support needs that were expressed by the participants was the need for an autism school that could provide specialised services and facilities to ASD children.

"I wish we can have more autism schools with hostels so that our children could stay there" (P1, GPPC)

Primary caregivers show a need for guidance and information about the reason for the difficult and unusual behaviour of their ASD child and want to be shown what to do when their child is acting unusually. As one mother commented:

"I have seen a lot of parents at the check-up those that they don't understand what is going on with their children, we need more information from the nurses". (P1, GPPC)

In terms of the ASD children's future, many primary caregivers were concerned about the child's level of independence and their ability to maintain relationships. Primary caregivers were also worried about what would happen to their children when they died and could no longer take care of them. Families in both provinces voiced their needs with regard to the future of their child, as evidenced in the following comment:

"The government must provide sheltered employment for this child just like another developed country because if we die they will experience a big problem on their own". (P2, GPPC)

4.8.5.2 Sub-theme 5.2C: Community, parental training and awareness needs for ASD outlined

Primary caregivers expressed a need to gain the understanding of their families, relatives, neighbours and the community. They also highlighted the need for community awareness to prevent the stigmatisation and rejection of their ASD child as evidenced by the following statement:

"… We should make the community aware of ASD because always we attend some awareness on HIV and cancer, but I have never heard of an autism awareness because they normally say our kids are mad. They label them so they must just be made aware let South Africa know about autism". (P1, GPPC)

One of the teachers from Gauteng Province also supported the idea of community awareness as evidenced by the following comment:

"So if churches can get on board, and the schools get on board you know HIV & AIDS are discussed in the normal mainstream syllabus why isn't disabilities being addressed in the mainstream schools, why isn't that part of life orientation program". (P5, GPT)

4.8.5.3 Sub-theme 5.3C: The need for specialists in ASD outlined

Families mentioned that a child with ASD needs someone with ASD knowledge, such as a health care professional or a home-based carer to continuously monitor the child at home to reduce the burden of caring.

"We need health professional's people that work with autistic children because there is a difference between knowing about autism and working with autism". (P5, GPPC).

4.8.5.4 Sub-theme 5.4C: The need for a free school and subsidised hostel accommodation for ASD children

Last but not least, families express their financial needs and how the government should meet those needs. One of the parents in Gauteng Province expressed her financial concerns as follows:

"Government must do something for those who can't afford school fees. The fees in one of the autism school in Pretoria are expensive but is a government school. If the government can do something for those who can't afford". (P1, GPPC).

4.8.5.5 Sub-theme 5.5C: The need for the establishment of support groups

The study found that there are no support groups for families with ASD children in either of the two provinces. Therefore, the participants suggested that support groups should be established, as evidenced by the following:

"I told the nurses one day that we need a support group because I have seen a lot of parents at the check-up those that they don't understand what is going on with their children". (P1, GPPC)

One teacher from Gauteng Province supported the idea of establishing a support group, as evidenced by the following comment:

"….but I feel perhaps it will be a good idea to create a parental group where they can talk about the things they have experience with their children and so on that might be good for them to have that". (P2, GPPC).

4.8.6 Theme 6C: Coping strategies for families with ASD children

The findings revealed that primary caregivers have coping strategies that assist them in managing stressful situations related to caring for these children. It was further indicated that the parents and families start employing coping strategies soon after the diagnosis of their child with ASD.

4.8.6.1 Subtheme 6.1C: An explanation that religion is used as a coping strategy for families of ASD children

The study revealed that the most useful coping strategy for both groups of participants (primary caregivers and teachers) of children with ASD was their religious beliefs. Most of the participants, whether strongly religious or not, have adopted this method in coping with the ASD situation.

Some caregivers believed that their ASD children are gifts from God, and that is what motivates them to cope with the situation, as evidenced by:

"I told myself that this is just a gift from God because I don't know what God's plan was when he gave me this child. So I'm able to cope with the situation. (P1, GPPC)

One teacher from Gauteng expressed her belief that being a teacher to ASD children is a blessing, as evidenced by her statement:

"I mean is just a blessing to be here and experiencing this, these children made me realize that I am blessed to have what I have, to be healthy, normal and mainstream schooling. This is because the grace of God is over my head". (P4, GPT)

4.8.6.2 Subtheme 6.2C: Grandparents support help in coping

The study revealed that the present support that the primary caregivers received from the grandparents, particularly the grandmothers, helps them to cope with their ASD children as evidenced by the following:

"The support that I received from my mother is enough for me to cope with the situation. I don't even worry when I am at work because they took good care of the child. Sometimes I took him to his grand grandparents in Mpumalanga they are also very supportive". (P2, GPPC).

4.8.6.3 Subtheme 6.3C: Supportive environment a coping strategy for families of ASD children outlined

The findings revealed that a supportive home environment is one of the coping strategies for primary caregivers. One primary caregiver in Gauteng Province described how a friend helped her to cope with the situation, as evidenced by her statement:

"I had a friend who supported me emotionally, financially and spiritually, if I want to go to the mall she will come and collect us. That time when I was looking for a space at school she was there to take me to different schools. She was always available to me, rather than my husband who was always busy to support us, her support was too much to me because sometimes she took the child for the weekend. So this made me be strong and cope". (P1, GPPC).

4.8.6.4 Subtheme 6.4C: Positive emotions: acceptance of the child

Most of the participating families reported having had a high level of dissatisfaction, frustration, and difficulty accepting their autistic children immediately after the diagnoses of their children. In this study, it was found that as time went on they gradually accepted their children's condition. As one primary caregiver commented:

"I accept what God gave me I'm able to face my challenges" (P2, GPPC)

The following section discusses the results of the semi-structured interviews for the primary caregivers in Gauteng Province.

4.9 DISCUSSION OF GAUTENG PROVINCE PRIMARY CAREGIVERS' FINDINGS

4.9.1 Theme 1C: Experiences of primary caregivers when caring for ASD children

The experiences of primary caregivers in Gauteng Province were found to be similar to the experiences of primary caregivers in Limpopo Province. These include experiences related to the patterns of behaviour of ASD children, their communication skills, and the presence of different conditions and the effects of ASD on the family.

4.9.1.1 Sub-theme 1.1C: Family perceptions of the ASD child's patterns of behaviour (Analogous)

Families with ASD children in Gauteng and Limpopo provinces reported experiencing similar patterns of behaviour that are associated with children with ASD as discussed in section 4.5.1.1. Based on the participants' responses, it is without a doubt that caring for a child with ASD is challenging for the families in both provinces. This is shown in the findings of a study by Gorlin, et al. (2016) who found that families viewed ASD as a mysterious and complex condition, with severe behavioural and communication challenges. The range of significant autism-related kinds of behaviour discussed include tantrums, severe sleep issues, impaired communication, and self-injurious behaviour.

4.9.1.2 Sub-theme 1.2C: ASD children's communication skills: problematic to improve (Analogous)

Most of the primary caregivers in Gauteng Province stated that their ASD children had severe communication deficits which are similar to the experiences of caregivers in Limpopo Province, as discussed in 4.5.1.2.

Based on the participant's responses from both provinces their child's language deficiency is still a source of stress long after the child's diagnosis. The absence of adequate language skills was most stressful for families. Many ASD children have very little or no helpful language skills. This is often a frustrating obstacle for a few families, who are understandably reluctant to simply accept the poor prognosis for their child's language development (Azad & Mandell, 2016). It was to find medical help. Others have also noted that poor language development inspired families to seek treatment for their children with ASD. Typically, initial medical consultations take place between the ages of two and three because of language-related problems (Bauman, 2010).

4.9.1.3 Sub-theme 1.3C: Existence of different conditions in the ASD child outlined (Analogous)

As in the case of primary caregivers in Limpopo, primary caregivers in Gauteng Province stated that their ASD children experienced delayed milestones. In some cases, an infant appears to develop normally until age one to three years of age. Then, sudden changes may occur that indicate the presence of ASD and that condition is associated with other conditions, such as behavioural problems and epilepsy. This is similar to the experiences of caregivers in Limpopo Province as discussed in section 4.5.1.3.

Based on the responses from both provinces children with ASD exhibit disruption in developmental domains in the first year of life, including their motor development, attention, and temperament (Landa, 2013).

4.9.1.4 Sub-theme 1.4C: Effects of ASD child on the family (Analogous)

Primary caregivers in Gauteng Province reported experiencing stress that is related to their children's condition and this is similar to the experiences of the Limpopo Province caregivers, as discussed in section 4.5.1.4.

Based on the results, it is without a reasonable doubt that primary caregivers in the Gauteng and Limpopo provinces who are raising children with ASD exhibit severe stress. This is supported by the study conducted by Goedeke, Shepherd, Landon, and Taylor (2019) which shows that caring for a child with ASD is stressful and this subsequently affects parents’ ability to manage their child’s symptoms. Similarly, parents of children with ASD reported having lower subjective well-being and increased physiological stress according to a study by Costa, Steffgen and Ferring (2017). In the findings of the study conducted by Fernańdez-Alcántara, García-Caro, Pérez-Marfil, Hueso-Montoro, Laynez-Rubio and Cruz-Quintana (2016) parents of ASD children indicated that the different emotional aspects of the upbringing of a child with autism spectrum disorder are related to the feeling of unexpected child loss, associated with shock, negation, fear, guilt, anger, and, or sadness. Parents in the study conducted by Madiba et al. (2015) were reported to feel stressed out, frustrated, unhappy, bitter, and experienced inner pain due to their child's diagnosis.

4.9.2 Theme 2C: Existing support for ASD children and family

Primary caregivers in Gauteng Province experienced a lack of support from the community, partners and extended families, which is similar to the experiences of caregivers in Limpopo Province.

4.9.2.1 Sub-theme 2.1C: Parents and relatives' support (Analogous)

It was found that most of the fathers of children with ASD in Gauteng Province did not provide the necessary support to primary caregivers as they placed the blame on their partners for having a child with ASD in their homes. It was found that mothers were blamed for having a child with ASD, which is similar to what was experienced by mothers in Limpopo Province as discussed in section 4.5.2.1.

Based on the results primary caregivers from both provinces seemed not to receive the necessary support from spouses and relatives. The possible reason could be due to limited knowledge regarding ASD and its causes. The results are similar to that of the study conducted by Schlebusch, (2015) which reported that mothers felt responsible for, and were blamed for their child's condition. Mothers blamed their partners, feeling guilty and ashamed, and even felt hatred and anger toward their partners for their perceived responsibility. Fathers have an important role to play in improving outcomes for their children with ASD. With more fathers taking on the primary caregiver's role, it is important to understand their experience with ASD and they need to be assisted in becoming actively engaged in their roles as fathers (Frye, 2016).

4.9.2.2 Sub-theme 2.2C: School support

Primary caregivers in Gauteng Province reported positive feelings with regard to the support provided to their ASD children in the special schools. ASD children were reported to benefit from vocational skills training and language development which is similar to the experiences in Limpopo Province. Based on the results, ASD children in both provinces were reported to benefit from the training in the special schools as discussed in section 4.5.2.2.

4.9.2.3 Sub-theme 2.3C: Neighbours and community support (Analogous)

Based on the results, families of children with ASD in Gauteng Province also received no support from the community as they were subjected to rejection, exploitation, and discrimination, just as was the case in Limpopo Province. As discussed in section 4.5.2.3, the Mental Health Care Act No 17 of 2002 states that a person witnessing any form of abuse against a mental health care patient must report this fact in the prescribed manner. Furthermore, steps must be taken to ensure that users are protected from exploitation, abuse, and any degrading treatment.

4.9.2.4 Sub-theme 2.4C: Government support for ASD children and family (Analogous)

In South Africa, the primary caregiver of children with a disability receives a Care Dependency Grant from the South African Social Security Agency (SASSA) for their children as they need permanent care due to the disability. ASD children receive free medical treatment in the public health institutions, and there are feeding schemes in the special schools. As discussed in detail in section 4.5.2.4, this means that the South African government provides support to ASD children and their families However, some of the support is not provided, such as sheltered employment after exiting the special schools.

4.9.3 Theme 3C: Challenges experienced by caregivers regarding caring for ASD children

The main challenges experienced by primary caregivers in Gauteng Province were the long waiting lists for admission to the special schools, particularly the autism schools because many ASD children have to wait for admission. Furthermore, participants indicated that the tuition and hostel fee is not affordable, particularly for those who are self-employed.

4.9.3.1 Sub-theme 3.1C: Financial constraints blamed on expensive school fees

Primary caregivers who are self-employed reported that transport, school and hostel fees are expensive for them due to financial constraints. Some parents indicated that they want their children to stay in a hostel, but they cannot afford it. Caregivers of children with ASD in Africa have a variety of experiences, some of which are different from caregivers who live in countries with more resources, such as the USA, UK and Northern Ireland (Cloete & Obaigwa, 2019).

4.9.3.2 Sub-theme 3.2C: Constant care required by ASD exerts pressure on primary caregivers

Most of the primary caregivers in Gauteng Province reported that they are working which makes it difficult to provide care to their children with ASD without someone to assist them.

4.9.3.3 Sub-theme 3.3C: Long waiting list problematic in the timeous admission of ASD children into special schools

The right to education for children with ASD was found to be obstructed due to the long waiting lists for admission to the special schools. Families also voiced their concern that autism schools in urban areas are always full. Families expressed their concerns about the long waiting lists for admission to the special schools.

Families in Gauteng Province reported that there is also a need to increase the number of autism schools as the waiting lists are too long.

In Gauteng Province, public and private special schools focus specifically on autism. According to the Department of Education (2014), the best resourced special schools are in urban areas. In 2014, 967 learners with ASD were enrolled (Department of Education (2014). In 2014, 967 learners with ASD were enrolled (Department of Education, 2015). Participants also indicated that adult autism centres are also required because when ASD learners leave school at 18 or 21 years, they have nowhere to go.

4.9.4 Theme 4C: Knowledge of families related to caring for ASD children

The findings revealed that primary caregivers of children with ASD in Gauteng Province had limited knowledge with regard to ASD, its causes and management. Therefore, primary caregivers must collaborate with health professionals to acquire relevant knowledge about ASD children.

4.9.4.1 Sub-theme 4.1C: Limited knowledge regarding ASD

Some families of children with ASD in Gauteng Province proved to have some knowledge as a result of training in regard to the care of children with ASD. Occupational and speech therapists were reported to conduct parent meetings where they address different topics on how to communicate with the ASD child, sensory issues, feeding, and providing emotional support.

Providing families with quality information regarding the diagnosis, available services, and support services is essential for the families of children with ASD over the whole lifespan of the child. Knowledge and skills about ASD enable families to take positive steps towards learning how to help their child (Greeff & Van der Walt, 2010).

4.9.4.2. Sub-theme 4.2C: Limited knowledge regarding the management of behavioural problems (Analogous)

Behavioural problems, such as impaired social communication, interaction and limited repetitive patterns of behaviour were shown to be a source of stress for some of the families of children with ASD in Gauteng Province, similar to the findings in Limpopo Province. It was found that health care practitioners did not give accurate information and explanations to the families regarding ASD and the management of its behavioural problems. This was evident in this study because the families reported that health care providers did not inform them about their children's condition. Lack of access to proper information on the diagnosis of the condition is a barrier to the management of the ASD child for the families as the child grows older (Russa, et al., 2015).

4.9.4.3 Sub-theme 4.3C: Adequate knowledge on how to take medication due to health education given by nurses (Analogous)

Participants knew about the medication that their ASD children were prescribed and how to take it. This was because of the health education given to the caregivers by nurses and pharmacists. However, other parents complained that the treatment made their children sleep too much, they were always drowsy and passive and the result is that they skipped giving their child his or her dosages. Decisions about if and when to try medications can be difficult. However, parents need to weigh up the benefits for their children against the possible risks. Feeling sleepy or tired is one of the side effects as indicated by Uys and Middleton (2014).

4.9.5 Theme 5C: Identified needs of families with ASD children suggested by caregivers

Primary caregivers in Gauteng Province revealed their needs in caring for ASD children. Needs priorities were different for each primary caregiver involving a greater number of autism schools, free schools, and subsidised hostel fees, community awareness and the establishment of support groups.

4.9.5.1 Sub-theme 5.1C: The need for more autism schools outlined

Primary caregivers in Gauteng Province suggested that there is a need for more autism schools in the province because the waiting list is problematic. The results are similar to those of Limpopo Province because the most important need expressed by the participants in Limpopo Province was for an autism school for the specialised education of ASD children. Participants reported that the autism school would provide the children with specialised, high-quality and well-resourced teaching and support. It was further indicated that an autism school is needed with professional, caring and dedicated staff with autism qualifications. This is supported by the study conducted by Chung, et al. (2015).

4.9.5.2 Sub-theme 5.2C: Community, parental training and awareness needs for ASD outlined (Analogous)

Just as in Limpopo Province, primary caregivers in Gauteng Province expressed the need for the education of family, relatives, neighbours and the community. They also highlighted the need for community awareness to prevent the stigmatisation and rejection of ASD children as discussed in section 4.5.5.2.

Stigmatisation of children with developmental disabilities is a widespread phenomenon that constitutes a barrier to help-seeking and the development of health care services. Effective programmes have been developed for promoting mental health in everyday settings, such as families, schools and workplaces (Wahlbeck, 2015).

4.9.5.3 Sub-theme 5.4C: The need for no fee school and subsidized hostel accommodation for ASD children

Participants suggested that there is a need no fee school fees and subsidized hostel accommodation in special schools due to the financial constraints of parents. The South African government allows parents with a low salary to apply for school fees exemption. Therefore, parents who cannot afford school fees must be informed about this (Department of Education, 2014).

4.9.5.5 Subtheme 5.5C: The need for the establishment of support groups

Families of children with ASD, experience parental stress and severe isolation. They seek to figure out where they can receive social support. It may be difficult for these families, however, to find any social support from the community, family members, friends, or others. The majority of the primary caregivers expressed a need to meet other parents of children with ASD either at the special schools or in the community, and to share their experiences, particularly about the management of behavioural problems. Therefore, strategies should be put in place to facilitate this as indicated in the study conducted by Kissel and Nelson III (2014). Participating in support groups would provide an environment in which parents would feel understood, obtain coping strategies regarding their parental stress, share their experiences, and receive emotional support (Ozkaya, 2017).

4.9.6 Theme 6C: Coping strategies for families with ASD children

The findings revealed that primary caregivers of children with ASD in Gauteng Province have coping strategies that assist them in managing stressful situations related to caring for ASD children. These strategies are similar to the strategies applied by the primary caregivers in Limpopo Province because both groups experience significant stress and challenges in caregiving (Lai & Oei, 2014).

4.9.6.1 Subtheme 6.1C: An explanation that religion is used as a coping strategy for families of ASD children (Analogous)

The study revealed that the most useful coping strategy for the primary caregivers of children with ASD in Gauteng Province was religion, and this was similar to the Limpopo Province results. Most of the participants whether strongly religious or not have adopted this method in coping with the ASD situation as discussed in section 4.5.6.1.

4.9.6.2 Subtheme 6.2C: Grandparents support help in coping (Analogous)

The results revealed that parents who are working in Gauteng Province managed to cope because of the still living grandparents who have been assisting them with the burden of caring. This result is similar to the Limpopo Province results in this regard as discussed in section 4.5.6.2.

4.9.6.3 Subtheme 6.3C: Supportive environment: a coping strategy for families of ASD children outlined (Analogous)

Social support from friends, partner and siblings were reported to be another coping strategy since the primary caregiver’s burden of caring was shared amongst family members. Participants reported coping better physically and psychologically with social support as discussed in section 4.5.6.3

4.9.6.4 Subtheme 6.4C: Positive emotions: acceptance of the child (Analogous)

Most of the participating families in Gauteng Province reported that they used their acceptance of the child’s condition as a coping strategy. It was reported that as time passed they gradually accepted their children's condition and they could then move on with their lives. It was also indicated in this study that the acceptance of autism by others could be important for the mental health of autistic individuals for several reasons. The results are similar to that of the Limpopo Province as discussed in section 4.5.6.4.

4.10 GROUP D: GAUTENG PROVINCE TEACHERS’ RESULTS

This section captures the experiences of Gauteng Province teachers in teaching a child with ASD, its challenges, existing support systems, identified support needs, knowledge regarding ASD and the coping strategies. Five themes and sixteen subthemes emerged from the results as illustrated in Table 4.6.

Table 4.6: Themes and subthemes for Gauteng Province Teachers (GPT)

THEME 1D: Experiences of Gauteng Province teachers regarding teaching children with ASD	**Sub-theme 1.1D:** An explanation of the ASD child's patterns of behaviour **(analogous)**
	Sub-theme 1.2D: An explanation of teaching methods for ASD children **(analogous)**
	Sub-theme 1.3D: Teaching children with ASD described as frustrating **(analogous)**
THEME 2D: Support for Gauteng Province teachers and children with ASD at special schools	**Sub-theme 2.1D:** Adequate parental support experienced with a good communication system
	Sub-theme 2.2D: Adequate school support for teachers with teaching and learning resources
	Subtheme 2.3D: Adequate ASD children support through peer group support system
THEME 3D: Challenges experienced by Gauteng Province teachers in the special school	**Sub-theme 3.1D:** Challenges in teaching ASD children: blame on rented infrastructure
	Sub-theme 3.2D: Challenges in teaching ASD children blamed on distance travelled by children
	Sub-theme 3.3D: Inappropriate sexual behavior of ASD learners outlined
	Sub-theme 3.4D: Challenges in teaching ASD children: blame on poor management support (**analogous)**
THEME 4D: Knowledge regarding ASD	**Subtheme 4.1D:** Existence of knowledge appraisable in benchmarking, formal and on-the-job training
THEME 5D: Identified needs for teachers of ASD children	**Sub-theme 5.1D:** The need for more ASD special schools and adult ASD centres in Gauteng Province described
	Sub-theme 5.2D: The need for more up-to-date information on ASD for teachers described **(analogous)**

	Subtheme 5.3D: The need for a formal curriculum for ASD children outlined **(analogous)**
	Sub-theme 5.3D: The need for debriefing and emotional support of teachers of ASD children outlined **(analogous)**
THEME 6D: Coping skills for teachers of ASD children	**Sub-theme 6.1D:** Professional experience and background of teachers marked as a coping skill
	Subtheme 6.2D: An explanation of the various coping strategies. Putting more effort into activities, passion, religion, and hobbies**.**

4.10.1 Theme 1D: Experiences regarding teaching children with ASD There are some similarities with regard to the teacher's results from Gauteng and Limpopo province more especially in respect of Theme 1. The experiences of teachers with regard to teaching ASD learners which is Theme 1 in both provinces revealed similar findings. These may be because ASD learners present with similar manifestations and teachers experience almost the same behaviour in class.

4.10.1.1 Sub-theme 1.1D: An explanation of the ASD learner's pattern of behaviour (analogous)

The teachers identified different characteristic of learners with ASD in grade R, as evidenced by the following statement:

"I got an autistic learner in my class who does very well with activities can complete pictures on his own, he is very comfortable and confident with that, but he struggles to talk and he is struggling to play with the friends, there is another learner in my class who has been diagnosed with autism who is very verbal he can talk very loud he is very social but he struggles with activities and the roles" (P1, GPT).

“Poor eye contact so you will never know if they are listening to you or if they do hear you. They don’t understand the world around them and they also don’t play with other children” (P3, GPT)

The teachers expressed concerns with regard to the communication skills of the ASD learners and how they are encouraged to talk in class, as described in the following comments:

“..With the language, it is very difficult because it takes time for the child to start talking. In my class, we play, laugh a lot, roll around in the carpets and play a lot of games. So *they start talking because they enjoy what they are doing but it takes longer for them to start, but as soon as they start they enjoying themselves in the life skills”(P1, GPT).*

“So in grade R we only encouraged them to talk by asking them a question if they don’t answer we go on to the next friend, and we give a lot of encouragement when they do talk”.

“They need direct instructions” (P2, GPT)

Children with ASD were found to experience tantrums when their routine is distracted as one teacher commented:

“They get tantrums when their routine got distracted and is not a tantrum is that the child cant adapts to the change. Some always sitting in the same seat, if they come in and they sit in a different place the child can’t focus can’t listen he is upset he sometimes cries” (P2, GPT).

Another teacher from a senior class expressed concerns about learners who damage the school as evidenced by the following:

When he/she is angry he just stands up and brakes the windows like what just witnessed now. Or just stand up and pick up the chair and hit it down or hit someone. (P5, GPT)

4.10.1.2 Sub-theme 1.2D: An explanation of teaching methods for ASD children (analogous)

Gauteng province teachers described various teaching methods used for ASD children. As one teachers commented:

"I use trial and error because after I realized that this is not gonna work and then I try something else, so there is no specific method. We need to keep them motivated, we need to have an activity that is motivating for them. So we use a lot of visuals aids for them to understand better the ASD children are visual learners. visual aids we use pictures, picture symbols so that the picture exchange communication symbols, they use a picture to communicate with you a picture of help, food whatever they need they have pictures for. Some of the children can communicate with you but you support them with sign language the tiny hands" (P4, GPT)

4.10.1.3 Sub-theme 1.3D: Teaching children with ASD described as frustrating (analogous)

"It's frustrating because at the beginning they will look at you not responding to anything, the better they get to know you the more comfortable they feel". (P3, GPT)

"There was one learner whom I thought he was deaf because he was not reacting when calling him by his name at the beginning, and this was frustrating *because I never knew if he was listening to me or if he does hear me" (P4, GPT).*

4.10.2 Theme 2D: Support for Gauteng Province teachers and children with ASD at special schools

The study revealed that special schools in Gauteng Province provide support to teachers, ASD children, and their families. These include adequate resources, parental and peer group support, and good communication systems between the families and teachers.

4.10.2.1 Sub-theme 2.1D: Adequate parental support experienced with a good communication system

Teachers in Gauteng Province mentioned communication systems that they utilise to communicate with the parents of children with ASD, as evidenced by:

“We have a contact system such as a message book and they don’t answer me I send them a message on my phone and sometimes I put a note in a dirty lunch box say please look at your contact book, when parents are more educated and most of them have whatsappp, so I made a watsup group with all of them with their permission and now they have each other’s numbers I know the parents are supporting each other, they are talking to each other and asking for help or encouraging each other”.(P3, GPT)

“We do have a watsup group where we contact each other with my support but is not for social things and so on is academic. I have a little plastic file with the communication book which I write in every day, I paste the letters in there I put the communication in the file and file in the learner bag. I also have got a communication book that I send every day, so every day I would say what we did in class, what they did at school, if something happens whatever, (P5, GPT)

I use a lot of telephone communication I phone them I watsup them, and with the other parents if we realize there is really important information and they are not reading the communication book we phone them, (P3, GPT)

“…… with the parents, there is a lot of meetings with the parents and we have got an individual plan for each child, so depending on the child’s needs you would trace the autistic behavior”. (P4, GPT)

In addition, parents in Gauteng Province were reported to receive training from one of the autism schools with regard to communication with the child and how to feed children with eating difficulties. As the teacher commented:

“….the school tries to give them a lot of support, for instance, the OT and speech therapist they have got parents meetings where they address things like different topics like how to communicate, and they use the Hanna program, or they make use of pictures, and they train the parents on pictures, also of the sensory issues they will get someone in with feeding difficulties and they will give training like that to help the parents to cope. With the individual plan discussions once a year we meet as the team with the parents to discuss what is the challenges and how can we help them to address these challenges”. (P5, GPT)

“…..then also with the parents, there is a lot of meetings with the parents and we have got an individual plan for each child, so depending on the child’s needs you would trace the autistic behavior”.(P6, GPT)

4.10.2.2 Sub-theme 2.2D: Adequate school support for teachers with teaching and learning resources

The study revealed that the teaching and learning resources for ASD children in Gauteng Province were sufficient. Gauteng Province teachers described their experiences with regard to teaching and learning resources in their special schools, as evidenced by the following statement:

“We are fortunate we are the lucky group at the school we got the money every month to buy ingredient to use in our class for art, for sensory activities, for baking and tasting, for spoiling them, then we are fortunate. We fundraise every day of our life at the school to be able to have those funds to give it back to the children. (P3, GPT)

“I think our school is very privileged we have everything we need the department and the district is very good for us more especially for the Grade R learners so I have got everything I need in my class to help me, to make sure that I can give them what they need and make a fun for them, so I really can’t say there is anything that I feel like I need in my environment”. (P1, GPT)

“We also have the gym here at the back where they do cycling, bicycles they exercise a little bit”. (P4, GPT)

“But we have got a lot of resources, each class has its little things, for maths, language, and staff puzzles, books, and dictionaries, so we are a privileged school we have a lot of resources and the teachers make use of the resources there isn’t something that is on the cupboard that is not working.” (P6, GPT)

“The school is doing a lot of fundraising they make sure that each class has a class assistant”. (P3, GPT)

Teachers also pointed out that there are health care practitioners in the special schools, as a teacher commented:

"Our school have all health care providers, psychologist, OT, Physiotherapist, a nurse, Speech and hearing therapist". (P3, GPT)

4.10.2.3 Sub-theme 2.3D: Adequate ASD children support through peer group support systems

The results revealed that ASD children in Gauteng Province support each other at school through peer group support systems as teachers commented

"So what we do we call it buddy-buddy system to get the stronger children to help another child to go down to the playground, they take their hands and make sure they get to the playground with them, they don't lose them on the way". (P3, GPT)

"We have a system at school with wheelchair pushers, senior children who can understand and knows all the safety rules they are allocated to different classes and when we go for assembling in the morning they bring them here and in the afternoon they take them down to the school buses or the taxi so we have senior children to help us to get our children to move. So we always have the support of everybody in the school is helping everybody". (P3, GPT).

4.10.3 Theme 3A: Challenges experienced by Gauteng Province teachers in the special schools

Gauteng Province teachers described the challenges encountered when teaching children with ASD in the special schools. These include infrastructural problems, distances travelled by ASD children, inappropriate sexual behaviour and poor school management support.

4.10.3.1 Sub-theme 3.1A: Challenges in teaching ASD children blamed on rented infrastructure

The study revealed that physical resources are a challenge in one of the autism schools in Pretoria, Gauteng Province. Teachers voiced concerns with regard to the infrastructure of the school that affects the number of admissions, as in the following teachers' comments:

"We are renting from another school the facility is not ours so we don't even have a building and then again is limited to the number of children that we can accommodate at the school", (P4, GPT)

"The infrastructure limits us to do more vocational skills we do a little bit of the garnering, planting, and seedlings due to limited space" (P5, GPT).

4.10.3.2 Sub-theme 3.2A: Challenges in teaching ASD children blamed on distance traveled by children

The results revealed that parents in Gauteng Province prefer to take their children to the special schools in town rather than to those in the townships where they stay, as teachers commented:

"The parents prefer to bring their children here in town at our school and let their children travel very far to come to our school because I don't know their schools but there are other schools in places nearer to their homes". (P2, GPT)

"I have got child B she gets in the taxi at 03h30am. I spoke to the driver again yesterday he said he gets up at 03h00 to drive to her place in Soshanguve because is very far and then he comes back and picks up other children. Then they are here roundabout 06h15 or 07h30 because he has got other children in the transport who must go to other schools so that is why they also sleep in class in the afternoon because they are so tired, so when they get into the taxi from 13h30 they only arrive at 17h00 sometimes at home, so our children have difficulties". (P3, GPT)

In addition, one teacher expressed concerns about the renewal of social grants which would affect the teaching and learning progress, as evidenced by:

"The processes of sorting out the grant are also affecting other learners teaching and learning as they are always going up and down to different offices". (P5, GPT).

4.10.3.3 Sub-theme 3.3D: Inappropriate sexual behaviour in ASD children outlined

Teachers of ASD senior classes expressed their concerns with regard to the challenges experienced by ASD learners during the adolescent stage in the following comments:

"They start to recognize themselves and they don't know who they are really, and they start to recognize the difference between them and the other schools, starting to recognize girls or maybe boys but they don't know how to control this". (P6, GPT)

"Sometimes in their teenager's stage they develop certain feelings, so others they just do it in public, sometimes when they are playing or in class, he gets an erection he just rubs his private part in front of other kids, you must call him to go and do it in the bathroom not just around others. It is very different from teenagers, there are more challenges". (P6, GPT)

Teachers described how this kind of behaviour is being managed in the school in the following comments:

"We have got the psychologist at school who have once a week social classes with the learners, that's where we address some of these issues during the social classes, we also make use of the social stories with the learners, then we also prepare them for leaving the school, things like how to dress properly, how to approach other people things like that we use in class, we have got different vocational skills that they focus on for kitchen, garden car washes things like that".

4.10.3.4 Sub-theme: 3.4D: Challenges in teaching ASD children blamed on poor management support

Teachers in Gauteng Province expressed their concerns about the lack of support from the school management. Teachers in Limpopo Province reported similar experiences as follows:

"We don't always have the support that we need from upper management to support us as teachers in the class and to participate in classes. Just to come down and see how it goes with the teachers because this is difficult to work with these children. We don't see a lot of progress with this children you kind of doubt yourself as a teacher, you think I'm not doing the right thing so you just need other support as well coming to you". (P4, GPT)

"Most government schools don't have the funds, and I also feel like the department is pushing us into a box and ASD doesn't fit in a box you know, because they want us to have more children in the class and is really difficult handling more for me is difficult I have nine children with one assistant". (P3, GPT).

4.10.4 Theme 4D: Knowledge regarding ASD

Gauteng Province teachers were found to have adequate knowledge regarding the teaching of children with ASD as a result of existing knowledge, benchmarking, formal and informal training.

4.10.4.1 Sub-theme 4.1D: Existence of knowledge appraisable in benchmarking, formal and on-the-job training

The results revealed that teachers in Gauteng Province were knowledgeable about the teaching of ASD children. The existence of knowledge appraisable in formal and informal on-the-job training, social media and through reading. As teachers commented:

"*I'm very comfortable with my knowledge, special needs, and what the children need and so on. With autism specifically I read a lot all the time, I have got my medial pages and my Facebook friends and so on they usually give tips specifically. As I said sometimes you got a challenge where you don't know how you are going to deal with this you go to the medical side and see what you can find from other teachers who have done that or had similar happening in class and you take that out. We have to learn all the time you cannot say I know about autism because autism changes. After all, every child is unique". (P1, GPT)*

“My knowledge regarding ASD is satisfactory, I studied teaching and specializing in life support and psychology and then now I’m busy with my honors in AAC, especially for ASD learners or anyone who struggles with language. What I know about ASD is that they struggle a lot with the language, struggles socially, struggles emotionally, and so they need a lot of sports and a lot of love, a lot of adapted learning strategies that you need to use yaa, the symptoms I won’t go through them because you know them”. (P5, GPT)

Teachers maintained that the special schools in Gauteng Province provide a lot of on-the-job training, as teachers commented:

“With the workshops, I think our school made a lot of provision for the teachers and assistant for the training. We all have tiny hands training, picture training, TEEACH training, AAC training, behavior and emotional training form the psychologist. The school psychologist and another therapist also give us training at school, if they go and attend a course they give us feedback on what they have learned or have seen”. (P5, GPT)

“With regards to in house training, I have attended a lot of courses now and then. We get speakers at school who have got the knowledge, to come and informed us about different levels of ASD. Sometimes they invite people with autistic children to come and inform us how they deal with their children. Our school has got a very good training system”. (P3, GPT)

“I have done about three or four workshops on autism and how to deal with them in the classroom, it was not a medical conference or medical workshop is more from the psychological education point of view”. (P1, GPT)

“I attended a lot of workshops, like the sign language workshops, teaching and learning methods all those courses”. (P4, GPT)

Another teacher pointed out that they acquire even more knowledge from other special schools for ASD learners through benchmarking, as a teacher commented:

“sometimes once or a year or every second year our school send someone down to ASD schools in Cape Town to go and see what they are doing to compare it with what we are doing, and come back with things that the school is doing quite well and we can learn”. (P5, GPT)

4.10.5 Theme 5D: Suggested needs for Gauteng Province teachers

The last essential theme identified in this research was the suggestion that there is a need for more special schools, centres and facilities for the teaching of children with ASD.

4.10.5.1 Sub-theme 5.1D: The need for more ASD special school and adult ASD centers in Gauteng province outlined

Gauteng province teachers in one of the autism school identified needs with regard to infrastructure and more human resources. The suggested needs were similar to those suggested by teachers in Limpopo Province, in the following comments:

So one of the things we as the school we want is the bigger building as well so we can support more children. If we have a bigger building and huge facilities we could accommodate 300 plus learners, but now we have a limited of 116. (P4, GPT)

“one assistant per class, we would love more assistance but that’s again one of the limitations the barriers, challenges we experience we are only two hands on our children especially this year this children level of functioning is very low so they need hands and support the whole time, although is the two of us here we will be busy here with the child, she will be busy with another child, then we so we are between them the whole time so if we can have more hands they can be more one on one learning because some of the children need that one-on-one learning”. (P3, GPT)

Teachers reported that special schools in Gauteng Province provide parental training for families with ASD children as evident in the following comment:

"you know what the school tries to give them a lot of support, for instance, the OT and speech therapist they have got parents meetings where they address things like different topics like how to communicate, and they use the Hanna program, or they make use of pics, and they train the parents of pics, also of the sensory issues they will get someone in with feeding difficulties and they will give training like that to help the parents to cope". (P4, GPT)

"With regards to the individual plan discussions once a year, we meet as the team with the parents to discuss what is the challenges and how can we help them to address these challenges, and there is also a doctor who visits the school to help with medications prescriptions and stuff like that". (P5, GPT).

4.10.6 Theme 6D: Coping skills for Gauteng Province teachers

The professional experience and the background of teachers in Gauteng Province were found to be used as coping strategies, in addition to religion, passion, and love of the children.

4.10.6.1 Sub-theme 6.1D: Professional experience and background of teachers identified as a coping skill

The results revealed that the professional experience and background of teachers in Gauteng Province were indicated as a coping strategy. As commented by teachers: *"Coping is not a problem because I studied here as a student so it was very overwhelming. While I was studying I was working with autistic children, on one and that I gained a lot of knowledge and experience".* (P4, GPT)

"I cope very well because I got experience out of the school, I had an opportunity to learn from well-trained therapists who were also teaching at the University of Pretoria before. I had a lot of training they help me to get acquitted with the AAC. For about 15 years I was working with these therapists". (P3, GPT)

"I am coping very well because before I did education I studied psychology, therefore my psychology background assist me a lot". (P4, GPT)

“We enjoy our job very much, even when the schools close you still keep on calling their names and remembering them every day”. (P5, GPT)

“My first day was not so tough because we have got one in the family, the neighbor to have got a child-like these. The experience assisted me”. (P5, GPT)

4.10.6.2 Subtheme 6.2D: An explanation of the various coping strategies outlined. Putting more effort in activities, passions, religion, and hobbies (analogous)

Teachers of children with ASD in Gauteng Province also reported using religion, hobbies, passions, and love for children as coping skills, as evidenced by the following comment:

“I just put a little bit of more effort and a little bit of attention on what they do” (GPT, 1).

“If they don’t understand the activity we leave it and we will do it tomorrow” (GPT, 1)

“The first thing you need to have a passion, patience and you have to love these children”. (P1, GPT)

“Exercise also assist me to copy”. (P2, GPT)

“The first thing you have to love the child, it doesn’t matter who it is, and it doesn’t matter what his background is what disability or diagnosis is, if you are willing to do this job you will love them the same”, (P3, GPT)

4.11. DISCUSSION OF THE FINDINGS ON GAUTENG PROVINCE TEACHERS

4.11.1 Theme 1D: Experiences of Gauteng Province teachers regarding teaching children with ASD

Teachers from both provinces were found to have similar experiences when teaching children with ASD. These include patterns of behaviour, communication skills, and feelings of frustration.

4.11.1.1 Sub-theme 1.1D: An explanation of the ASD child's patterns of behaviour (analogous)

Teachers in both provinces were found to experience similar patterns of behaviour in ASD children in the classroom. These include class disruption, temper tantrums, stereotyped behaviour, repetitive behaviour, and other kinds of behaviour as discussed in section 4.7.1.1. Teachers were found to use a structured environment, such as routine activities, the continual repetition of activities and giving simple and clear instructions to manage ASD children's patterns of behaviour.

4.11.1.2 Sub-theme 1.2D: An explanation of teaching methods for ASD children (analogous)

Teachers of children with ASD in Gauteng Province were found to have adequate skills and knowledge regarding the training of children with ASD. Teachers reported that they have got a good training system, they attended several workshops and in-service training related to ASD, including sign language, teaching and learning methods, Makaton, tiny hands training, picture training, TEACCH training, AAC training, Applied Behavioural Analysis, and the Sunrise method. A school psychologist, occupational therapist and another therapist also gives them training at school. As most of the ASD learners experience impaired communication, these professional development programmes are utilised to create an inclusive environment where every child feels welcome and valued in the classroom.

In France, the main training programme for teachers of children with special needs is called the Certificate of Aptitude in the schooling and adaptation of students with disabilities and is offered by the Ministry of Education. The course contains a choice of seven options depending on the type of disability of the child being taught. Option D is recommended for teachers working with children with ASD because its content covers educational and teaching methods adapted to children with substantial cognitive difficulties (Caraglio & Delaubier, 2012).

4.11.1.3 Sub-theme 1.3D: Teaching children with ASD described as frustrating (analogous)

Teachers from both provinces were found to experience frustration when teaching ASD children. It was found to be frustrating to the teachers whether resources are available or not because these feelings were experienced by both teachers from less-resourced and well-resourced special schools as discussed in section 4.7.1.3.

4.11.2 Theme 2D: Support for Gauteng Province teachers and children with ASD at special schools

Gauteng Province special schools were found to provide more support to the teachers, ASD children, and their families than special schools in Limpopo Province. Teachers reported that teaching materials and human resources are satisfactory, and there is a good communication system with parents even though other parents do not respond. ASD children also support each other through peer group support systems.

4.11.2.1 Sub-theme 2.1D: Adequate parental support experienced with a good communication system

The special schools in Gauteng Province were found to have a good communication system with the families of children with ASD. This was achieved through contact books which travel back and forth from the child’s home to school and back again, letters, and WhatsApp groups.

Families are essential partners in the education of children with autism (Azad & Mandell, 2016). Numerous conceptual articles encourage parents and teachers to openly communicate about their concerns regarding their children. It is of importance for parents to maintain consistent and reliable communication with teachers (Gabovitch & Curtin, 2009), especially because their child with disabilities may not be able to talk about the school day. According to Azad and Mandell, (2016) parents and teachers communicate to exchange information related to the child’s needs and performance, stay informed, and brainstorm strategies to resolve problems that arise at home or school. Parental involvement in their child's educational programme is essential for all children to experience success. It is even more so in the case of a child who has ASD (McCulloch, 2015).

4.11.2.2 Sub-theme 2.2D: Adequate school support for teachers with teaching and learning resources

The study also found that there were adequate learning and teaching support materials and other material resources in the special schools in Gauteng Province. It was reported that special schools have resources needed for the training of ASD children. Teachers reported that their schools do a lot of fundraising and the Department of Education provides them with the necessary materials. A study conducted by Donohue and Bornman, (2014) in Gauteng Province revealed that most learners with disabilities received specialised support services as Gauteng Province is the richest and most resourced province of South Africa.

In Gauteng Province, each special school was found to have professional specialist support personnel and a teacher assistant for each class. It was found in the study conducted by Russa, et al., (2015) that the needs of ASD children who have special educators or therapists are significantly met.

4.11.2.3 Sub-theme 2.3D: Adequate support of ASD children through peer group support system

It was found in this study that ASD children in Gauteng Province support each other at school through peer group support. Senior learners who understand and know safety rules help other children with severe or profound intellectual disabilities. They hold their hands and make sure that they get to, and from the playground. This is called a peer buddy system. Another peer support system used is called the wheelchair pushers whereby senior learners push those that make use of wheelchairs to the assembly point in the morning and when the school is out they take them to the school buses.

This was also found in the study conducted by Foster (2011) which maintains that students with disabilities could increase their interaction with typical peers as a result of participating in a peer buddy programme. Peer mentors encourage and motivate children with ASD to become more active socially.

4.11.3 Theme 3D: Challenges experienced by Gauteng Province teachers in the special school

Teachers in Gauteng Province reported the challenges that they encounter while teaching children with ASD in special schools, including infrastructural problems, distance travelled by ASD children, inappropriate sexual behaviour and poor school management support.

4.11.3.1 Sub-theme 3.1D: Challenges in teaching ASD children blamed on rented infrastructure

Lack of physical infrastructure was also observed in Gauteng Province because one of the autism schools was found to be renting a building from another school. This resulted in a limited number of children being admitted to that school. One of the standards for physical infrastructure according to the Department of Education (2014) is that the design of the physical infrastructure should take into consideration the programmes offered at the school, the anticipated learner who would be enrolled in the programmes and that full accessibility of the whole school environment should be ensured. This includes, but is not limited to, the classrooms, laboratories, workshops where necessary, administration, library, computer room, ablution block, soundproof room for audiometric testing, hostel, therapy rooms, observation facilities, as well as pathways leading to these facilities.

4.11.3.2 Sub-theme 3.2D: Challenges in teaching ASD children blamed on distance travelled by children

In Gauteng province, teachers were concerned about children who stay in the townships but acquire their schooling in town as they travel from very far to attend school. Some children were reported to catch a taxi around 03h30am and this was found to interfere with the educational programmes as children arrive at school very tired and they sleep in class.

The Department of Education (2015) indicated that children with special needs are prevented from enrolling in full-service schools that have been upgraded and they spend an unreasonable amount of time on the road because they do not have transport. Furthermore, the cost of special schools in providing transport is one of the most serious challenges. Therefore, the school transport policy is currently being developed and will take an integrated approach which does not separate transport for special schools from that of the transport of ordinary schools.

4.11.3.3 Sub-theme 3.3D: Inappropriate sexual behaviour in ASD learners described

Adolescents with ASD were found to exhibit inappropriate sexual behaviour, such as masturbating in public as reported by their teachers. ASD adolescents have sexual needs but may not understand their physical and emotional development resulting in inappropriate sexual behaviour. Similarly, inappropriate sexual behaviour, such as hyper masturbation, public masturbation, inappropriate romantic gestures, inappropriate arousal, and exhibitionism were found in the study conducted by Beddows and Brooks, (2016). Such kinds of behaviour are thought to be caused by a lack of understanding of normal puberty, the absence of appropriate sex education, the severity of their ASD and other associated problems. Schöttle, Briken, Tüscher, and Turner (2017) state that individuals with ASD seem to have more hypersexual and paraphilic fantasies and behaviour than the general population. The hypersexual types of behaviour which were frequently reported included excessive masturbation. It was suggested that excessive masturbatory behaviour could reflect the desire to be sexually active although the individual is not able to achieve this because of limited social skills.

Beddows and Brooks (2016) suggested strategies to minimise behaviour of this nature, including individualised, repetitive education started from an early age in an accessible form. Social skills development is also important before more technical aspects of sex education are taught. Johnson, George, Armstrong, Lyman, Dougherty, Daniels, and Delphin-Rittmonet (2014) suggest that school-based behavioural interventions specifically target problem behaviour that occur in the school setting, and they use teachers and school staff as interveners in the management of student behaviour.

4.11.3.4 Sub-theme 3.4D: Challenges in teaching ASD children blamed on poor management support (analogous)

Many teachers expressed the view that the senior management of the special school does not provide the necessary support to deal with the multitude of stressful factors related to teaching children with ASD. These include problems with classroom resources, physical infrastructure, manageable class sizes, support personnel, emotional support, and sufficient training. It was further suggested that senior management should visit classes to motivate teachers and check on how they are coping with the stress of teaching ASD children.

Lack of support from senior management is one of the stressors in the teaching profession (Boujut, et al., 2016). Management support practices are management practices aimed at creating a satisfactory working atmosphere for staff to effectively discharge their duties in a professional manner (Egboka, 2018). Many studies have demonstrated that teachers of children with ASD retire earlier than other professionals because they feel exhausted. This is particularly due to the harmful consequences of stress on performance, career decisions, physical and mental health, and global wellbeing (Boujut, et al., 2016). Provision of supervision, motivation, ensuring the professional development of staff and the application of other supportive management functions to improve instructional delivery or the attainment of school goals and objectives, are highlighted as the management support practices in school (Egboka, 2018).

4.11.4 Theme 4D: Knowledge regarding ASD

Gauteng province teachers were found to have adequate knowledge regarding teaching ASD children as a result of formal and informal training in the special schools and benchmarking with other autism schools.

4.11.4.1 Subtheme 4.1D: Existence of knowledge appraisable on benchmarking, formal and on-the-job training

One of the autism schools in Pretoria was found to be comparing their training, teaching and learning with another autism school in Cape Town for best practices. The school sends one teacher to go and benchmark for best practice a few months every year to other autism schools that are doing quite well with regard to teaching children with ASD. The school learns best practices from another autism school. The knowledge of teachers regarding ASD in that school has increased due to learning best practices from one of the best autism schools in South Africa.

The education industry faces new challenges every day as new regulations, new technologies, and new organizations are being created continuously as a result of public policy. Managers of special schools need to respond to these challenges with sound performance evaluation and decision-making (Ozcan, 2014).

4.11.5 Theme 5D: Suggested needs for teachers of ASD children

Teachers in Gauteng Province suggested that there is a need for the Department of Basic Education to build more autism schools, to provide access to up-to-date information, to develop a specific curriculum for ASD children and to provide emotional and debriefing support to all ASD teachers.

4.11.5.1 Sub-theme 5.1D: The need for more ASD special school and adult ASD centres in Gauteng Province outlined

In Gauteng Province, there are public and private special schools that focus specifically on autism. The best resourced special schools are in urban areas (Department of Education, 2014). The number of learners with ASD who were enrolled in 2014 was 967 according to the Department of Education (2015). Families in Gauteng Province reported that there is also a need to increase the number of autism schools as the waiting list is too long. Participants also indicated that adult autism centres are also required because when ASD learners leave school at 18 or 21 years they have nowhere to go.

4.11.5.2 Sub-theme 5.2D: The need for more up-to-date information on ASD for teachers outlined

Lack of access to current information is a barrier to the management of ASD children. Teachers in Gauteng Province suggested that current information regarding ASD should be provided because there is much research regarding ASD that is being conducted. This can be achieved by giving teachers a chance to attend research conferences, consult the media, and benchmark with developed countries with good practices on teaching children with ASD (Matenge, 2013).

4.11.5.3 Subtheme 5.3D: The need for a formal curriculum for ASD children outlined (analogous)

Similar to Limpopo Province results, teachers in Gauteng Province also emphasised that there is a need for a curriculum specifically for ASD learners. Because the current curriculum cannot prepare ASD learners for independent living they would be dependent on their families indefinitely (Ahmadi, Zalani, & Amrai, 2011).

4.11.5.4 Sub-theme 5.4D: The need for debriefing and emotional support for teachers of ASD children outlined (analogous)

Teachers have suggested that they need emotional support to deal with challenging kinds of behaviour that are particularly difficult for teachers to manage and are associated with high levels of stress. This finding is in agreement with the findings of the study conducted by Boujut, Dean, Grouselle and Cappe (2016) which states that teachers recommend increased social support for teachers to reduce the effects of stress and exhaustion linked to having students with ASD. Counselling and debriefing sessions by the psychologist must be provided to the teachers every quarter or whenever necessary.

4.11.6 Theme 6D: Coping skills for teachers of ASD children

Teachers in Gauteng Province revealed that background or past and professional experiences assist in coping with the stress related to teaching children with ASD. Also, teachers reported that passion, love for children and their religious beliefs are other coping skills for them and this corresponds to the results in Limpopo Province.

4.11.6.1 Sub-theme 6.1D: Professional experience and background of teachers identified as a coping skill

Teachers with previous experience of working with ASD children, with well-trained educational backgrounds, and those with health-related courses were found to cope more effectively than teachers without an educational background or past experiences. One teacher was found to have done psychology courses before doing teaching courses, and a background of psychology was reported to be utilised as a coping skill. Another teacher was found to have more than 15 years of teaching experience of children with ASD in a previous school and to have worked hand-in-hand with the physiotherapists. One teacher reported that during training she was exposed to children with ASD, and therefore, she could cope. Well-trained teachers were also found to be aware of what adaptations to make to foster good learning conditions.

This was supported by the study conducted by Brackenreed, (2011) which states that teachers generally need the experience to use the most effective coping strategies, such as relying on experience or following a pre-designed plan of action. Teachers who are less well-trained or not trained at all are not necessarily aware of the changes needed to promote good learning conditions for a child with ASD, or how to encourage good peer relationships. Moreover, they are not usually aware of the long-term negative consequences of social and behavioural inadequacy in school on these children (Boujut, Dean, Grouselle, & Cappe, 2016).

Brackenreed (2011) states that methods of coping are related to the basic characteristics of the teacher, teacher preparation, and years of teaching experience. Coming up with a plan and implementing it, and concentrating on the next steps requires expertise and experience on the part of the teacher. Therefore, mentors for novice teachers could play a significant role in mediating the coping strategies for novice teachers, alleviating levels of stress and helping to ensure the retention of teachers.

4.11.6.2 Subtheme 6.2D: An explanation of the various coping strategies outlined. Putting more effort on activities, passion, religion, and hobbies (analogous)

Teachers in Gauteng and Limpopo provinces were found to utilised similar coping skills as both reported that religion, passion, and love for the children motivates them to cope with the stress of teaching ASD children as discussed in section 4.7.5.2. However, some teachers in Gauteng Province also indicated that if the learners do not understand an activity they put more effort into that activity or leave it until the next day.

4.12 CONCLUDING STATEMENTS

- Both semi-structured and focus group interviews yielded similar results for each group of participants which include experiences, challenges, needs and coping skills and knowledge regarding ASD.
- Families and teachers are confronted with the multiple characteristics of children with ASD. ASD was found to be complex because it is an invisible and unpredictable condition with diagnostic challenges. Both groups of primary caregivers in Gauteng and Limpopo provinces emphasised similar behavioural symptoms experienced when caring for ASD children. These include a list of associated behavioural symptoms, such as restlessness, hyperactivity, noisiness, the humming of a tune or singing a song, disruptiveness, destructiveness, aggressiveness, anxiousness, and obsession with an object. Primary caregivers also experienced that ASD children are isolated, have impaired communication and social interactions. Similarly, these characteristics were also experienced by teachers at school. These associated behavioural symptoms were present from early childhood and interfere with everyday functioning.
- Teachers described other characteristics that were displayed by the ASD children at school. These include disturbing the class, repetition of words, poor eye contact, blocking of ears with fingers as they do not like too much noise, self-injury, bullying, damaging the school. Children with ASD were also reported to learn through repetition and routine.

- The child’s pattern of behavior also included the abrupt changes that occurred from day to day and over time, such as the child suddenly losing the ability to talk. Communication deficits were most stressful to the families and teachers. Due to stress associated with the absence of adequate language development, some mothers used to put their children on a couch in front of the television so that they would not cry. This resulted in children learning how to speak using the English language only.
- ASD children reach developmental milestones at their own pace. ASD was also found to be associated with other illnesses, such as epilepsy and behavioural problems.
- ASD was found to have effects on the caregivers and teachers. Families experienced severe stress which was influenced by a poor prognosis, impaired communication, modelling of self-care, developmental milestones, caring for an older child who acted like an infant, denial, disbelief, concern about the future, and severe isolation as a result of the caring burden. Teachers experienced frustration related to teaching ASD children.
- Families experienced a lack of social support which was influenced by a lack of school transport, lack of money due to unemployment, lack of spouse support as a result of blaming each other, and a knowledge deficit with regard to ASD. ASD children are rejected by the community due to ignorance about the condition. ASD children are subjected to sexual abuse, stigmatisation, being placed on long waiting lists for admission to schools and having to wait for long times at the hospital during follow-up visits.
- Existing support systems for ASD children and their families from the government include care and dependency grants and disability grants, feeding schemes at the special schools, free health services, and free education in some special schools.
- Teachers in Limpopo Province experienced a lack of formal and informal support in the special schools. Lack of formal support was influenced by lack of autism schools, material and human resources, inadequate learning

space, substandard infrastructure, poor infrastructural conditions, inadequate learner-teacher ratios, overcrowding and limited on-the-job training, whilst informal support was influenced by lack of parental involvement.

- Gauteng Province teachers experienced adequate formal and informal support in the special schools which were influenced by adequate material and human resources, many workshops in respect of ASD and a good communication system between teachers and parents. However, teachers from both provinces lacked support with regard to the formal curriculum for ASD children and school management support.

- Families in Limpopo Province demonstrated knowledge deficits with regard to ASD as evidenced by their not knowing what ASD and its causes are, and limited knowledge about the management of behavioural problems. However, knowledge on how the child should take medication was adequate as influenced by health education given by the nurses. Whilst families in Gauteng Province displayed somewhat limited knowledge regarding ASD they were assisted by parental training at the special schools.

- Teachers in Limpopo Province maintained that their limited knowledge regarding teaching a child with ASD was influenced by a lack of training, whilst in Gauteng Province a considerable amount of training is provided to the teachers, and, therefore, they had adequate knowledge.

- Teachers in Limpopo Province experienced a lack of collaboration with parents and health care practitioners as influenced by the shortage of health care practitioners at the special schools and poor parental involvement. An individual plan is developed by the teachers only instead of by all stakeholders which include parents, health care practitioners and senior management. On the other hand, in Gauteng Province, teachers, health care practitioners, parents and senior management work together as a team and together they develop individual plans for these children.

- Families used their acceptance of the child's diagnosis, religion, a supportive environment, and a dual role as parent and teacher of ASD children as coping strategy, whilst teachers described the dual role, passion, patience, and love of the children, and their background and professional experience as their main coping strategies.
- Behavioural problems of the ASD child were managed by families through the installation of a fence, keeping the child under lock and key, and community education about the behaviour of ASD children. On the other hand, teachers give the child activities to keep him or her busy, allowing the child to sit next to her as the teacher or in front, giving a favourite toy, and during break time two teachers and support staff look after the learners outside.
- Teachers from both provinces utilised various teaching methods to teach ASD children to influence their behaviour and speech. These include Makaton, Applied Behavioural Analysis (ABA), Sunrise, Augmentative and Alternative Communication (ACC), TEACCH methods, lip-reading, individual teaching, trial and error, and visual aids sign language (the tiny hands).
- Families portrayed a variety of social support needs that should be met to meet the needs, concerns, and priorities of the ASD child and their families. This includes **emotional support** by health care professionals to cope with the stress caused by having a child with ASD; **informal support** including compassionate support from a partner, friends, families, siblings, community, and significant others to gain support; **Informational support**, including parental training and community awareness for access to quality information, the establishment of a support group for sharing of experiences between parents with ASD children. Continuous assessment of the ASD child by a specialist and to have more specialists in ASD for diagnosis and proper management of the child is required; Instrumental **support** including autism schools, sheltered employment, and school transport for ASD children for a better future for the children; **Appraisal**

support, such as getting feedback, and a home visit by nurses for needs assessments.

- Teachers in Limpopo Province expressed the need for adequate human and material learning and teaching resources, physical infrastructure, a manageable number of learners, autism schools and autism centres with a hostel, parental involvement, and practical demonstrations of behavioural management during the workshop for quality education for ASD children. Both teachers from Limpopo and Gauteng provinces expressed the need for a formal curriculum to meet the needs of ASD learners, and senior management support for emotional and debriefing support.
- The results indicated that both the primary caregivers and teachers have responsibilities for the development of the ASD children, these include the educationally, socially and physical needs. Both participants described in detailed the support needs for families and ASD children based on the lived experiences, which contributed to the development of the social support model.

4.13 INTEGRATION OF WATSON'S THEORY OF CARING WITH THE FINDINGS

Watson's theory of human caring (2008) was initiated to explore the experiences of families with ASD children by means of semi-structured interviews. The ten curative factors inherent in the theory provide a guide to the implementation of the theory as illustrated in Table 4.5. Watson states that in a holistic approach to caring for a human, there are mind, body and spirit sub-dimensions.

During the face-to-face interviews, the families and teachers expressed positive and negative feelings in regard to caring for, and teaching a child with ASD. Various characteristics of a child with ASD were described by the families as well as the teachers (see Table 4.7). Participants also described their experiences with regard to the effects and challenges of caring for, and teaching a child with ASD. All of these positive and negative experiences of the participants are linked to one of the curative factors which are expressed in positive and negative feelings and experiences.

The second curative factor is the systematic use of scientific problem-solving methods for decision-making. It is linked to the methods used by participants to manage the behavioural problems of their ASD children. Because behavioral problems were found to be one of the challenge factors affecting both groups of participants, the participants formulated a plan to manage the behaviour. The third factor is the formation of a humanistic-altruistic system of values. This factor is linked to the coping strategies utilised by participants to cope with their caring or teaching role. This factor influence the issue of love and kindness to others. Thus, participants indicated that their passion, patience, acceptance, and love for the children motivated them to cope with these children.

Participants maintained that their religion gives them the ability to go on with life. These feelings are linked to the instillation of faith and hope which is the fourth factor. Furthermore, families invite a miracle to take place with their children, particularly in the case of those children who are unable to speak by placing the child in front of the television until such time as his or her speech develops. This action could be linked to the allowance of existential-phenomenological forces.

Teachers in Gauteng Province develop a helping, trust relationship with the families of learners with ASD by creating a good communication system. In providing services to meet the basic needs of the ASD children and their families the government is assisting them in the gratification of their human needs.

Those parents who performed dual roles established a support group, providing mentoring and coaching to other parents with ASD children. ASD children in Gauteng Province assisted each other through peer group support systems (wheelchair pushers and buddy-buddy systems), as a response to their own and other families' needs and a feelings factor. Parents and teachers should be trained and community awareness should be introduced because there is a lack of knowledge about ASD. These actions are associated with the promotion of interpersonal teaching and learning for families. Lastly, families of ASD children must be provided with a suitable, conducive environment that is supportive. The implementation of Watson’s theory (2008) of human caring in this study is displayed in Table 4.7 below.

Table 4.7 Integration of Watson's theory (2008) of caring with the results

Jean Watson's 10 Curative factors	Families of ASD children findings	Teachers of ASD children findings
I. Expression of positive and negative feelings and experiences	**Characteristics of Child with ASD:** - Impaired speech, follows the instructions, hyperactive, poor interaction, plays alone/with favourite toys, eats too much, eats unusual objects, smells food before eating, does not want surprises, anxious, angry and throws tantrums, hums a tune, fighting, hits and kicks others destroys property, escapes from home, abrupt change in speech, speaks only English, delayed milestones, has epilepsy **Effect of ASD on Families:** - severe stress, worry about the future, models self-care, caring for an older child who acts like an infant, long waiting times at the hospital, denial, disbelief, separation, severe isolation, helplessness, gives up on treatment, poor prognosis, poverty (not working) dependent on social grant **Challenges** - Lack of money, Unemployed - Rejection, stigmatization - Lack of school transport, Constant care, Severe isolation	**Characteristics of learners with ASD:** - Disturbs the class, must be taught through repetition, routine, communication behaviour problems, echolalia, poor eye contact, staring at the roof for the whole day, not used to flushing of the toilet, does not like noise, blocks ears with fingers, self-injury, throw themselves on the ground, scratch themselves with their nails, bump into objects, bullying, breaking of windows, **Effects of ASD on teachers** - Frustration **Challenges** - Lack of teaching material and human resources, lack of health care practitioners, learner-teacher ratio inadequate, overcrowding, parents do not attend meetings, no formal curriculum for ASD, lack of autism schools in Limpopo Province, - Rented infrastructure - Traveled distance by children - Inappropriate sexual behaviour - Poor management support

	- Lack of support from the church, long waiting lists for admission	
II. The systematic use of scientific problem-solving methods for decision-making	**Methods to manage behavioural problems at home** - Installation of a fence and keeps the child under lock and key - Community education about the behaviour - Re-establishment of support groups	**Methods to manage behavioural problems at school** - Give a favourite toy - Assign an activity - Child can sit next to the teacher - A child sits in front and, or next to the teachers - During break time two educators and support staff are outside to look after the learners, - Demonstrate practical life skills,
III. Formation of humanistic-altruistic system of values	**Coping strategies for families** - Acceptance of the child - Religion - Supportive environment - Dual role	**Coping strategies for teachers** - Dual role - Passionate, patient, and love of children - Background and professional experience
IV. Instillation of faith and hope	**Families instill faith and hope through:** - Religion - Attending church even though other church members misunderstood the condition	**Teachers instill faith and hope through:** - Religion
V. The allowance of existential-phenomenological forces	**Allowing miracle to take place** - Families had denial and disbelief - Families believed that it is God's will - Gradually families accept what God gave them. - ASD Children with a lack of speech developed speech later after exposure to television.	**Allowing miracles to take place** - ASD children with lack of speech developed limited speech after speech therapy

VI.	Development of a helping trust relationship	**Developing helping trust relationship for families** - Partner support as parents were blaming each other - Community support	**Developing helping trust relationship for teachers** - Good communication between teachers and families
VII.	Assist with the gratification of human needs	**Services provided by the government to meet ASD children's needs at home:** - Care dependency grant (Social support) - Free medical services (Physical and emotional support)	**Services provided by the government to meet ASD children's needs at school:** - Feeding schemes at schools (Physical support) - Free education (Education support) - Health care practitioners in special schools
VIII.	Cultivation of sensitivity to self and others	**Responsive to self and other family's needs and feelings:** - Parents with dual roles established a support group, provide mentoring and coaching to other parents with ASD. - Teach community regarding ASD	**Responsive to ASD children's needs and feelings** - Special schools in Gauteng Province do fund raising - ASD children in Gauteng Province assist each other through peer group support systems (wheelchair pushers and buddy-buddy systems)
IX.	Promotion of interpersonal teaching and learning	**Promotion of interpersonal teaching and learning for families** - Families lack knowledge regarding ASD - There is a need for parent training and community awareness - Parents involvement in teaching - Access to quality information - Management of disruptive behaviour	**Promotion of interpersonal teaching and learning for teachers** - Teachers utilise various teaching methods to teach ASD child: Makaton, Applied Behavioural Analysis (ABA), Sunrise, Augmentative and Alternative Communication (ACC), TEACCH methods, lip-reading, individual teaching, trial-and-error, visual aids, sign language: the tiny hands method - Formal curriculum for ASD children must be developed - Inadequate knowledge for teachers in Limpopo Province - There is a need for job training

		- Benchmarking with other special schools - Other teachers attended conferences on ASD - Reading about ASD
X. Provision of a suitable conducive environment	**Support needs for families** - School transport - Supportive environment - Support from partner, friends, families, siblings, community and significant others - School support - Support groups - Government support - Sheltered employment for ASD children - Continuous assessment of the ASD child by specialist - Specialists in ASD	**Support needs for teachers** - Adequate human and material teaching and learning resources in Limpopo Province - Physical infrastructure - Peer group support - A manageable number of learners - Autism schools and autism centres with a hostel - Senior management support - Emotional and debriefing support - Practical demonstrations during the workshop, - Specific diagnosis of the medical report

4.14 CONCLUSION

All of the participants' results and discussions relating to the care and support of families with ASD children were identified with the aim of developing a support model to facilitate the process whereby families of children with ASD will assume responsibility for meeting their own emotional, physical, spiritual, and academic support needs once the identified deficits are addressed.

In chapter 5, a concept analysis is explained by means of concept development, classification and definition. A review of the literature contributes to the definitions of the main concepts by linking them to the survey list (Dickoff et al, 1968) to show its relevance to social support.

CHAPTER 5

CONCEPT ANALYSIS

5.1 INTRODUCTION

The preceding chapter presented and discussed the findings of the study. This chapter discusses the analysis and classification of concepts relevenrt for the development of the a model.

Walker and Avant (2011) define concept analysis as a process of examining the basic elements of a concept. The purpose of concept analysis is to distinguish a concept from other concepts that are similar to it. It also enables the researcher to distinguish the similarities and differences between concepts. Furthermore, it helps clarify those over-used or vague concepts that are prevalent in nursing practice so that everyone who subsequently uses the term will be speaking of the same thing. Walker and Avant (2011) identified eight steps in concept analysis namely:

Select a concept

1. Determine the aims or purposes of analysis
2. Identify all users of the concept that you can discover
3. Determine the defining attributes
4. Identify a model case
5. Identify borderline, related, contrary invented and illegitimate cases
6. Identify antecedents and consequences
7. Define empirical referents

5.2 STEP 1: SELECT A CONCEPT

The first step in concept analysis include concept selection. The concept to be chosen should be the one that the researcher is interested, associated with the research study, important and useful for development of the model (Walker and Avant (2011). In this study the findings in Chapter 4 show that there is a lack of social support for families as well as teachers of children with ASD at home, community, and school. The findings revealed that families of children with ASD experienced the following: severe stress as a result of anxiety about the future of their children, namely denial, disbelief, separation, severe isolation, modelling self-care, the long waiting times at the hospital, a lack of money, unemployment, rejection, stigmatisation, the lack of school transport and constant care. In addition, teachers more specifically in Limpopo Province experienced a lack of teaching material and human resources, a lack of health care practitioners, inadequate learner-teacher ratio, overcrowding of learners in classrooms, lack of parent involvement, the lack of a formal curriculum for ASD learners, the lack of autism schools in Limpopo Province, inadequate infrastructure, and poor school management support.

Therefore, the study participants often spoke of the following kinds of support as the desired outcome:

- Emotional support (support from partner, friends, families, siblings, community, and significant others, religion, support groups, management support, counselling, debriefing, love)
- Instrumental support (human and material resources at the special schools, school transport, infrastructure, autism schools, no fee school, subsidized hostel accommodation)
- Informational support (community awareness, parent training, teachers' workshops, specialists in ASD, benchmarking, curriculum, good communication) and
- Appraisal support (needs identification, monitoring and evaluation of support services, sheltered workshops).

The concept selected for model development in this study is **the lack of social support**. The term 'social support' is often used interchangeably with terms such as 'social networks' and 'social interaction'. The concept is relevant as it reflects the topic and area of great interest in this study. Support for the families of children with ASD is the most critical concept as it influences the caring of, and teaching of ASD children by the families and teachers. Besides, the model to be developed also accommodates the **provision of social support**.

Utilising the concept analysis method described by Walker and Avant (2011), the meaning of the provision of social support is explained and its attributes and characteristics are examined. Sample cases from research and practice with families and teachers of ASD children illustrate the concept further and help to develop an operational definition.

5.2.1 Definition of concepts

5.2.1.1 Definition of social support

Social support is an interpersonal transaction involving one or more of the following: **emotional support** (liking, love, and empathy), **instrumental aid, information, and appraisal support** (information relevant for self-evaluation) (Lin, Dean & Ensel, 2013). Kahn and Antonuci (1980) view social support as transactional, potentially involving both giving and receiving. It consists of continuing social aggregates that provide individuals with opportunities for feedback about themselves and validation of the expectations of others. These supportive others are said to provide information, cognitive guidance, tangible resources, aid, and emotional sustenance in times of need. Nestmann and Hurrelmann (2012) define it as giving or exchanging something, be it aid, affect, or affirmation. The entity could be tangible, such as the act of lending money or intangible, such as the act of showing love or affirmation.

Cobb (1976 cited in Heaney & Israel, 2008) and Lin, et al., (2013) define social support as information leading the subject to believe that he or she is cared for, loved, esteemed, and valued and is a member of a network of communication and mutual obligations. It appears that social support can protect people in crises from a wide variety of pathological states. Furthermore, social support may reduce the amount of medication required, accelerate recovery, and facilitate compliance with prescribed medical regimens. Three additional forms of social support are instrumental support (counselling), active support (mothering) and material support.

Social support is a term that has been widely used to refer to the mechanisms by means of which interpersonal relationships presumably protect people from the deleterious effects of stress. It is regarded as a personal experience rather than as a set of objectives, circumstance or even assets of interaction. It is the kind of behaviour that helps the person to cope with difficulties and develop new competencies (Lin, Dean, & Ensel, 2013). According to (Boujut, Dean, Grouselle, & Cappe, 2016) social support refers to all the efforts made by the subject to find sympathy or help from others.

One commonality in the definitions is that social support is considered to be a multidimensional construct. These aspects include emotional support, esteem support, belonging support, network support, appraisal support, tangible support, and instrumental support.

The term social support has been defined and measured in numerous ways. According to a seminal work by House (1981 cited in Heaney & Israel, 2008), social support is the functional content of relationships that can be categorised into **four broad types** of supportive behaviour or acts:

- **Emotional support** involves the provision of empathy, love, trust, and caring.
- **Instrumental support** involves the provision of tangible aid and services that directly assist a person in need.
- **Informational support** is the provision of advice, suggestions, and information that a person can use to address problems.
- **Appraisal support** involves the provision of information that is useful for self-evaluation purposes, in other words, constructive feedback and affirmation. Social support has been categorised into **informal and formal support** by Roffeei et al., (2015). Informal support is described as those kinds of support that come from a network that may include family, friends, and parents of other children with disabilities. **Informal support** plays an important role in helping caregivers reduce the feelings of isolation and helplessness often associated with raising a child with a disability. **Formal support** is provided through an organisation or agency, such as medical professionals, school staff, and day-care providers.

Social support is always intended (by the provider of the support) to be helpful, thus distinguishing it from intentional negative interactions. Attempts have been made to identify **sources of support which include:** the family doctor or paediatrician, professional helpers, a spouse, friends, relatives, school or day care centre parents, early intervention, other parents, a spouse’s parents, professional agencies, a spouse’s relatives, a spouse’s friends, children, parent groups, co-workers, social groups or clubs and a church minister (Ekas, Lickenbrock, & Whitman, 2010).

Social support in this study is the on-going care and support of families with ASD children to minimise the negative effects of having a child with ASD and identified emotional, spiritual, social, physical informational and instrumental needs through interactions with professional practitioners, teachers, and significant others.

Provision of social support in this study refers to an on-going provision of emotional, informational, instrumental and appraisal support services to families of children with ASD to address complex needs and assist families in building their capacity to care for and protect their ASD children through adequate healthcare provision. It requires the creation of a supportive environment at special schools for ASD children and their families to facilitate participation in their healthcare.

5.2.1.2. Definition of provision

According to *Collins English Dictionary* (2018), and *Collins English Thesaurus* (2018) the word ‘provision’ means a clause in a legal instrument, a law, providing for a particular matter or stipulation; supplying of something, especially of food or other necessities; the arrangement or preparation beforehand, as for the doing of something, the meeting of needs, the supplying of means; something provided; a measure or other means for meeting a need; a supply or stock of something provided.

In this study, the provision refers to the action of supplying support services to families of children with ASD in the Gauteng and Limpopo provinces of South Africa.

5.3 STEP 2: DETERMINE THE AIMS OR PURPOSES OF ANALYSIS

The results of this analysis should enhance the understanding of the concept and its theoretical and practical implications for nursing more broadly. It will clarify the meaning of the concepts in the model, develop operational definitions and add existing theory (Walker & Avant, 2011).

5.4 STEP 3: IDENTIFY THE USES OF THE CONCEPTS

The term “social support” has been used across health disciplines. Social support has been proposed by Ekas et al. (2010) as an important mediator of the relationship between optimism and psychological adjustment specifically because optimistic individuals appear to be able to establish greater social support resources and build more effective social networks in times of stress. Social support may be seen as the emotional, instrumental, and financial aid that is obtained from one's social network.

McIntyre and Brown, (2018) examined the utilisation and usefulness of social support for mothers with young children with ASD. Social support utilisation varies as a function of a different child, family, and service variables. Understanding these variables may help professionals guide families in gaining access to, and in using social support. Singh Ghosh, Nandi, (2017) points out that social support is used to assess subjective burdens, depression, and the moderating effect of social support in mothers of children with autism spectrum disorder in India. Ekas et al., (2010) used structural equation modelling to examine the relationship between multiple sources of social support (e.g., partner, family, and friends), optimism, and well-being among mothers of children with ASD. Social support was examined as a mediator and moderator of the optimism-maternal well-being relationship.

Ekas et al. (2010) defines social support as a vital function in parental coping and Coping in general. Positive coping strategies in families of children with ASD are often associated with the presence of adequate social support. It has been identified as a critical factor that reduces the negative psychological effects of raising a child with ASD as well as other disabilities. It can provide or withhold desired resources or approval.

5.5 STEP 4: DETERMINING THE DEFINING ATTRIBUTES OF SOCIAL SUPPORT

Defining attributes are critical characteristics of the concepts that appear over and over again (Walker & Avant, 2011). Determining the defining attributes of a concept is the heart of concept analysis. Six key defining attributes have already been identified for the concept of social support: emotional, informational, instrumental and appraisal, formal and informal support. The defining and related attributes for social support are summarised in Figure 5.1.

Defining attributes of social support

- Emotional support
- Informational support
- Instrumental support
- Appraisal support
- Formal support
- Informal support

Related attributes of social support

- Social networks
- Social relationship
- Spousal/partner support
- Friends support
- Family support
- Siblings support
- Peer support
- Support groups
- Interactional exchange
- Planning
- Supplying
- Equipping

Figure 5.1: Defining and related attributes for social support

5.5.1 Definitions and contextual meaning for essential attributes of social support

Emotional support	It involves expressions of empathy, love, trust, and caring (Feeney & Collins, 2015). In this study, emotional support refers to giving support to families of children with ASD during a stressful period by professional practitioners and significant others. These include family therapy, genetic counselling, individual and group therapy, psychosocial support, support groups, spousal and spiritual support.
Instrumental support	Involves the provision of tangible aid and services that directly assist a person in need, such as money, food, shelter, or other things that the person needs to live (Feeney & Collins, 2015). In this study instrumental support refers to the provision of financial assistance, material goods and other services that are tangible to families with ASD children in the Gauteng and Limpopo provinces.

Informational support	Involves the giving of advice, suggestions, and information that a person can use to address problems (Ko, Wang & Xu, 2013). In this study, informational support refers to the provision of advice, guidance, suggestions, training, awareness or useful information regarding ASD to families with ASD children in the Gauteng and Limpopo provinces.
Appraisal support	It involves information that is useful for self-evaluation (Feeney & Collins, 2015). In this study, appraisal support refers to the provision of information that is useful for families with ASD children and self-evaluation in the Gauteng and Limpopo provinces.
informal support	This means that the support comes from a network that may include family, friends, and other parents (Shiba, Kondo, & Kondo, 2016). In this study, informal support includes specific support services provided by non-professionals, such as family, neighbours, society, siblings, friends, community leaders and the church. Informal family support services include services, such as recreational facilities and services, socialisation, spousal support, spiritual support, support groups, parent-to-parent, peer-to-peer, and family-to-family support.
Formal support	This refers to support provided through an organisation or agency, such as medical professionals, school staff, and day-care providers (Shiba et al., 2016). In this study, formal support refers to specific services provided to the families with ASD children by professional practitioners and teachers of ASD children in the special schools of the Gauteng and Limpopo provinces of SA. Formal support includes services, such as medical care, basic education, counselling vocational skills,

resources, referral, parenting and education classes or workshops, community awareness, home visiting, child care, ASD specific information, early childhood mental health, financial assistance.

5.6 STEP 5: IDENTIFY MODEL CASE FOR THE PROVISION OF SOCIAL SUPPORT

A model case is an example of the use of the concept that demonstrates all the defining attributes of social support (Walker & Avant, 2011). The model case is one that is absolutely an instance of the concept. The following model case example has been constructed by the researcher:

Vusi, a 10-year-old boy was referred to a special school from an ordinary school due to impaired speech, repetitive behaviour and poor social skills which affected his academic progress.

Before admission to the special school, sufficient information was gathered by the professional nurse as the **facilitator** for admission and relevant tests were done by the other health care professionals. The child's overall developmental profile was considered, and the child's case was discussed at the Multi-Disciplinary Team (MDT) and a decision as to whether the child would meet the criteria for a diagnosis of autism was reached**. Informational support** was provided to the parents by allowing them to discuss and process information with the psychiatrist and psychologist. Furthermore, current and accurate information regarding ASD was provided. **Emotional support** was available to all family members as they have different reactions to having a child with ASD. Vusi was placed on the waiting list for six months and then admitted the following year.

For **appraisal support** the parents were interviewed about their **needs, priorities** and the environment. The professional nurse had to sit together with, and **collaborate** with the family in identifying their needs. During this session, the parents and professional nurse had time to discuss important issues concerning the child and family. The objective was to set a standard for future interactions between the families, professional nurses, and teachers by opening the door for communication, trust, collaboration, and possibly eliminating frustration related to their concerns.

A family tree was used to assess the make-up of the family and the wider support network, to provide an opportunity to explore the views of who is currently providing informal support or could offer informal support in the future if necessary. Vusi's grandparents were there to provide extended family support by assisting Vusi's parents with the burden of caring. During school holidays Vusi visits his grandparents. When Vusi's mother is busy with household chores, goes shopping or attends social functions his brother or sister provide sibling support by remaining and playing with him. Vusi's father provides spousal support to his wife with regard to the management of the child's behavioural problems by accompanying and taking Vusi to the bus stop every day in the morning and after school. The school bus is available for all ASD children free of charge. Vusi's mother receives a Care Dependency Grant every month which forms part of the **instrumental support** from the government.

Vusi's mother also has informal support from a friend, whom she talks to about problems and can count on if things go wrong. Her friend has also encouraged her to commit herself to religious devotion for spiritual support as it can reduce family stress, and personal and emotional effects.

Appropriate formal support strategies and services that meet family needs were identified and provided through the **interactional exchange process** between the families, teachers, and health practitioners. The services include genetic counselling, emotional support, family therapy, family education, workshops, and training. These help family members to gain **confidence** and **motivation** in supporting the development of the ASD child. Training programmes are aimed at dealing with a topic, such as the management of the ASD child, the ASD child's functional life skills, play and leisure skills or social communication.

Vusi's parents were encouraged to join parents' support groups at the schools for **formal support** so that families with ASD learners can share their common experiences.

Vusi's **needs**, strengths, and weaknesses were identified by both parents and the teacher. Vusi was involved in a wide range of formal and informal activities, including speech therapy, gardening, cooking, swimming, yoga, exercises, and fitness, walking, jogging, running, hiking, weight-lifting, health and wellness, bowling and community outings. These activities help Vusi to develop problem-solving skills, learn responsibility, and increase self-esteem, all while having fun and making friends which forms part of the **appraisal support**. Vusi was referred to the speech pathologist to assist him with sign language or augmentative devices. A peer support system as a form of **informal support** is encouraged at school by identifying peers with strong social skills and pairing them with Vusi so that he would have good models for social interaction.

The needs, concerns, and priorities of ASD teachers were assessed by the management of the special school. Various support services were provided to the ASD teachers, such as **informational support** in the form of continuous professional development (CPD) which includes training courses and workshops, benchmarking, studying for a qualification, online courses, and encourages personal reading. **Instrumental support** was available as each ASD class has one teacher and teacher assistant and adequate teaching materials. The total number of ASD learners in each class is between six and eight learners to a teacher. **Emotional support** services are provided to the teachers by the health care professionals every quarter or when necessary to avoid frustration caused by teaching ASD children.

Vusi's parents support the teachers by participating in the academic activities of their child including the development of individual teaching plans and attending parent meetings. There is a good communication channel between the teachers and parents through WhatsApp messages, phone calls, and message books. For **appraisal support,** teachers discuss Vusi's learning progress with the parents at the end of each term or when necessary. ASD teachers also receive **informal support** from colleagues during breaks when supervising ASD learners' movements in the school yard. Teachers and ASD children pray every morning for spiritual support.

The school organises autism awareness day on 2nd April each year for **informational support** to the community regarding ASD. This day provides an opportunity for people to understand ASD and its impact on the children and the family.

The management of the school, mental health care professionals, and teachers together with Vusi's family **reviewed** whether planned support services goals were achieved. Alternative support strategies were considered if goals were not met.

5.7 STEP 6: IDENTIFY BORDERLINE AND CONTRARY CASES FOR THE PROVISION OF SOCIAL SUPPORT

5.7.1 Identify a borderline case

Borderline cases are those examples or instances that contain most of the defining attributes of social support but not all of them (Walker & Avant, 2011). These cases are inconsistent in some way from social support and they help to clarify thinking about the defining attributes of social support. Below is an example of a borderline case:
Jacob, 14 years old from Pretoria diagnosed with ASD, attends one of the autism special schools in Gauteng Province. His school has adequate human and material resources for ASD learners which form a part of the **instrumental support**. His peers are very supportive of the school. Teachers and health care practitioners have specialised skills in teaching and caring for ASD learners. They identify training needs for families through an **interactional exchange process**. They conduct training programmes and awareness for all parents with ASD children for **informational support** regarding ASD which forms part of **formal support**. During parental training, the health care professionals encourage the parents to identify and support the potential of their ASD children for **appraisal support**.

However, the home environment is unsupportive as his father, siblings, and grandparents do not relate to him very well. The neighbours gossip about his condition. His mother is the only one who cares about him, but she is not working any longer due to the burden of care, and she is unable to attend community functions as nobody is willing to take care of Jacob when she is not there. She feels very isolated and emotionally distressed as a result of the **lack of emotional and informal support** from her spouse, other children, grandparents and the community. She is unable to urge for spiritual support as Jacob is so disruptive at church.

5.7.2 Identify a contrary case

Contrary cases are not the examples or instances of the concept (Walker & Avant, 2011). The following is an instance of a contrary case:

Mary and John are a married couple residing in a rural area in Limpopo Province. Mary is unemployed while John is working for a construction company. They were blessed with a son (Thabo) eight years ago. Thabo’s developmental milestones were delayed, particularly his speech. He uses nonverbal communication and sounds to communicate with his parents. Thabo plays alone as he is having difficulty in establishing a relationship with other children, has temper tantrums and is hyperactive.

Thabo was taken to the clinic by his mother when he was four years old because of his delayed speech. He was referred to the hospital where he was diagnosed with autism.

The parents were in denial, feeling guilty and angry at each other and could not believe their son’s diagnosis. John blamed Mary for the condition of the child. John could not assist in caring for the child. Thus, there was a lack of her spouse’s support. He requested his manager to transfer him to the Eastern Cape Province so that he could be away from the situation.

Thabo’s parents were never provided with information regarding autism at the hospital or genetic counselling or emotional support. Mary did not know how to manage the behaviour of the child (hyperactivity, temper tantrums, lack of speech) at home. Thabo's impaired speech was never attended to at the hospital.

The neighbours laughed at the child’s behaviour because they lacked awareness with regard to autism and extended family members were also not involved in caring for the child. Spiritual support was not provided as Mary stopped attending church due to the child’s behaviour. Mary was struggling financially as the father did not send her money after he went to the Eastern Cape. She was isolated as she was unable to attend social functions like weddings or funerals as there was no one to take care of the child while she was away. In other words, Mary lacked informal support from her spouse, neighbours, church and the extended family.

Thabo was roaming around the village not attending school as Mary lacked knowledge about schools for special needs children. Mary was worried about her son’s future. However, one day someone advised her to take the child to the special school which was 70 km away from home.

The special school’s physical environment had inadequate learning space, substandard infrastructure, poor infrastructural conditions, a lack of teaching materials and only one health care practitioner who was a nurse. There was a lack of resources for the development of communication, social and self-help skills for children with autism. Teachers had insufficient knowledge about teaching children with autism. Classes were overcrowded with no teacher assistants. There was poor communication between teachers and parents.

5.8 STEP 7: IDENTIFY ANTECEDENTS AND CONSEQUENCES FOR THE PROVISION OF SOCIAL SUPPORT

Walker and Avant (2011) define antecedents as the events or incidents that must arise or be in place before a concept is put to use. Consequences are those events or incidents that occur as a result of the occurrence of the concept, in other words, the outcome of the concept.

5.8.1 Antecedents for the provision of social support

Certain antecedents must be in place to provide social support to families with ASD children. These are listed below.

Human resources are required. These include **professional nurses** as the facilitators of the model, **teachers** and **other professional specialists** for training, diagnosing, caring, treatment and rehabilitation of the ASD child and provision of support to the families.

An interactional exchange process between the families, teachers and other professional specialists for needs identification, planning, delivery and evaluation of the support services is required.

Fiscal, human and material resources, such as appropriated funds, special grants, donations; and types of equipment are required.

Facilities, such as **special schools** with adequate **resources** for teaching, treating and supporting ASD children and their families should be put in place.

Legal, political and professional frameworks should guide the provision of a social support model.

Other antecedents required to support the model include **time** invested by professional nurses, teachers, and other professional specialists.

The involvement of collaborators, including community, state and non-governmental organisations, such as Autism South Africa is called for.

A **stable social environment** is required that enables sustained engagement with people and social networks to establish positive and reliable relationships. Social networks include support from a spouse, siblings, extended families, friends, other parents, and the broader community.

Antecedents for the provision of social support with examples are summarised below:

Antecedents	**Examples**
Facilitator	Professional nurse
Teaching personnel	Teachers for ASD children
Professional specialist support personnel	Guidance and counselling specialists and psychologists for the provision of marital, genetic and emotional counselling, Therapists: occupational, speech, and language audiologists, Physiotherapists for reinforcement of vocational skills and to assess and diagnose emerging communication and feeding disorders. Social workers for social problems, Nursing personnel; child and youth care workers.
Families with ASD children	Parents, siblings, grandparents, foster parents and extended family members.
Interactional exchange process	Between the families, teachers and professional specialists
Facilities	Special schools with adequate resources
Legal, political and professional framework	Policies to guide the provision of support to families with ASD children
Fiscal, human and material resources	Appropriated funds, special grants, donations; professional practitioners, teachers, pastors, and equipment.
Involvement of collaborators	

	Community, state and Autism SA
Social environment	Spouse, siblings, extended families, friends, other parents, church and broader community social networks
Needs identification	Identify and address emerging needs, worries and concerns
The delivery and evaluation plan	For monitoring and evaluation of support services.

5.8.2 Consequences of the provision of social support

Consequences are the outcomes of the provision of social support. Possible consequences of the provision of social support may include **reducing parental stress** and psychological distress in families of children with ASD (Zaidman-Zait, et al., 2018). Families may report a better adjustment to having a child with an ASD due to **increased caring practices**, **knowledge and skills**. Parents will have a positive perception of their ASD children (McIntyre & Brown, 2018). The receipt of social support to an individual may allow that individual to feel better about himself or herself, have **confidence and motivation**. For ASD children, one would expect that being supported by parents, other family members, friends and teachers will allow the child to develop optimally. A well-supported ASD child would be much more likely to be able to successfully confront a stressful event than an ASD child without support, and this support would lead to reductions in caregiver burdens.

Mothers of children with ASD who perceive receiving higher levels of emotional support will report lower levels of depression-related somatic symptoms and fewer marital problems (Ekas et al., 2010). Social support may improve the health of the families and ASD children because it improves access to resources and material goods which form part of the instrumental support.

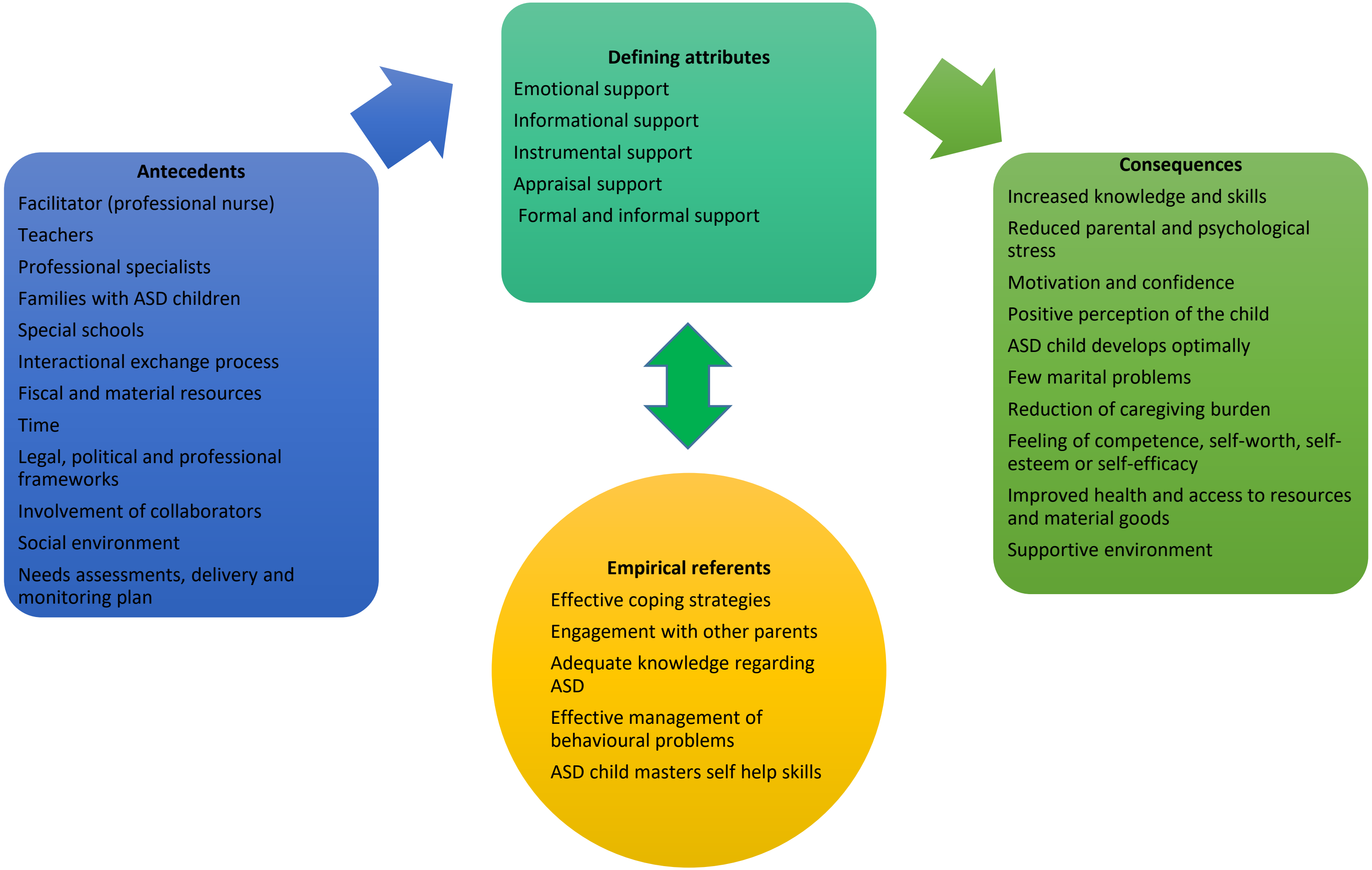
This support will provide a positive base or cushion, a general feeling that problems can be solved. Social support will provide an opportunity for the families for expression or ventilation of feelings and provision of advice. All these factors combined may provide a **supportive environment** to enable the families to approach, and successfully meet the challenges of life (Zaidman-Zait et al., 2018).

5.9 DEFINE EMPIRICAL REFERENTS FOR PROVISION OF SOCIAL SUPPORT

Walker and Avant (2011) define ‘empirical referents’ as classes or categories of actual phenomena that by their existence or presence demonstrate the occurrence of the concept itself in spoken or written language. Empirical referents for the provision of social support for families of children with ASD may include (a) effective coping strategies; (b) active participation in the process and problem-solving; (c) regular attendance at parents meetings at school; (d) goal-setting, engagement with other parents; (e) high-quality health care or improved wellbeing; and (f) effective skills in the management of behavioural problems (McIntyre & Brown, 2018).

Some of the empirical referents demonstrated by the model case that are observable and measurable include adequate knowledge regarding ASD among both teachers and families, attendance and participation in parental training and ASD awareness programmes, such as the use of communication books

As far as the ASD child is concerned it may include the mastering of self-help skills, reduced dependency on the caregiver, regular attendance of classes and good progress, and regular visits for follow-up with the psychiatrist. Figure 5.2 summarises the antecedents, defining attributes, empirical referents, and consequences for the provision of social support.



Antecedents

Facilitator (professional nurse)

Teachers

Professional specialists

Families with ASD children

Special schools

Interactional exchange process

Fiscal and material resources

Time

Legal, political and professional frameworks

Involvement of collaborators

Social environment

Needs assessments, delivery and monitoring plan

Defining attributes

Emotional support

Informational support

Instrumental support

Appraisal support

Formal and informal support

Empirical referents

Effective coping strategies

Engagement with other parents

Adequate knowledge regarding ASD

Effective management of behavioural problems

ASD child masters self help skills

Consequences

Increased knowledge and skills

Reduced parental and psychological stress

Motivation and confidence

Positive perception of the child

ASD child develops optimally

Few marital problems

Reduction of caregiving burden

Feeling of competence, self-worth, self-esteem or self-efficacy

Improved health and access to resources and material goods

Supportive environment

Figure 5.2. Antecedents, defining attributes, empirical referents, and consequences for the provision of social support.

5.10. CLASSIFICATION OF THE MAIN CONCEPTS FOR MODEL STRUCTURE

The main concepts of the study identified in Figure 5.3 were classified according to the survey list developed by Dickoff et al (1968) and defined according to a dictionary and subject definitions. The survey list highlights six activity aspects which include ways of looking at family support in the hope of revealing different features. All aspects of the activity list are important and should, thus, be taken into account to obtain a full exploration of the experiences of families of children with ASD in regard to care and support as perceived by the primary caregivers and teachers of children with ASD. Six questions relating to the activity aspects are used to survey activity and these include:
1) Context: - In what context is the activity performed?
2) Agent: Who or what performs the activity?
3) Recipient: Who or what is the recipient of the activity?
4) Procedure: What is the guiding procedure, technique or protocol of the activity?
5) Dynamics: What is the energy source for the activity?
6) Goal: What is the endpoint of the activity?
A brief explanation is given below of how the general concepts and the main concepts were used to answer the questions in the survey list of Dickhoff et al, (1968). Figure 5.2 illustrates the classification of the main concepts using the survey list of Dickoff et al (1968). The application of the survey list to this study is as follows:

5.10.1 Agents

Dickoff et al., (1968) refer to the agent as “who or what performs the activity”? In this study, the primary agents are the **professional nurses** working in the special schools of the Gauteng and Limpopo provinces who will be responsible for the facilitation of the social support model. The term ‘professional nurse’ refers to a person registered under section 31 of the Nursing Act, who supports, cares for, and treats a health care user to achieve or maintain health where this is not possible (*Nursing Act No 33 of 2005*). Special schools in South Africa have professional teaching personnel and professional specialist, non- teaching personnel and administrative support personnel. Professional specialists include professional nurses, social workers, psychologists and therapists appointed on a full-time or part-time basis depending on the programme offered at the school.

The professional specialist provide health and other therapeutic, psychological and social support that enhances learners’ capacity to achieve maximum benefit from learning experiences (Department of Basic Education, 2014). The professional nurse is the health care expert in the school and is in a unique position to meet the actual and potential needs of all learners with special needs. The professional nurse is a valuable resource on the multidisciplinary special education team (Cluskey & Schwend, 2015).

Teachers of ASD learners and other professional specialist support personnel are the secondary agents in this study as they work together with the professional nurses, interact with families, train and manage ASD children at the special schools. **Teachers of ASD children** are persons who teach ASD learners in the special schools of the Gauteng and Limpopo provinces (*Oxford English Dictionary,* 2012). These teachers have certificate or diploma in special education or inclusive education, their roles include communication with the parents regarding the progress of the children, facilitation of vocational skills, training and teaching of ASD children, development of curriculum for ASD children, attend workshops, in-services trainings, conferences regarding to ASD. Teachers spent more time with the ASD children in class than any other professional in the special school. Therefore it is important for teachers to be agents in order to participate in facilitation of the model.

All teachers of ASD children should possess at least a first degree or a diploma which includes training in special needs or inclusive education (Department of Basic Education, 2015).

Professional specialist support personnel refer to personnel that provide health and other therapeutic, psychological and social support that enhances ASD learners' capacity to achieve maximum benefit from learning experiences (Department of Basic Education, 2014). Depending on programmes offered at the special school, professional specialist support personnel should include, but not be limited to, guidance and counselling specialists, psychologists, sign language interpreters, and mobility instructors; therapists: occupational, speech, and language; audiologists, music teachers, and physiotherapists; social workers; nursing personnel; rehabilitation workers; child and youth care workers.

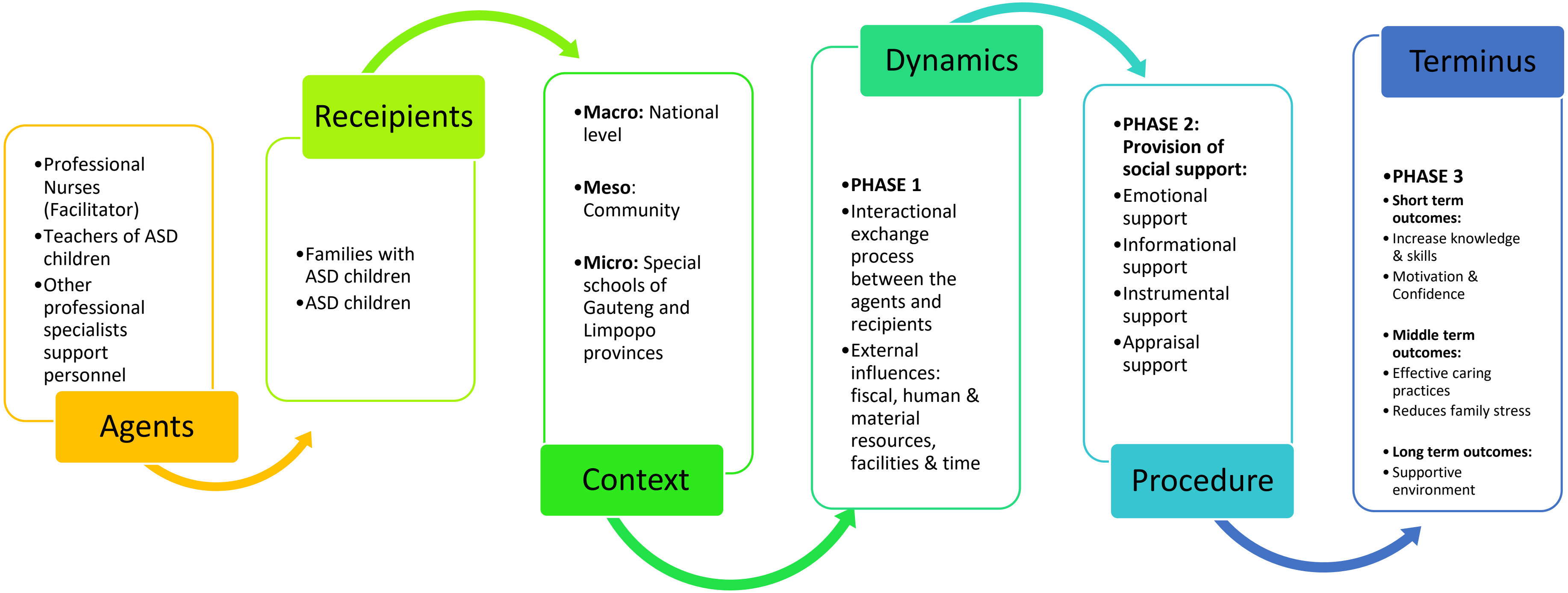


Figure 5.3: Classification of the main concepts using the survey list in Dickoff et al (1968)

5.10.2 Recipients

Dickhoff et al., (1968) refer to the recipient as “who or what is the recipient of the activity”. The primary recipients in this study are the **families with ASD children** attending special schools in the Gauteng and Limpopo provinces. Sharma (2013) defines ‘family’ as a unit of two or more persons united by marriage, blood, adoption, or consensual union, in general consisting of a single household, interacting and communicating with each other. Families of children with ASD were found to be unsupported and stressed owing to denial and guilt for being the parents of an ASD child, and anxious about the negative attitudes of the community, social isolation, and lack of educational support services. Therefore, these families need support facilitated by the professional nurse to manage the complex needs of having a child with ASD, and to build their capacity to care for, and protect their children. **ASD children** are also the primary recipients as they need support facilitated by the professional nurse, teachers and other professional specialists for optimum development. ASD children are defined in this study as those children in the Gauteng and Limpopo provinces with a serious developmental disorder that impairs their ability to communicate and interact.

5.10.3 Context

Dickhoff et al., (1968) refer to context as “in what context is the activity performed”? The study context is divided into three levels, that is a macro- level (**National**), meso-level (**community**) and micro-level (**special schools**). The activity is performed in the special schools which are responsible for catering to the needs of children with ASD in the Gauteng and Limpopo provinces of South Africa. A special school is a school equipped to deliver specialised educational programmes to learners requiring access to intensive educational and higher support either on a full- or part-time basis (Department of Education, 2014). The Department of Basic Education (2014) states that special schools must ensure that they support the families of ASD learners enrolled in their schools. Such support may include educational guidance, and psychological and emotional support. Special schools must advise parents on the best possible career opportunities available to learners. The support to be provided to the ASD children, their families and teachers will occur in these contexts.

5.10.4 Dynamics

Dickhoff et al., (1968) refers to context as “what is the energy source (motivation) of the activity”? To meet family support needs, the **process of interactional exchange** between the agents and recipients must occur. The interactional exchange process is a communication process that involves the exchange of information, feelings, and meanings employing verbal and non-verbal messages between two or more persons (*Oxford English Dictionary,* 2012). This involves working together with professional nurses, teachers of ASD children and other professional specialists in the provision of social support services to meet the family needs. This working relationship includes the exchange of information, sharing, and grouping together resources for the mutual benefit of families with ASD children.

This process will stimulate growth, development, or change within families with ASD children and special schools.

External influences, such as fiscal, material and human resources, facilities and time are the secondary dynamics for the provision of high-quality social support services in this study. Fiscal resources may include appropriated funds, special grants, and donations from the Department of Basic Education, business companies or non-governmental organisations (McCrawley, 2013). Adequate facilities, such as special schools, adult autism centres, health establishments, and community centres must be provided for the success of the social support model. Enough time must be invested by the agents in providing social support to families with ASD children. Dynamics is the first phase of the accomplishment of the social support model.

5.10.5 Procedure

According to Dickoff et al (1968) procedure refers to the path, steps or general pattern on the way to the accomplishment of a goal. To realize the goal for the provision of social support to the families with ASD children the model adopts three phases.

The procedure in this study involves the provision of social support which is the second phase of the model. The **provision of social support** focuses on the provision of emotional, informational, instrumental and appraisal support to the families of children with ASD.

Emotional support may include counselling, psychotherapy, spiritual support, spousal support, and the support of family and friends. **Informational support** may include family education and training, guidance, referrals, awareness, social media, and support groups. **Instrumental support** may include teaching and learning materials, recreational facilities, vocational skills, school transport, and social grants. **Appraisal support** may include needs identification, a service delivery plan, feedback, decision-making and problem-solving skills, monitoring and evaluation. The implementation of each support is described in detail in section 6.6.5.1.

5.10.6 Terminus

According to Dickhoff et al., (1968) the word ‘terminus’ encompasses the questions “What is the endpoint of the activity”? And what will the aim of developing a support model for families of children with ASD in the Gauteng and Limpopo provinces be? The model aims to facilitate a **supportive environment** to enhance a positive outcome for ASD children and their families. The terminus or the outcomes is the third phase of the social support model. The outcomes for each support service are as follows: **informational support** goals include changes in community attitudes regarding ASD and increased knowledge and skills which will lead to effective caring practices. **Emotional support** results in reduced parental and psychological stress, fewer marital problems, a reduction in the caregiving burden and a positive perception of the ASD child. I**nstrumental support** will improve health, access to resources and material goods and the ASD child will develop optimally. **Appraisal support** will provide motivation, confidence, and feelings of competence in the families. The ultimate goals of the model are grouped according to the short-, intermediate- and long-term benefits based on the McCrawley (2013) logic model format.

- **Short-term outcomes**

Short- term outcomes are changes in skills, attitude, and knowledge after the provision of social support services (McCrawley, 2013). **Increased knowledge and skills, motivation and confidence** are the short-term goals of the social support model for families with ASD children in the Gauteng and Limpopo provinces of South Africa. Families with ASD children will have increased knowledge regarding ASD through the provision of social support services. The benefits of social support services will motivate and help families gain confidence in their abilities to care and support the development of their ASD children.

Knowledge is the information a person has in specific content areas that is necessary for successful performance in a competency area (Guitelervez, 2014). **Skill** refers to the ability to use that information and apply it in a context (Neelon & Briley, 2011). It refers to the information and skills that the families with ASD children acquire through the provision of the social support process, including theoretical as well as practical understanding.

Confidence refers to one’s ability to use certain kinds of behaviour to achieve certain outcomes (Beaumont et al., 2015). Confidence could also be a result of interventions from health professionals and experiential learning. In this study, it refers to the families’ feelings of trust in their abilities, qualities, and judgement in caring for their

ASD children. Families' confidence increases through the experience of having mastered caring activities. Confidence is a positive belief that in the future families with ASD children can generally accomplish what they wish to do.

Motivation is defined as the energy that moves people forward towards performing a certain action; motivation strengthens the willingness of people to work, and in turn, it will increase their effectiveness and competence (Parashar, 2016). People who are motivated are more ambitious, innovative, creative, and are more persistent in achieving desired goals. Families with ASD children will have courage and confidence that initiates, guides, and maintains goal-oriented behaviour which will make them feel respected and accepted.

- **Intermediate-term outcomes**

Intermediate-term outcomes include changes that follow the short-term outcomes, such as changes in the practices and behaviour of the families of ASD children (McCrawley, 2013). **Effective caring practices, access to resources** and **reduced family stress** are the intermediate-term goals for a social support model for families with ASD children in the Gauteng and Limpopo provinces of South Africa. Increased knowledge and skills, confidence and motivation will result in the development of effective caring practices and reduced family stress among families with ASD children.

Effective caring practices refer in this study to families that are successful in enhancing ASD children's growth, the development of self-help skills, and the support and maintenance of a healthy lifestyle.

Families identify the appropriate actions to take when caring for their ASD children. Families use effective caring practices and strategies for healthy ASD child development. Family guidance of a professional informed decision, the use of effective caring strategies, parent education and training, ensures that these families can make significant strides toward regaining a sense of stability.

Access to resources

Access to resources is referred to in this study as consisting of a supply of materials, staff, facilities, money and other assets that can be obtained by families with ASD children to function effectively. Informational, emotional, and instrumental support provided to families with ASD children will encourage access to resources and the families will function optimally.

Reduced family stress

Families who perceive that they are receiving higher levels of social support will report lower levels of stress and will be able to cope, having access to resources and material goods, feelings of competence, self-esteem, or self-efficacy. Families with ASD children will be able to face and deal with responsibilities, problems, or difficulties, particularly successfully or calmly and adequately. Details regarding the classification of concepts are discussed in the next chapter.

- **Long term outcomes**

Long-term outcomes follow intermediate-term outcomes when changed behaviour result in changed conditions (McCrawley, 2013). In this study, the long-term goal is a **supportive environment**. Social support services (emotional, informational, instrumental and appraisal support) provided by professionals and non-professionals should facilitate the development of a calm, safe and supportive environment that is conducive to learning, coping, and managing ASD symptoms.

A supportive living setting refers to an environment in which families of children with ASD feel socially, emotionally, spiritually, and physically safe and valued. The environment indicates where the child and family live, their local community, their home, where the child plays and special schools. The supportive environment facilitates the development of self-confidence, self-efficacy, independence, enhancement of skills and coping with new kinds of behaviour towards the families. A calm supportive living environment offers the development of potential, independence, and competency while allowing the family to choose the best support services to support their needs. Families with ASD children feel more cared for when they are empowered to make their own choices about family support intervention strategies. A supportive environment should achieve the following:

- facilitate knowledge of the community and the families regarding the rights of ASD children
- ensure acceptance of ASD children and their families in the community
- avoid stigmatisation or rejection from the community
- facilitate the community in understanding that ASD children deserve the same dignity as all other children
- Facilitate knowledge of the community and recreational services for their children
- Provide access to quality information

- Ensure availability of autism schools with adequate resources to meet the educational needs of ASD learners

5.11. CONCLUSION

This chapter focuses on the process of concept analysis. Provision and social support are the main concepts identified for model development. The strategy employs the processes of analysis to extract the defining attribute of a concept. The concept analysis steps as highlighted by Walker and Avant (2011) were followed including selecting the concept, determining the aims of analysis, identifying all uses of the concept, determining the defining attributes of the concept, identifying the model case and contrary case, identifying antecedents and consequences, and determining empirical referents.

The main concepts of the study were classified according to the survey list developed by Dickoff et al. (1968). Six questions relating to the activity aspects were used to survey activity and these include agent, recipient, dynamics, context, procedure, and terminus. The next chapter describes the model for the provision of social support for families with ASD children in the special schools of the Gauteng and Limpopo provinces of SA.

CHAPTER 6

A MODEL FOR PROVISION OF SOCIAL SUPPORT TO FAMILIES WITH ASD CHILDREN IN THE SPECIAL SCHOOLS OF GAUTENG AND LIMPOPO PROVINCES OF SOUTH AFRICA: PHASE 2

6.1 INTRODUCTION

The preceding chapter analysed and classified the concepts relevant for model development to this study. In this chapter, a model for the provision of social support to families with ASD children in the special schools of Gauteng and Limpopo provinces, South Africa are described. The model description is structured according to the following sub-headings: an overview of the model, context, purpose, and assumptions on which the model is based. The structure of the model is divided into four phases comprising the definition, relation statements and process description of the model. Guidelines for operationalisation or implementation in the special schools and community settings are developed.

According to Chinn and Kramer (2008), a model is a creative and rigorous structuring of ideas that projects a tentative, purposeful and systematic view of a phenomena. Describing a model is a process of posing questions about its purpose, concepts, definitions, assumptions, relationships, and structure and responding to questions with reference to the literature. Some elements will remain clear, some will depend on tentative interpretations, and some will remain unclear. Chinn and Kramer (2008) proposed questions for describing a model which include:

- What is the overview of the model?
- What is the purpose of the model?
- What is the concept of the model?
- How are the concepts defined?
- What is the nature of relationships in the model?
- What is the structure of the model?
- On what assumptions does the model build?

All questions are not necessarily answerable for a single model. However, while answering the questions that apply to a model, concepts are tentatively identified and the purpose should emerge. As definitions become evident the nature of the relationships will be clear. From the nature of relationships, the structure of the model can be addressed. The assumptions help to form an understanding of the model. The questions are described below.

6.2 OVERVIEW OF THE MODEL

The overview of the model is based on the model illustrated in figure 6.1 which serves as a frame of reference for providing social support to families with ASD children in the special schools of the Gauteng and Limpopo provinces. The model is made up of nine circles with arrows connecting the blocks to illustrate the linkage between components. One arrow goes out of the box to show the direction of flow from one step or action to another. There is a double arrow between the agent and recipient blocks indicating communication between the professional nurses, stakeholders, and families. The model shows a simple single chain of relationships with vertical and horizontal flows of actions and consists of three phases.

Phase 1 indicates the unsupportive environment for ASD children and their families, the interactional exchange process between the professional nurse, families and other stakeholders together with the external factors that may influence the model. Phase 2 indicates the provision of social support and Phase 3 shows the outcomes of the families with ASD children after the provision of social support interventions.

6.3 THE PURPOSE OF THE MODEL

The overall purpose of the model is to guide the provision of social support to families with ASD children in the special schools of the Gauteng and Limpopo provinces. It is also intended to address complex needs and assist families to build their capacity to care for, and protect their ASD children. The model can serve as a reference framework for professional nurses in different spheres of health care and education, and to promote social support to families with ASD children. The purpose of the model within the discipline of nursing is for it to be a practice model that adds to the professional body of nursing knowledge in the form of social support focussing on families with ASD children. It is anticipated that the professional nurses working in special schools would facilitate the process until the families’ needs are met. The families’ needs for social support could be met by the interactional exchange process between the professional nurses, other professional practitioners, teachers, the community and families. The purpose of the model is realised by regionally, provincially, nationally and internationally caring for, protecting and supporting families with ASD children.

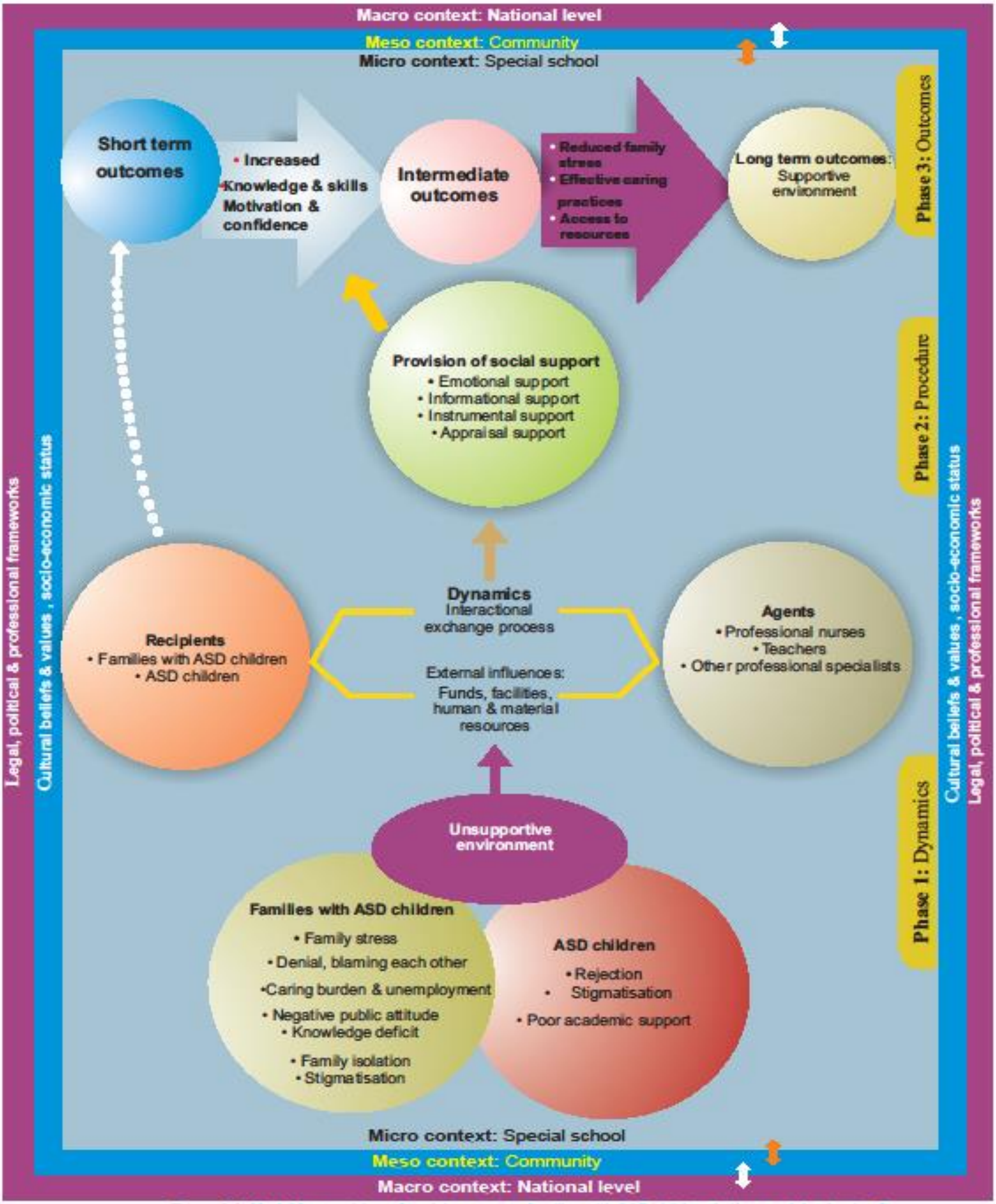


Figure 6.1: Model for provision of social support to families with ASD children in the special schools of Gauteng and Limpopo provinces

6.4 IDENTIFICATION AND DEFINITIONS OF CONCEPTS IN THE MODEL

In Chapter 5 decisions were made about the concepts which were central to the model by means of concept analysis as described by Walker and Avant (2011). The major concept with sub-concepts organised under it was identified from the experiences of families and teachers of children with ASD, based on the details provided in Chapter 4. Concepts and main concepts were classified according to the survey list drawn up by Dickoff et al (1968) in Chapter 5 (see figure 5.2). The concepts in the model for the provision of social support in the special schools of the Gauteng and Limpopo provinces are comprised of the agent, procedure, recipient, context, dynamics, and outcome and definitions provided in Chapter 5.

6.5 THE NATURE OF RELATIONSHIPS IN THE MODEL

According to Chinn and Kramer (2008) relationships are the linkages among and between concepts. The relationship statement comprises a reasonably complete explanation of how the concepts of the model interact. The relationship between the main concepts in this model began to take form as the concepts were identified and emerged, taking into account the direction, strength, and quality of interactions between the concepts. This relationship statement speculates that one event precedes a second event, and so on. The structure of the model emerged from the relationships between the six main concepts. The model illustrated in Figure 6.1 is divided into its different parts according to the main concepts to assist in the meaning of the discussion and to explain the links between the concepts. All the concepts of the model for the provision of social support for families with ASD children in the special schools of Gauteng and Limpopo provinces are interrelated. The concepts are interrelated in such a way that their relationships converge to a single concept, provision of social support, which indicates the purpose of the model.

6.6 DESCRIPTION OF THE STRUCTURE OF THE MODEL

The structure of a model addresses the overall form of conceptual interrelationships according to Chinn and Kramer (2008). The structure of a model for the provision of social support to families with ASD children in the Gauteng and Limpopo provinces has one basic form. The main feature of the model is that it has a flow chart format. These kinds of models use circles with arrows connecting the circles to illustrate the linkage. The steps or action is written inside the circle. Usually, only one arrow goes out of the circle to show the direction of flow from one step or action to another. The model is a simple single chain of relationships with vertical and horizontal flow of actions and three phases. The visual presentation of the model is in colour. The selection of the colour is to exhibit the visual presentation.

6.6.1 Context of the study

The context of the model is the special schools in the Gauteng and Limpopo provinces of SA. The study context, however, is divided into three levels, namely. The macro-level (basic education), meso-level (community) and micro-level (special schools) as illustrated in Figure 6.1. The three levels of context are linked and have important influences on the provision of social support for families of children with ASD.

6.6.1.1 Macro context

The Macro-level refers to the national level, and its context includes legal, political and professional framework facets characterised by various legislation that provides a guideline to the special schools on how to provide support, care, treatment, rehabilitation, and education to children with special needs. Special schools are public schools, and, therefore, their functioning is guided by the basic education laws and policies that guide other public schools. In addition to the basic education laws and policies, the Department of Health has the responsibility of providing developmental appropriate healthcare for those with intellectual disabilities, such as ASD children. Therefore, the following legal frameworks should guide the health team working in the special schools with regard to the provision of social support:

The Mental Health Care Act (2002) for the provision of care, treatment and rehabilitation services for children with ASD.

- The national mental health policy framework and strategic plan, 20132020 (Department of Health, 2007) addresses the provision of social support and integration of families and caregivers of those with mental illness to broaden the network of support and care.
- Policy on Screening, Identification, Assessment, and Support, (SIAS) 2014 to provide standardisation of the procedures to identify, assess and provide programmes for all learners who require additional support to enhance participation and inclusion in the school.
- Rights of persons with intellectual disability

  The environment of the special schools is influenced by complex factors impacting on one another. The national-level context influences the processes and procedures of the special schools for the provision of social support to families with ASD children. Figure 6.1 illustrates the context of the model.

6.6.1.2. Meso context

The meso context refers to the provincial level where national legislation and policies are implemented. It also includes a community in which the ASD children and their family members live. The context includes the cultural beliefs and values in respect of intellectual disabilities, parental skills, socio-economic status and the level of education which may have an impact on the provision of informal support to the families with ASD children. It also includes the social networks in the community that play a role in the provision of informal support, such as a spouse, extended family members, friends, neighbours, community leaders, churches and the community at large.

6.6.1.3 Micro context

The micro context includes the special schools in the Gauteng and Limpopo provinces where ASD children are admitted. It is made up of elements, such as vision, mission, and values accompanied by strategy and strategic goals that influence the education process within that specific institution. In the micro context, policies are implemented for identification, screening, assessment, and support of ASD learners. The special schools determine the number of teaching, support staff, professional specialists and infrastructure based on the needs of the children admitted to that school. The provision of support for families with ASD children will be facilitated in this context by the professional nurse together with the other professional specialists and teachers. Figure 6.2 illustrates the context of the model.

Figure 6.2: Context of the social support model

6.6.2 Agents of the social support model

The primary agent is the professional nurse working in the special schools of the Gauteng and Limpopo provinces. The professional nurse as a member and coordinator of professional specialists in the special schools will take an active role in facilitating the provision of social support to the families with ASD.

The professional nurse has an important role in the school health team, such as collaboration between the family and school, involvement in staff training and health promotion classes. She also participates in individual teaching programmes developed together with the teachers and parents. Additionally, she is responsible for ordering and administering medication to all learners, provides leadership in promoting a healthy and safe school environment, and is in control of the case management of chronically ill children and referrals to essential community resources (Cluskey & Schwend, 2015).

Teachers in the special schools of the Gauteng and Limpopo provinces are the secondary agents in this study as they provide academic intervention and support for children with ASD and also interact with their families. Teachers of children with ASD work with professional nurses, other professional practitioners, and family members to write an individualised education programme (IEPs) for the ASD children to meet their academic, social and personal needs.

Professional specialists in the special schools of the Gauteng and Limpopo provinces are also secondary agents in this study. They provide health and other therapeutic, psychological and social support to ASD children and their families that enhance their capacity to achieve maximum benefits. Figure 6.3 identifies the agents in the model.

Figure 6.3: Agents of the social support model

6.6.3 Recipients of the social support model

The recipients are the families of children with ASD in the special schools of the Gauteng and Limpopo provinces. Families with ASD children are defined in this study as a group of parents, primary caregivers, adoptive parents, foster parents, grandparents, siblings and other relatives responsible for the care of ASD children. According to the findings reported in Chapter 4, special schools in the Gauteng and Limpopo provinces of South Africa are shown as not furnishing support to families with ASD children.

These include families experiencing feelings of frustration, stress, and worry for the future due to the recognition and diagnosis of autism in their children, and the impact of having a child with autism on their family. Often the family as a whole is greatly affected by the diagnosis. Low levels of education, lack of resources in the special schools, lack of knowledge about ASD, living in rural areas, stigmatisation, low family income, the behavioural problems of the child, excessive caring burdens, lack of school transport and family isolation results in limited support being provided to the families and their ASD children and this leaves them unsupported and stressed.

ASD children are also the primary recipients in this study as the findings showed that they lack support from the community and special schools. Figure 6.4 illustrates the recipients in the model.

Figure 6.4: Recipients in the social support model

6.6.4 Phase 1: Dynamics of the social support model

The primary dynamics that need to be invested in a social support model or that should be brought to bear on this model is the interactional exchange process between the agents and the recipients. The interactional exchange process will enable the agents and the recipients to assess the family needs, plan for service delivery and evaluate the progress. External influences, such as fiscal, human and material resources, time, and facilities serve as the secondary dynamics of the social support model.

6.6.4.1 Interactional exchange process the professional nurse becomes aware of the ASD children and their families during referrals from teachers who identified the ASD children in mainstream schools. Some are referrals from the hospitals after the parents seek help to explain the poor developmental milestones of their children. The professional nurse initiates an **interactional exchange process** between the agents (a professional nurse, teachers and other professional practitioners) and the recipients (families with ASD children and ASD children) during which the professional nurse checks the condition of the child, his or her diagnosis, age, medical and psychological reports as requirements for admission. During the admission processes of ASD children, the professional nurse will draw up a comprehensive history of the ASD children and their families' needs, concerns and anxieties. Individual therapy and a home visit will be organised to inquire about more details regarding the needs and concerns of the families. This working relationship includes the exchange of information, sharing, and grouping together resources for the mutual benefit of those families with ASD children. This becomes the entry point of interaction and communication, as well as Phase 1 of the model.

After history-taking, individual therapy and home visits, the professional nurse as the facilitator of the model will identify the emerging needs, concerns and anxieties of the families. This process will also allow families to identify what is working well, what they are worried about, and what they think needs to be done. These needs range from basic needs to complex psychological needs. This enables the professional nurse to analyse the information within the assessment and to formulate statements about anxieties and goals with the family.

The strengths of the family and their wider network to support them in what needs to happen next should be identified. To attend to all the needs of the families, the professional nurse and the family create a service delivery plan which sets out how the social support interventions should be delivered based on their needs. At this stage, all stakeholders responsible for the provision of formal and informal intervention services must be coordinated by the agent. The voice of each family member within the needs assessment is important as it ensures that professionals understand the impact of issues on those individuals. With the consent of the families, the professional nurse then approaches other multidisciplinary team members, school principals, teachers, and other relevant stakeholders for formal support services. The following individuals will be approached to provide informal support services: siblings, pastors, community leaders, other parents with ASD children, friends, extended family members and neighbours to initiate individual communication with them as they are important role players in the social network required for the provision of social support to the families.

The professional nurse explains his or her role to stakeholders in facilitating the provision of social support for the families with ASD children. Initiating one- on-one communication with stakeholders to introduce a social network through the interactional exchange process. Individual meetings between the professional nurse and other stakeholders should be set to ensure the cooperation of the stakeholders in a social network and to provide them with the background information on the families. The stakeholders have to pave the way for the formation of a social network in facilitating the provision of social support for families with ASD children as social support is considered a multidimensional construct.

The professional nurse further explains to each of the role players how they can participate in the social network to provide social support to the families with ASD children. The families with ASD children can participate at an early stage by identifying the children's poor developmental milestones, such as impaired communication and social interaction skills and help them to seek health care services at the clinic or hospital. They could provide support to each other during the diagnosis of, and caring for the ASD child, involving all family members in the provision of care and acceptance of the child. They should avoid hiding ASD children from the community, and allow ASD children access to education.

Professional specialists can participate by assessing, diagnosing, and treating the physical and psychological problems of the ASD children and their families. They should compile medical reports for ASD children that would be utilised to identify the needs and services required. They could assist in the provision of quality information regarding ASD, parental training on self-help skills, management of disruptive behaviour and coping mechanisms. They could ensure the provision of genetic, marital and emotional counselling, psychotherapies for stress, denial, disbelief, marital problems, and guilt feelings. They could contribute to organising ASD awareness in the community. The speech therapist could assist ASD children with impaired communication. The social worker could assist the family in confronting social problems related to ASD, in dealing with applications for a disability grant, home visits and the establishment of support groups.

School-based support teams (SBST) could participate by providing proper infrastructure, equipment relevant for ASD children, adequate human resources and material resources, on-the-job training for teachers in the special schools. These teams could also assist in providing school transport that would be adequate for all ASD learners and would ensure that learners attend school daily instead of only attending on alternate school days because the school buses are too full and on some days having to hire private transport. Overcrowding of ASD learners in a class should be avoided and teacher assistants should be provided in each class to assist teachers with the management of the ASD children. Support teams should advocate for ASD children to get sponsors to start their own businesses after vocational training at the special schools. Quarterly parent meetings should be arranged to discuss challenges or achievements in the school. Opportunities should be provided to ASD teachers to achieve professional growth and to acquire relevant knowledge about ASD. SBSTs need to support teachers and caregivers in this process by providing opportunities for regular, collaborative problem-solving in areas of concern and facilitating the provision of support where needed.

Teachers can participate by identifying children with ASD symptoms and referring them for assessment and admission to the special schools, and caring for, and training ASD children in the classroom in respect of vocational and social skills. ASD children should be supervised during breaks. Meetings should be arranged with the parents to discuss the progress of the ASD child, and families should be involved in planning individual programmes, and should communicate with the parents regarding the child's progress or any other school activities through communication books. When the child leaves the special school he or she should be assisted in completing an application form for employment at sheltered factories. Teachers must be willing to be a lifelong learner in acquiring new information regarding ASD and should conduct their own research. Pastors can participate by providing spiritual support to the families and teachers with ASD, whereas friends, neighbours, and the community can participate by providing social networks and refrain from stigmatising and rejecting families with ASD children. Planning for delivering support services ends when the social network is formed into a recognised structure ready to provide social support to families with ASD children by individual members.

6.6.4.2 External influences

Adequate fiscal, material and human resources need to be invested by the Department of Basic Education for the provision of social support services. Facilities, such as adequate special schools must be built in rural areas and the agents must invest enough time to facilitate the programme. Figure 6.5 illustrates the dynamics of the social support model.

Figure 6.5: Dynamics of the social support model

6.6.5 Phase 2: Provision of social support

The provision of social support in this study refers to the process whereby the families with ASD children are provided with a wide range of support services through the interaction between the professional nurses, other professional specialists, teachers, families, and the community. Social support should be based on the needs, culture, values, and preferences of the families. It is a comprehensive and coordinated set of strategies that are designed to ensure that families with ASD children have access to family-centred resources, support services, and other assistance to cope with difficulties and develop new competencies.

Phase 2 describes the provision of social support services which include emotional, informational, and instrumental and appraisal support as described below and illustrated in Figure 6.5.

6.6.5.1 Provision of social support interventions

During this phase members of the social network provide social support services to families with ASD children as described below. The social network that is available to provide social support to families with ASD children consists of professional nurses, professional specialists, school-based support teams, teachers, pastors, friends, extended family members, neighbours, and the community.

During the admission process of children with ASD at the special schools, the professional nurse conducts an assessment and makes a nursing diagnosis, checks medical and psychological reports for medical history and the medical diagnosis of the children. She collects information from the parents or caregivers with regard to the pregnancy of the mother and the delivery of the child, developmental milestones, school history, medical history, family history, socioeconomic and marital status of the parents, educational level of the parents and any other relevant information. The professional nurse utilises a family tree to assess the make-up of the family and wider support network, and to provide an opportunity to explore the views of who is currently providing **informal support** or could offer **informal support** in the future if necessary.

The professional nurse identifies the needs, concerns, and priorities of the families during the individual sessions. She opens the door for communication, trust, collaboration, and possibly eliminating frustration related to their concerns. The professional nurse provides **emotional and informational support** by counselling the families, informing the families about ASD, its causes and symptoms and teaches the families about communication principles as ASD children have impaired communication skills. She limits the setting, medication and behavioural modifications for the ASD child’s behavioural problems. She encourages the parents to follow a routine as ASD children cope well in a structured environment. The professional nurse involves the families in decision-making regarding the support needs and priorities for **appraisal support**. She informs other stakeholders about the support needs of the families and arranges a meeting between the families and other stakeholders based on their support needs. The professional nurse arranges dates for the support group meetings in the special schools where families share experiences with regard to caring for children with ASD.

Teachers of ASD children demonstrate love, acceptance, and passion for ASD children and their families. Teachers and parents discuss the needs, strengths and weaknesses of the ASD children to identify their abilities and to draw together the individual teaching plans for the children. The teachers involve ASD children in a wide range of vocational skills which forms part of **informational and instrumental support**, such as gardening, cooking, swimming, yoga, exercise, and fitness, walking, jogging, running, hiking, weight-lifting, health and wellness, bowling and community outings. The aim is to develop problem-solving skills, learn responsibility, and increase self-esteem, all while having fun and making friends which forms part of the **appraisal support.** Teachers arrange meetings with the parents to discuss the progress of the ASD children and encourage the parents to reinforce the activities at home. Teachers open the door for communication with the parents through communication books, phone calls or messages. Teachers will assist the children later when they are young adults in applying for sheltered employment when exiting the special school. To improve the social skills of ASD children, teachers identify peers with strong social skills and pair them with other ASD children so that they can have good models for social interaction.

School-based support teams (SBST) ensure that the infrastructure is conducive for learning with relevant types of equipment for teaching ASD children. School transport for ASD children is available. Teachers and teacher assistants with relevant knowledge regarding ASD are adequate. They organise workshops and conferences for ASD teachers.

The psychologist provides the family with genetic and marital counselling to assist the parents to cope with stress, guilty feelings, and the disbelief of having a child with ASD. She provides parental education on coping skills. She conducts family therapy to identify the needs of each member and to clarify the role of each member with regard to caring for the ASD child. She assesses the functioning abilities of the ASD children since these form part of **emotional support.**

The social worker conducts a regular home visit, and teaches the families social skills for those who are unemployed. He or she provides counselling for parents undergoing separation or divorce due to their denial of having an ASD child. He or she applies for a disability grant for ASD children and teaches the families how to manage the grant for **instrumental support**.

The speech therapist will have regular sessions with all ASD children with impaired speech. He or she provides ASD children with instrumental support, such as communication devices and teaches the children and their families how it works. The speech therapist provides parental training on communication principles with ASD children.

An occupational therapist will have sessions with the ASD children to reinforce their vocational skills. The vocational activities of ASD children should be based on their abilities, interests, and strengths. Parents should be invited and functions organised to celebrate important days on the calendar. A dietician will assist the caregivers on the diet of their ASD children because they are selective when it comes to food.

During autism month every year, the professional nurse organises an ASD awareness at the community halls where information regarding ASD will be provided to the community for **informational support**. The community will be informed about the awareness day through the village leaders and local radios. At the school level, in autism month a celebration day will be organised, where all parents with or without ASD children will be invited.

Traditionally the church serves as a major source of **emotional support** for individuals and families to provide guidance (Chatters, Taylor, Woodward, & Nicklett, 2015). The families with ASD children will be encouraged to affiliate with churches and to frequently participate in prayer and religious activities for spiritual support.

Siblings, extended family members, friends, neighbours, and the community will be encouraged to provide **emotional support** during a home visit and ASD awareness. The support of the spouses will be encouraged during spousal counselling and parental training. Informal family support services include services, such as recreation, socialisation, spousal support, spiritual support, support groups, parent-to-parent, peer-to-peer, and family-to-family support.

After the provision of social support interventions, the professional nurse needs to monitor and evaluate whether the needs of the families and ASD children were met. This leads to the next step.

The professional nurse communicates with the families of ASD children during home visits and school parent meetings to monitor improvement with regard to the support strategies provided by different stakeholders. If the needs of the families and their ASD children are not met alternative activities will be considered by the professional nurse together with the families. Families will be allowed to identify what is working well and what they think needs to happen. The support service delivery plan will be modified by making telephone calls, writing emails and visiting stakeholders to find out if each member is still prepared to participate in the provision of social support to the families of ASD children. This is done as part of the monitoring and evaluation of the process as well as to support and encourage members to provide continuous support strategies.

Phase 2 ends when the informational, emotional, instrumental, appraisal and support needs of the families with ASD children have been successfully provided. Figure 6.5 illustrates the provision of social support.

Figure 6.5: Provision of social support

6.6.6 Phase 3: The outcomes of the social support model

The outcome of the model includes a supportive environment which will lead to coping for the families with ASD children. A supportive environment and coping will be measured in terms of short-, middle- and long-term benefits based on the McCrawley (2013) logic model format.

Short-term outcomes are the benefits or changes that families with ASD children experience soon after the provision of intervention support services. These generally include changes in behaviour, attitudes, **skills, and knowledge** in regard to ASD because they have the courage and **confidence** that in the future they can generally accomplish what they wish to do. Furthermore, they will have the **motivation** to initiate, guide, and maintain goal-oriented behaviour which will make them feel respected and accepted.

Intermediate outcomes will be measured within several months after the social support interventions and include actions by families based on what they learned or received. These include **reduced parental stress** and psychological distress, **access to**

resources and **effective caring practices,** better adjustments, and positive perceptions of their ASD children which results in the optimal development of the child.

Long-term outcomes are outcomes measured in one year or several years after the provision of social support services strategies and, or interventions. These include changes in social and environmental conditions. Social support services provided by the professionals and non-professionals should facilitate the development of a calm, safe and **supportive environment** that is conducive for families with ASD children. Therefore, families of children with ASD will feel socially, emotionally, spiritually, and physically safe and valued. The model outcomes are illustrated in Figure 6.6.

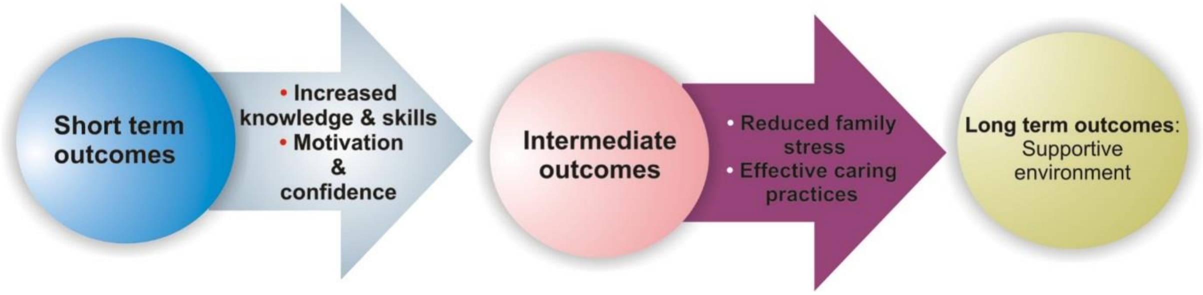


Figure 6.6: The outcomes of the social support model

6.7 ASSUMPTIONS OF THE MODEL

The model for the provision of social support to families with ASD children is based on the following philosophical assumptions taken from Watson's (1968) philosophy and science of caring nursing practice.

The model is based on the assumption that social support for families with ASD children takes into account the total support needs from a physical, psychological, spiritual, and sociocultural perspective and this represents the family’s supportive living environment.

Social support to families with ASD children consists of a range of intervention strategies and services, to meet the multiple and complex concerns, needs, and priorities of the families. Intervention strategies include informational, instrumental, emotional and appraisal support.

A calm, supportive, loving environment offers the increased knowledge and skills, effective caring practices, confidence and motivation, development of potential, independence, competency, reduced parental stress, psychological distress, better adjustments and positive perception of the ASD child while allowing the family to choose the best support services to support their needs. Families with ASD children cope well when they are empowered to make their own choices about family support intervention strategies.

Social support for families with ASD children can be effectively demonstrated and practiced only if the families, professionals (health and educational) and community are working together. Community and family members need to be equipped with knowledge and skills to enable decision-making. Therefore, the professionals and the families must work together to achieve the goal of facilitating a supportive environment for families with ASD children.

Effective social support promotes ASD children and family growth. It can directly contribute to the overall welfare of the ASD children and their families.

The practice for the provision of social support is central to professional nurses working in special schools. Therefore, professional nurses must facilitate the provision of social support services to families with ASD children to be effective at improving the health and wellness of the families.

6.8. GUIDELINES FOR THE OPERATIONALISATION OF THE MODEL IN PRACTICE

Broad guidelines proposed for operationalising the provision of a social support model to the families with ASD children are discussed using the three levels, namely: macro-, meso-, and micro-level. The objectives and services or activities to address the objectives are indicated. Table 6.1 illustrates the guidelines, objectives, and strategies for the operationalisation of the model at macro-, meso- and micro-levels.

Table 6.1**:** Guidelines for the operationalisation of the social support model

Guidelines	**Objectives**	**Strategies**
(Macro level) **Guideline 1:** Enhance review, monitoring, and evaluation of guidelines and policies that support children with special needs and their families	Objective (i) to enhance the review of guidelines to ensure quality education and support in special schools and special school resource centres in South Africa.	• Establish a ministerial task team to review the guidelines to ensure quality education and support in special schools and special school resource centres, working with the minister of basic education, health, social development and other team members from education and health institutions in South Africa. With inputs from teachers, professional nurses, Autism South Africa, and other applicable members of the public, as well as policy guidelines set by the health professional councils.
	Objective (ii) to establish collaboration and equality between the special schools in South Africa.	• The Department of Basic Education at the national level should monitor all special schools regularly and provide the necessary support. Aspects to be monitored include curriculum planning and delivery, infrastructure provisioning, human resource management, and transport.
	Objective (iii) monitoring and evaluation of the implementation of the national mental health policy framework and strategic plan, 2013-2020 with regard to the provision of social support and integration of families and caregivers of those with mental illness, to broaden the network of support and care	• The Department of Health should monitor and evaluate special schools with regard to the provision of social support and integration of families and caregivers of those with an intellectual disability through situation analysis of the special schools and semi-structured interviews with key stakeholders.
(Meso level) **Guideline 2:** Awareness of the influences of cultural	Objective (i) to assess families' beliefs about child development, interpretation of the symptoms of ASD, its aetiology and course, level of education,	• The professional nurse as the facilitator should explore the community perceptions regarding ASD, beliefs about the causes of ASD, how ASD is experienced and expressed, where families with ASD children seek help, and

beliefs, attitudes and social structural factors associated with ASD in the community	socioeconomic status and their experiences with the health system influence treatment decisions	types of treatment families prefer by asking questions during the community awareness or history taking. • Assess the level of awareness, knowledge, and perceptions regarding ASD among the general population as a greater risk of misdiagnoses, thus making their children more difficult and resistant to therapy through research projects. • Assess socioeconomic status amongst the families that may interfere with access to health care providers who could make the diagnosis and provide needed support, through research projects. • Assess the availability of resources in the community, such as special schools, clinics, day-care centres, hospitals, support groups, and sheltered employment • Advocate for basic physical needs to be met through communication with the community leaders, social workers, and councillors.
(Micro level) **Guideline 3:** Provision of **emotional support** to overcome stressful reactions and adopt a coping mechanism	Objective (i) to provide family therapy for the families to understand the condition and support each other	• Family therapy should be conducted by a psychiatric nurse and psychologist with a good understanding of family systems, dysfunctional family patterns, power struggles, and communication. • The facilitator should provide family therapy for families experiencing denial, blaming others and confusion of the diagnosis and of living with a child with a life-long disability. • ASD children should be involved in family therapy to understand their condition and support for siblings too.

	Objectives (ii) to provide genetic counselling to discuss the passing of the disorder on to their children, and an explanation of that risk	• The school health team should conduct assessments, investigations and make a correct diagnosis of the ASD child. • Genetic counsellor/facilitator should explain the nature and prognosis of the autism spectrum disorder, the treatment available and where to find it. • The facilitator should estimate genetic risks for parents and family members by drawing up a family tree. • Investigation of family members may also be conducted • Communication of genetic risks and the options for avoiding them should be explained to the families with ASD children • The facilitator should also describe the chances of parents and other family members of passing on the disorder to their children, and an explanation of that risk. • Mothers of children with ASD must be encouraged to attend the antenatal clinic in time to avoid risks associated with pregnancy complications. • The options in avoiding further affected children must be emphasised by the facilitator. • The facilitator needs to support the individual or couple in making the decision that is right for them.

	Objective (iii) to provide psychosocial support to overcome stressful reactions and adopt a coping mechanism	• Family members requiring specialised support through professional mental health services should be identified by the facilitator and be referred to the psychologist. • Individual or group therapy should be provided to the family members who will be more severely affected than others by the situation. • Psychosocial support should be available to all family members with ASD children as family members may have different reactions to having a child with ASD in the family. For this reason, psychosocial interventions are designed according to the particular family's needs and resources. • All interactions with the families with ASD children should be done with consideration of the psychosocial well-being of the family members.
	Objective (iv) to encourage the use of a spiritual support system for facilitation of hope to the families with ASD children	• Families with ASD should be encouraged to commit themselves to religious devotions as it is related to reductions in family stress, personal and emotional impacts. • Establishment of a spiritual support group aimed to satisfy families with ASD children's spiritual needs by incorporating the spiritual component into the dynamics of a group therapy setting. • The planning group meet regularly to define the aims of the spiritual support group, and the practicalities of running it. • The facilitator of the therapy should extend the individual's coping resources, offer families with ASD children hope, and help to give meaning to suffering.

	Objective (v) enhance significant others support (siblings, friends, extended families, neighbours) for informal social networks	• Families with ASD children need community and family support to restore a sense of normality in their lives enabling the family members to get on with daily tasks and demands.
Guideline 4: Access to quality information to increase knowledge and skills regarding ASD **(Informational support)**	Objectives (i) provision of family education and training regarding ASD	• Professional nurses should plan and conduct conferences, workshops, and training for families with ASD children. To help families gain confidence and competence in supporting the development of their ASD child. • Family education and training activities should be provided in community-based settings frequented by families, such as clinics, or community halls. • Training programmes should target topics, such as management of the ASD child, ASD child functional life skills, play and leisure skills or social communication. • Role-play and rehearsal, performance feedback, didactic sessions must be used to address the behavioural problems of the ASD child and to help caregivers to address disruptive behaviour with positive outcomes. • Feedback should be provided to the families during practice for positive child outcomes. • Training approaches can also include video models which can be provided free online for the families because they can be cost-efficient.
	Objective (ii) to provide accurate information, resources, and referral	• Once sufficient information has been gathered, and the child's overall developmental profile has been considered, the child is discussed by the multi-disciplinary team and a decision as to whether the child meets the criteria for a diagnosis of autism is reached.

		- Families should be given opportunities to discuss and process information with the psychiatrist or psychologist who is regarded as being more knowledgeable about ASD. - Information regarding ASD should be delivered on time and in a variety of modalities such as community radio, television, video, internet, and pamphlets. - The facilitator should inform the families with ASD children about their rights and responsibilities related to having a child with ASD and these should be reviewed with families regularly.
	Objective (iii): to increase community knowledge through community outreach and awareness	- Autism SA and professional nurses should promote ASD awareness, education, therapy, and advocacy for families with ASD throughout South Africa as the communities lack knowledge regarding ASD. - South African citizens should be encouraged to participate and show solidarity on world autism awareness day on 2nd April each year by wearing something blue. This day provides an opportunity for people to understand ASD and its impact on the children and the family. - A variety of activities that support children with ASD must be organised on this day in the special schools, community halls where children, parents and the community must be invited.

		• Social marketing strategies, such as support by key corporate and media partners, non-profit organisations, celebrities, and online resources will give momentum to the campaigns. • Other social marketing strategies include television advertising and direct mailings, logos, newspapers, and posters in combination with grassroots activities that involve collaboration with existing community networks. • Public awareness will assist in locating, identifying, and referring infants and toddlers who may require services. • Outreach and informational materials should be available in the 11 official South African languages and in places where families gather, such as clinics, churches, and schools. • Local coordinated public awareness efforts include ensuring early identification of infants and toddlers with ASD signs and symptoms, a referral system for service providers from a variety of disciplines, family support services, health service providers of ASD children and social services. • The referral sources for ASD in the community and contact information that facilitates appropriate referrals and family support services should be provided to the public.
	Objective (iv): to provide academic and professional development to all professionals and supporting staff working with ASD children in the special schools	• Nurses, teachers and other health professionals should be provided with continuous professional development opportunities, which include strategies to support ASD children and their families. Continuous Professional Development should include training courses and workshops, studying for a

		qualification or accreditation, online courses, personal reading or research and observation. - Coaching or mentoring should be provided by experienced colleagues, either from within or from outside the institution. - The collaborative approach should be encouraged between the professionals for caring/teaching to be seen as a united profession. - Family input should be used to identify knowledge and skill areas for personnel development and training of the professionals.
Guideline 5: Provision of tangible aid and services that directly assist ASD children and their families **(Instrumental support)**	Objective (i) to encourage utilisation of recreational facilities in the community	- Expose ASD children and their families to regular recreation that develops skills, promotes good health, relieves stress, facilitates social interactions, and provides a general joy for living. - Stimulate ASD children’s problem solving skills, learning responsibility and self-esteem by involving them in fun through their hobbies and recreational activities - Children with ASD can be involved in a wide range of activities, including gardening, cooking, swimming, yoga, exercise, and fitness, walking, jogging, running, hiking, singing, weight-lifting, health and wellness, bowling and community outings.
	Objective (ii) to establish support groups for families with ASD children to share experiences	- Professional nurses should establish parents-to-parents support services at the special schools, community setting or at the clinics for families with ASD children to share their common experiences.

		• Families with ASD children should be recruited during parent meetings in the special school through public service announcements on radio or television, posters, and flyers that can be posted in shops, schools or churches, or local newspapers. - Once members have been recruited, they should be contacted to let them know the date and time of the first meeting. - The date and time that will make it possible for most people to be there - The location should also be somewhere where people can feel comfortable enough to talk about their problems and are able to offer each other support. - When the group starts the meeting, encourage members to tell others about the support group. - The professional nurse should be the facilitator of the support group, responsible for opening and closing the meetings, sets the tone for the discussion, helps members learn how to listen and offer support to each other, and deals with any problems that come up during the meeting • The facilitator should encourage sharing common experiences to make the challenges faced by families with ASD children seem more manageable. • Sharing their experiences and expertise with other families, will promote emotional support, help families gather information, find solutions to problems, and, ultimately, advocate for their ASD child's needs.

		- Parent-to-parent support staff should receive training in effective practices for peer support.
	Objective (iii) to conduct a home visit to families with ASD children	- The professional nurses should join the family in their home base and see their reality by being part of their lived daily experience. The professional nurses as the facilitator will be on the spot and they can address issues as they arise. Bringing services to the family in their own home seems a self-evident solution. - Professional nurses should familiarise themselves with family needs and concerns by reviewing narrative notes to identify any potential issues that will need to be addressed during the home visit. - Professional nurses should observe family abilities. This should begin with observing how the family members greet and interact with the facilitator and continue until the interview is concluded. - Home visit services also require well-integrated professional practice that can support and encourage the families yet also firmly address anything that will jeopardise the safety and wellbeing of ASD children and their families. - The facilitator should visit families with multiple problems that are embedded in the social, emotional, psychological functioning and patterns of interaction that require home visit services.

		• Home visit services should also be provided to families with ASD children who experience poverty, unemployment, and a shortage of affordable housing, as it reduces the family's capacity to thrive. • Professional nurses should convey a feeling of interest, concern, well-being, and affection to family members to promote a sense of comfort and well-being.
	Objective (iv) to provide a conducive learning environment to ASD children in the classroom	• Autism schools with adequate material and human resources should be built in rural areas by the Department of Basic Education. • ASD children should be provided with school transport to be able to attend school as required • Families of ASD children should participate in the academic activities of their children including the development of individual teaching plans. • Teachers as facilitators in the classroom should get the child's attention before giving instructions, call the child's name, and go close to the child for them to be aware that the teacher is talking to them. • Facilitators should provide a quiet, distraction-free learning area because ASD children are sensitive to too much noise and movements and it may be difficult for some children to cope with. • Facilitators should have consistent classroom rules and routines so that children with an ASD understand what you expect of them and how they should behave.

		- Visual timetables should be drawn up by the facilitators to provide structure and help ASD children to see what is going to happen and when. - The facilitator should use visual clues or symbols along with the words to make instructions easier to follow. ASD children learn better when they see things.
	Objective (v) to facilitate the development of ASD children's communication skills	- The development of communication skills in children with autism cannot be the sole responsibility of the speech pathologist. Communication regarding wants and needs, as well as social interactions, occurs throughout the day and across settings, and the entire group of professional nurses, family, and teachers will be involved. - ASD children with emerging language should be provided with ongoing support building on receptive and expressive language skills. - ASD children with high verbal skills: the speech pathologist should focus on the more subtle aspects of pragmatics and conversational reciprocity.
	Objective (vi) to encourage social interaction of the ASD children to reinforce social behaviour	- Families with ASD children, teachers and professional nurses as the facilitators of the process should reinforce what the ASD children do well socially by praising them to reinforce the social behaviour. - ASD children should be taught context clues and to imitate the motor- as well as verbal actions of the people around them.

		• Families and teachers of ASD children should identify peers with strong social skills and pair the ASD child with them so that he has good models for social interaction. • The facilitators should break social skills into small parts, and teach these skills through supported interactions. • Teachers of children with ASD should not involve the children in social learning that is too challenging for the children. • The teacher should first teach the necessary skill, such as how to play in isolation, and then introduce it in a social setting with peers. • ASD children should be taught social boundaries like the things they should not talk about, whom they might talk to about sensitive subjects and maintaining personal space. • Children with ASD love music so the facilitators should use music to motivate interest in social interactions or to give them a chance to shine and be viewed as competent and interesting.
	Objective (vii) free government support	• Free school transport • More autism schools and adult autism centres in rural areas • Free education, reduced or no school fees and hostel fee in rural and urban areas • Establishment of sheltered employment after exiting special schools • Adequate teachers and school health teams • Provide food parcels for struggling families

		• Ease access to chronic medication • Dieticians to be involved in drawing up menus for feeding schemes in the special schools
Guideline 6: Providing affirmation, feedback, social comparison and self-evaluation **(Appraisal support)**	Objective (i) to determine the needs, strengths, concerns for the families with ASD children	• Professional nurses should assist families in identifying and understanding their individual needs and talents as well as their concerns, priorities, and resources. • All background information available about the families with ASD children should be gathered by the professional nurses. All the available documents available should be read to get as much relevant information as possible. Interview family members about their needs, priorities and the environment. • Families should be allowed to identify what is working well and what they think needs to happen. • A variety of assessment tools may be used to determine current capabilities, skills, and needs of a child and family. • All professionals working with families with ASD children must have a common core of knowledge and understanding about family needs and increased understanding and trust between professionals. • The make-up of the family and wider support network should be assessed through a family tree, to provide an opportunity to explore the views of who is currently providing support or could offer support in the future. • When all the assessment results for the families are completed, a meeting with the professional nurses who participated in the assessment should be arranged to explain the results, discuss the recommendations, and involve the families in making any related decisions.

		• Appropriate strategies and services that will meet family needs should be identified.
	Objective (ii) monitoring and evaluation of the family support interventions strategies	• The purpose of reviewing the progress of the family support process is to establish whether the short and middle-term objectives have been achieved or not. • Mental health care professionals, teachers together with the families of ASD children should review whether planned goals for family support services were achieved. • If the short and middle-term outcomes are not met, alternative family support service strategies should be considered. • Discussions between the professional nurses, teachers and the families should take place and decisions should be made about how to progress and how the family can be supported. • If the outcomes are reached, and the situation has improved for the family, changes in social and environmental conditions of the families will result.

6.9 CONCLUSION

In this chapter, the overview of the social support model, its purposes, concepts, and the nature of relationships within the model, description of the structure, the context, assumptions, and guidelines for the operationalisation of the model are described. The following chapter describes the validation of the social support model.

CHAPTER 7

VALIDATION OF THE SOCIAL SUPPORT MODEL: PHASE 3

7.1 INTRODUCTION

The foregoing chapter detailed the overview, purposes, relationship, structure, context and assumptions of the social support model, and guidelines for the operationalisation of the model. This Chapter presents and discusses validation of a social support model. Validation is described as the use and evaluation of a model for guiding practice and practice-oriented approaches that further contribute to empirical knowledge development (Chin & Kramer, 2008). The social support model is validated based on the criteria offered by Chin and Kramer (2008) (Annexure R). The model and guidelines for operationalisation were validated in two special schools by two professional nurses, two teachers and two mothers of children with ASD as well as four academics. The objective of this chapter is to validate the operationalisation of the social support model for families of children with ASD in the Gauteng and Limpopo provinces of South Africa.

The two professional nurses each have a nursing degree and have been working in a special school for more than five years. The two teachers have been teaching children with ASD for more than 12 years and they hold a dual role of being a parent and a teacher of children with ASD. They each have one child with ASD aged 17 and 21 years old respectively. The experiences of those teachers and parents with regard to ASD is broad as they have lived experiences, attended a lot of conferences, parental training, and workshops on ASD locally and internationally. At the time of the investigation, they were pursuing a master's degree in special education. The four academics hold doctoral degrees (three in nursing science and one in physiotherapy). Two of the four academics were professors (one in nursing and the other in physiotherapy). All these academics have knowledge and experience of model development. All were senior lecturers with expertise in qualitative research methods and had supervised many masters and doctoral students.

The research instrument or interview guide with open and closed-ended questions related to the validation of the model together with the model that had been developed were emailed to the panel members for validation. The following criteria were used to validate the social support model.

7.2 CRITERIA FOR VALIDATING SOCIAL SUPPORT MODEL

Chin and Kramer's (2008) validation criteria contribute to understanding how well the social model relates to practice, research, and educational activities.

7.2.1 How clear is the social support model?

In determining how comprehensible a model is and to create an understanding of the model, the panel of experts was asked how clear the social support model is.

All experts agreed that the social support model is clear. One academic said *"the model is graphically portrayed well and is cohesive. It contains the context, inputs, process as well as the expected outcomes".* Another academic added that *the concepts are clearly defined and applied to the study to connect with the process. Concepts were conceptualised and classified according to Dickoff, et al.* One professional nurse said that *"The structure is simple, clear and easy to follow starting from the national level, where policies and ACTs have been formulated for the caring and support of the ASD learners and their families. At the provincial level which is the community in which these ASD children stay, policies and acts are then implemented. The special schools is where the model will be implemented. The structure is clearly stated and the diagrams support one another".* One teacher added that *"The model is clear and involves all multidisciplinary team also include community and family. It shows where everybody and all stakeholders fit in the structure and all the responsibilities of everyone involved".* One parent said *"According to my understanding, I am saying yes the model is clear because it has been divided into three phases. All phases are well defined and explained, everyone can read and understand all structures".*

One academic suggested that *"The three phases that are indicated in chapter one are to be used to construct a model".* The researcher used the model development process which guided the three phases of the model as highlighted in Chinn and Kramer (2008), Dickoff et al (1968), Walker and Avant (2011). The phases in Chapter 1 are for the whole study not for model development.

7.2.2 How simple is the social support model

All experts agreed that the social support model was simple to follow as evidenced by one academic who said "*The number of elements and concepts are minimal and were used accordingly,* it shows the flow of the model. *The discussion was clear with the purpose of the model. The schematic presentation is easy to follow and explained in detail and their relatedness is highlighted in the description of the model. The relational components were discussed from the selected concepts".* One professional nurse *added that "The model is simple and clear for easy reading and understanding by everyone. Concepts are clear and relationship directional"* One parent said that *"The social support model is clear, understandable, and directional, relationship are directional e.g. it starts from a micro level, meso level and then macro level.* One academic indicated that *"No training is required to apply this model, it is what I consider, a "read and do/follow" model".*

7.2.3 How general is the social support model?

All experts agreed that the social support model is general and can be applied to a broad array of situations, as evidenced by one academic who said "*Being a Physiotherapist, I see this model as cutting across professions. It is precisely advocated for interprofessional education and collaborative practice (IPECP)".* Another academic added that *"The theory talks to the professional nurses and teachers working in the special schools of Gauteng and Limpopo provinces facilitating the provision of social support to the families with ASD. It is adaptable because of strong connectedness, It is focussed and following the trend. It can apply to general specialties.* One teacher said that *"In general the social support model can be applied in many areas, e.g., at the schools, health care institutions, including non-governmental organisations. One professional nurse also added that "The model can be applied to all families with disabled persons".*

7.2.4 How important is the social support model

All experts agreed that the social support model is of importance in practice, education and valuable for creating a desired future as evidenced by one professional nurse who indicated that "*The model is very important as everybody will be informed from government stakeholders to families about ASD management and attitudes towards ASD will improve".* One parent added that "*If this model is applied correctly it can bring a positive impact to the families of learners with ASD, teachers, professional specialists and ASD learners themselves. The more the families are given a high level of support, the lower the burden or the stress they will experience with their ASD children. Therefore, parents can report a higher level of positive support as they may be having a better understanding of this condition". One teacher added that "the model will assist ASD learners, families and all professionals who are hands-on with ASD learners. It will also serve as a tool or way forward for macro-level to take our learners and their families or recipients into consideration"* Lastly one academic said, *"The model is important because it provides the mental health care providers in the special schools and health establishment with practical guidelines on how to provide social support to families with ASD children".*

7.3 SUMMARY

In this chapter, the social support model to support families with ASD children was validated by experts from two special schools and three universities. Chin and Kramer's (2008) validation criteria were followed to validate the social support model. The experts were asked four questions which include how clear, simple, general and important the social support model is. The feedback from the panel was discussed extensively to create an understanding of the application of the model. The researcher considered the comments from the experts by making some changes to the model. The following chapter discusses the summary, recommendations, limitations, and conclusion of the study.

CHAPTER 8

SUMMARY OF RESEARCH FINDINGS, RECOMMENDATIONS AND CONCLUSION

8.1 INTRODUCTION

Chapter 7 dealt with the validation of the social support model for families of children with ASD. Chapter 8 presents a summary of the study, and focusses on its limitations, conclusion, and recommendations for the application of the model to facilitate support for families with ASD children in nursing practice, research and education.

8.2 CONCLUSION OF THE PHASES

The study aimed to explore and describe the experiences of families and teachers regarding the provision of support when caring for children with ASD, then to develop and validate a social support model for families of children with ASD in the Gauteng and Limpopo provinces of South Africa the model addresses the complex needs of families with ASD children and could assist families in building their capacity to care for, and protect their ASD children. The model could serve as a reference framework for professional nurses in different spheres of health care and education to promote social support to families with ASD children. The study had four objectives which were divided into three phases.

Phase 1: Objective 1: To explore and describe the experiences of families sand teachers regarding the support of families with ASD children in the Gauteng and Limpopo provinces of South Africa.

Objective 2: To identify and analyse the main concepts related to the support of families with ASD children leading to the development of a conceptual framework for the provision of a social support model for families with ASD children in the Gauteng and Limpopo provinces in South Africa.

Phase 2: Objective 3: To develop and describe a model for the provision of social support for families with ASD children in special schools of the Gauteng and Limpopo provinces in South Africa.

Phase 3: **Objective 4:** To validate the effectiveness of the social support model for families of children with ASD in the Gauteng and Limpopo provinces in South Africa.

The following description of the conclusions of the phases of the study will indicate whether the objectives mentioned above were met.

Phase 1: Objective 1: To explore and describe the experiences of families and teachers regarding the support of families with ASD children in the Gauteng and Limpopo provinces of South Africa.

This phase was achieved in Chapters 1, 2, 3 and 4 of the study. In Chapter 1, an overview of the research study was given to familiarise readers with the introduction and background of the research that led to the formulation of the problem statement. The statement of the problem specifies the experiential observations that influenced the study. Little was known about the support provided to families with ASD children in the Gauteng and Limpopo provinces and this lack of knowledge was viewed as a motivation for the study by the researcher.

In Chapter 2, a comprehensive review of earlier studies pertinent to the support of families with ASD children was conducted. The review of the literature is presented throughout the study to guide the exploration of the existing literature. The literature provided a basis for refining and delineating the main concepts and the relationships between them.

In Chapter 3, a qualitative, explorative, descriptive, contextual design employing a phenomenological approach and theory-generating study was conducted using semi-structured and focus group interviews to collect data from 37 participants consisting of 19 primary caregivers and 18 teachers. Saturation of data determined the number of participants. The participating teachers were employed at 11 special schools of which eight special schools were selected in Limpopo Province and three in Gauteng Province.

In Chapter 4, themes and subthemes are grouped according to the province and category of participants. This section was divided into four groups as follows:

Group A is referred to as the Limpopo Province Primary Caregivers (LPPC), Group B refers to the Limpopo Province Teachers (LPT), Group C refers to the Gauteng Province Primary Caregivers (GPPC) and Group D refers to the Gauteng Province Teachers (GPT). The themes and subthemes are supported by a literature control that reinforces the study results and participants' verbatim statements which are presented in italics.

The findings showed that families and teachers identified multiple characteristics of children with ASD. ASD was found to be complex because it is an invisible and unpredictable condition with diagnostic challenges. Both groups of primary caregivers in the Gauteng and Limpopo provinces emphasised similar behavioural symptoms that they observed and experienced when caring for ASD children. Similarly, the characteristics were also identified by teachers at school. These associated behavioural symptoms were present from early childhood and interfere with everyday functioning.

ASD was found to have effects on the caregivers and teachers. Families experienced severe stress which was influenced by a poor prognosis, impaired communication, need to model self-care, delayed developmental milestones, having to care for an older child who acted like an infant, denial, disbelief, concern about the future, and severe isolation from the caring burden. On the other hand, teachers experienced the frustration of teaching ASD children.

Families experienced a lack of social support which was influenced by deficient school transport for their ASD children, a lack of money due to unemployment, a lack of support from the spouse as a result of the blame laid on each other, a lack of emotional support from health care professionals, a lack of spiritual support, and a knowledge deficit with regard to ASD., Children with ASD are also rejected by the community due to their ignorance about the condition, and subjected to sexual abuse. The family is also stigmatised, and have to join long queues at the hospital as there are waiting lists for admission and long waiting times during follow-up visits.

Families identified a variety of social support needs to be provided to meet the needs, concerns, and priorities of the ASD child and their families. These include the following:

- Emotional support to cope with the stress caused by having a child with ASD. Informal support from a partner, friends, families, siblings, the community, and significant others to gain support. In addition,
- Informational support such as parental training and community awareness for access to quality information is needed. The initiation of a support group for the sharing of experiences between parents with ASD children is required. Continuous assessment of the ASD child by a specialist and more specialists in ASD to diagnose and properly manage the child are needed.
- Instrumental support such as autism schools, sheltered employment for adults with ASD, and adequate school transport for ASD children is required for a better future for the children;
- Appraisal support such as getting feedback from the specialists, and a home visit by nurses for needs assessments are needed. A model is, therefore, required to facilitate the provision of social support for families with ASD children to facilitate the interactional exchange process between families, professional practitioners and teachers to enable the families to access social support services.

Phase 1: Objective 2: To identify and analyse the main concepts related to the support of families with ASD children that led to the development of a conceptual framework for the provision of a social support model for families with ASD children in the Gauteng and Limpopo provinces in South Africa.

This Phase was achieved in Chapters 2 and 4 and it corresponds to objective 2. The provision of social support emerged as the main concept and other concepts related to it were identified. As suggested by Walker and Avant (2011), the identified concepts in the provision of social support were defined separately to give their conceptual and contextual meanings. Provision was defined in this study as the action of supplying support services to families of children with ASD in the Gauteng and Limpopo provinces, South Africa.

Social support in this study is the on-going care and support of families with ASD children to minimise the negative effects of having a child with ASD and identified emotional, spiritual, social, physical, informational and instrumental needs, through interactions with professional practitioners, teachers, and significant others. Provision of social support in this study refers to an on-going provision of emotional, informational, instrumental and appraisal support services to families of children with ASD to address complex needs and assist families to build their capacity to care for, and protect their ASD children, through adequate healthcare provision. It requires the creation of a supportive environment at special schools for ASD children and their families to facilitate participation in their healthcare.

A list of defining attributes for social support was generated for each concept. A model case, borderline and a contrary case were constructed and described to clarify the meaning of the central concept provision of social support. Antecedents, consequences and empirical referents for the provision of social support were identified and described. Finally, related concepts were identified and then classified by using a list suggested by Dickoff et al (1968).

Phase 2: Objective 3: To develop and describe a model for the provision of social support for families with ASD children in special schools of the Gauteng and Limpopo provinces in SA.

This objective was achieved in Chapter 5 and corresponds to the third objective of the study. The model for the provision of social support for families with ASD children in the Gauteng and Limpopo provinces of SA was developed through the steps of theory generating, which are: concept identification and concept analysis, description of relationship statements, evaluation of the model, and formulation and description of guidelines for implementation of the model. The model is innovative as it provides the health and basic education sector with knowledge of what social support for families with ASD children entails. The social support model for families with ASD children was developed and described in Chapter 6ix. Guidelines and actions for operationalisation at macro-, meso-, and micro- levels were outlined. The structure of the model, its purpose, context, concepts, nature of its relationships and assumptions were then described using the approach of Chinn and Kramer (2011).

Phase 3: Objective 4: To validate the operationalisation of the social support model for families of children with ASD in the Gauteng and Limpopo provinces in South Africa.

This objective was achieved in Chapter 7 and it corresponds to objective 4. The social support model was validated based on the criteria offered by Chin and Kramer (2008). Ten experts validated the model. All panel members agreed that the structure of the social support model was understandable and the relationships contained in the model were simple to follow. All members also agreed that the social support model is a general framework that can be applied to other disciplines and is of importance as it will serve as a tool to support families with ASD children.

8.3 LIMITATIONS

The limitations of the research study

- Access to the participants, particularly the primary caregivers, was a problem as most of them resided far from the special schools, some were working and others could not manage to attend interviews due to a lack of money for the transport. The number of teachers of children with ASD in special schools did not exceed more than two except in one of the autism schools in Gauteng Province. This meant that only a few teachers could participate in the focus group interviews due to the difficulties of gathering a group of primary caregivers or teachers together at the same place and time.
- The research investigation was conducted with participants in the selected public special schools in the Gauteng and Limpopo provinces in South Africa, thus limiting the findings to private special schools. However, it is foreseen that this model would be transferable to either private or public special schools.

Despite the limitations of this research study, its purpose, namely to develop and validate a model to support families with ASD children was achieved.

8.4 RECOMMENDATIONS

8.4.1 Recommendations for education

- This social support model must first be implemented in the selected special schools in which data was collected.
- This social support model, if successful and with the necessary changes can be implemented by other special schools in South Africa.
- Professional nurses in the special schools should undergo training sessions on the application of the model so that they can teach other health practitioners and teachers the scientific approach to supporting and empowering families with ASD children.
- A support model for families of children with ASD should form part of the mental health care and nursing education curriculum in general for the comprehensive four-year courses, one-year diploma in psychiatric nursing science and postgraduate courses for teachers of children with special needs.
- Mental health care nursing educators should undergo training sessions on the model so that they can teach the mental health care learner nurses to apply the model when treating families of children with ASD.

8.4.2 Recommendations for nursing research

- The social support model should be implemented within the special schools and its effectiveness, therefore, should be evaluated to make changes if necessary through a post-doctoral degree.
- This social support model could be presented at educational conferences and in published journal articles on this research study.
- It is recommended that further research be conducted on the following topics: A quantitative study to measure the level of stress among families with ASD children in rural and urban areas of South Africa.

8.4.3 Recommendations for practice

- Guidelines and actions for the operationalisation of the support model should be made available to all special schools in South Africa.
- Increased awareness of the support model for families with ASD children through presentations to the provincial department of basic education in the Limpopo and Gauteng provinces should be initiated.
- The current study suggests that mental health care providers who are involved in the diagnosis of children with ASD should provide families with relevant information regarding the condition of their children and skills in the management of behavioural problems.
- All special schools, particularly in Limpopo Province should have adequate mental health care providers (professional specialist support personnel) to provide support to the families of learners with ASD enrolled in their schools relating to parental educational guidance, psychological, emotional, social and instrumental support and other therapeutic support.
- The government should create more possible career opportunities for children with special needs after their training at special schools. Families must also be advised on the best possible career opportunities available to ASD learners as families are worried about the future of their children.
- Special schools must provide daily transport for all those learners who require transport to, and from school. All vehicles used to transport learners in general should be accessible for the transport of ASD learners as well.
- The Department of Basic Education at national, provincial and district levels should provide special schools with adequate physical infrastructure, learning and teaching support materials, assistive devices and technology.
- Special schools specialising in ASD and adult ASD centres should be built in Limpopo Province so that organised training in the field of various categories of disability can occur.

- Support groups for families with ASD should be established in special schools or communities for families to share their experiences with regard to their children with ASD.
- When planning the programmes special schools should consider personnel use, distribution and capacity building, curriculum delivery, physical infrastructure, learning and teaching support materials, assistive devices and technology and ICTs.
- Mental health care providers should be encouraged to take action and participate in the development of policies for children with special needs.

8.5 SUMMARY OF THE RESEARCH STUDY

In this final chapter an overview of the research process has been provided, which reflected on the purpose of the research and the objectives that have been achieved. The limitations of the study were identified. Recommendations for the support of families with ASD children in special school settings, and aimed at practice, education and research were presented.

In conclusion, the study has shown that having a child with ASD is an emotionally stressful situation with which to cope. The researcher believes that families can, and should be supported in this stressful environment. The aim of supporting families is to ensure that once their family support needs are met, they will live in a safe, calm supportive environment and assume responsibility for meeting their own support needs. However, to achieve this outcome, an interactional exchange process between the professional nurses, other professional practitioners, families, and teachers of ASD children is important.

This study should serve as a point of departure for the operationalisation of a model to support families with ASD children in the Limpopo and Gauteng provinces of South Africa.

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World Health Organization *see* WHO

www.municipalities.co.za Provide full bibliographical details of publication in which maps appeared

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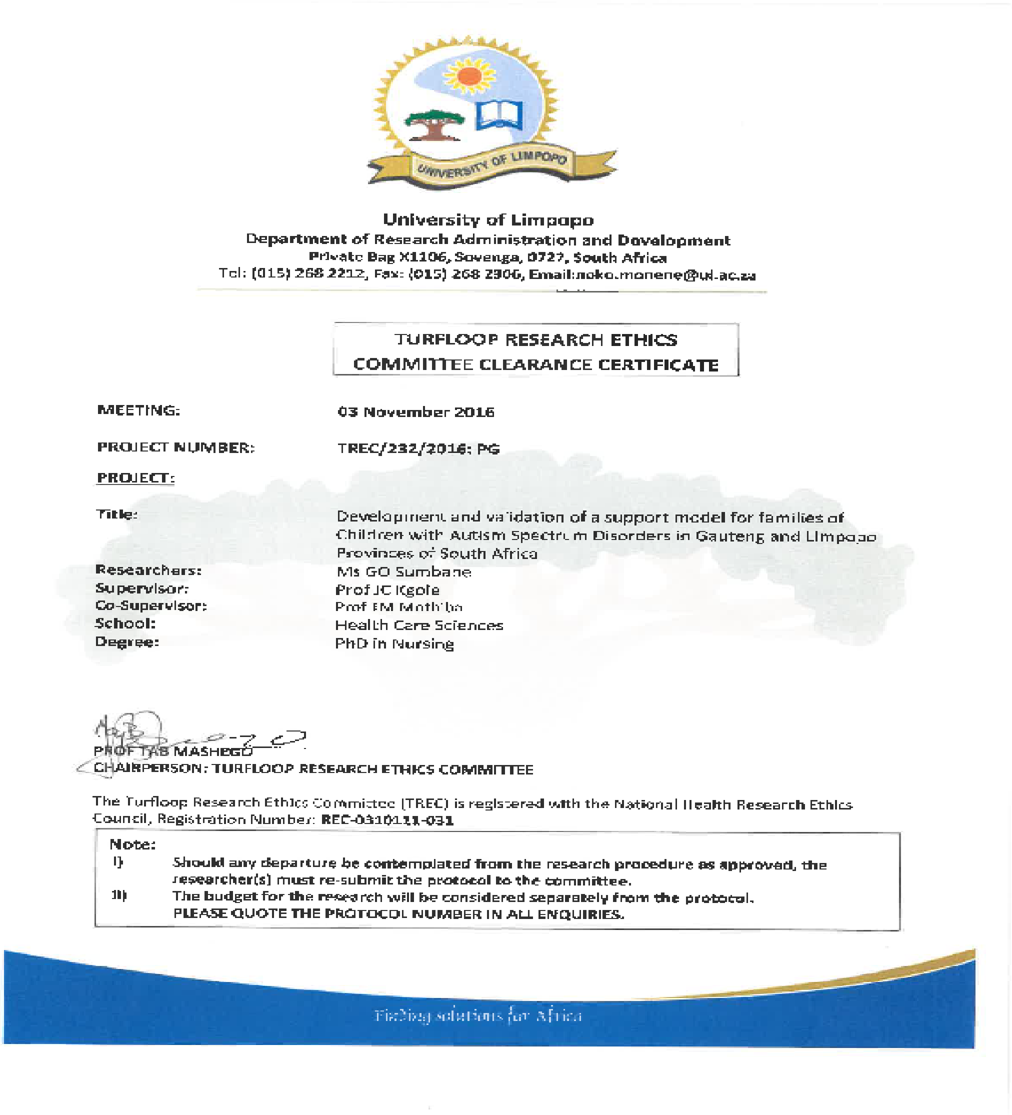
ANNEXURES A: Ethical clearance certificate



University of Limpopo
Department of Research Administration and Development
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 2212, Fax: (015) 268 2306, Email:noko.monene@ul.ac.za

TURFLOOP RESEARCH ETHICS COMMITTEE CLEARANCE CERTIFICATE

MEETING:	**03 November 2016**
PROJECT NUMBER:	**TREC/232/2016: PG**

PROJECT:

Title:	Development and validation of a support model for families of Children with Autism Spectrum Disorders in Gauteng and Limpopo Provinces of South Africa
Researchers:	Ms GO Sumbane
Supervisor:	Prof JC Kgole
Co-Supervisor:	Prof FM Mothiba
School:	Health Care Sciences
Degree:	PhD in Nursing

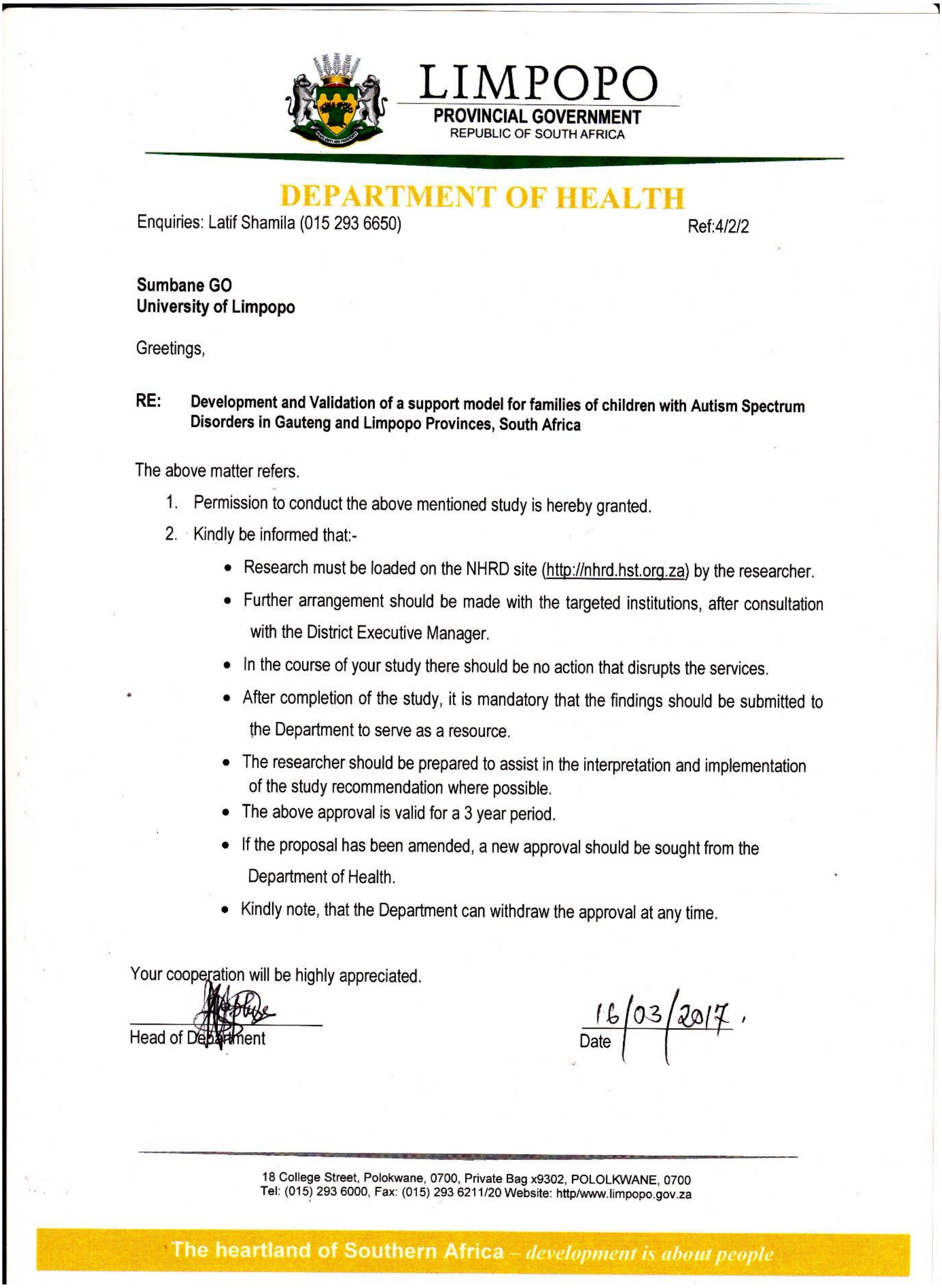
PROF TAB MASHEGO
CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE

The Turfloop Research Ethics Committee (TREC) is registered with the National Health Research Ethics Council, Registration Number: **REC-0310111-031**

Note:
i) **Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.**
ii) **The budget for the research will be considered separately from the protocol.**
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

Finding solutions for Africa

ANNEXURE B: Department of Health Permission to conduct research



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Latif Shamila (015 293 6650) Ref:4/2/2

Sumbane GO
University of Limpopo

Greetings,

RE: Development and Validation of a support model for families of children with Autism Spectrum Disorders in Gauteng and Limpopo Provinces, South Africa

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
    - Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.
    - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
    - In the course of your study there should be no action that disrupts the services.
    - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
    - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
    - The above approval is valid for a 3 year period.
    - If the proposal has been amended, a new approval should be sought from the Department of Health.
    - Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.

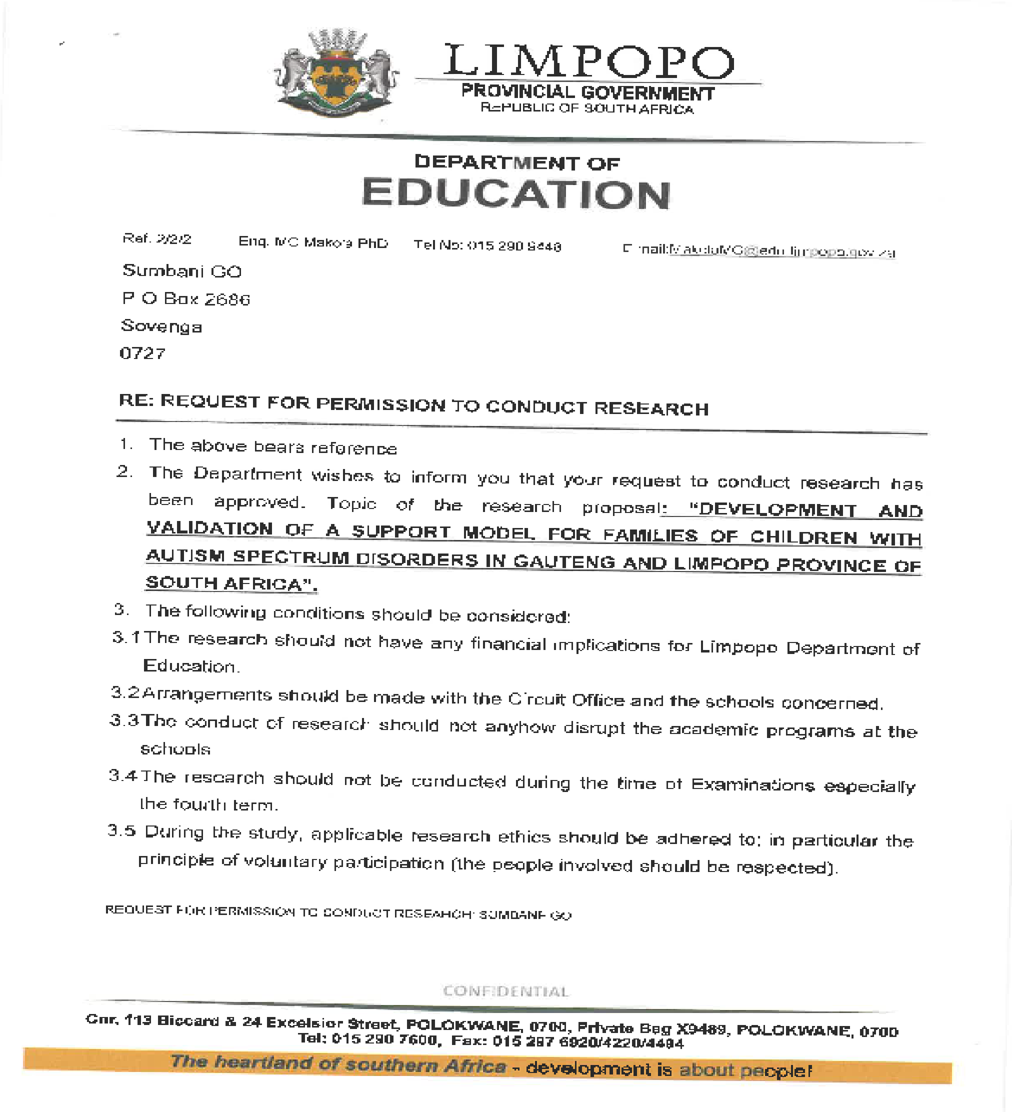
Head of Department

16/03/2017.
Date

18 College Street, Polokwane, 0700, Private Bag x9302, POLOLKWANE, 0700
Tel: (015) 293 6000, Fax: (015) 293 6211/20 Website: http/www.limpopo.gov.za

The heartland of Southern Africa – *development is about people*

ANNEXURE C: Department of Basic Education permission to conduct research



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF
EDUCATION

Ref. 2/2/2 Enq. MC Makola PhD Tel No: 015 290 9448 E-mail: MakolaMC@edu.limpopo.gov.za

Sumbani GO
P O Box 2686
Sovenga
0727

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH

1. The above bears reference
2. The Department wishes to inform you that your request to conduct research has been approved. Topic of the research proposal: **"DEVELOPMENT AND VALIDATION OF A SUPPORT MODEL FOR FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDERS IN GAUTENG AND LIMPOPO PROVINCE OF SOUTH AFRICA".**
3. The following conditions should be considered:

3.1 The research should not have any financial implications for Limpopo Department of Education.

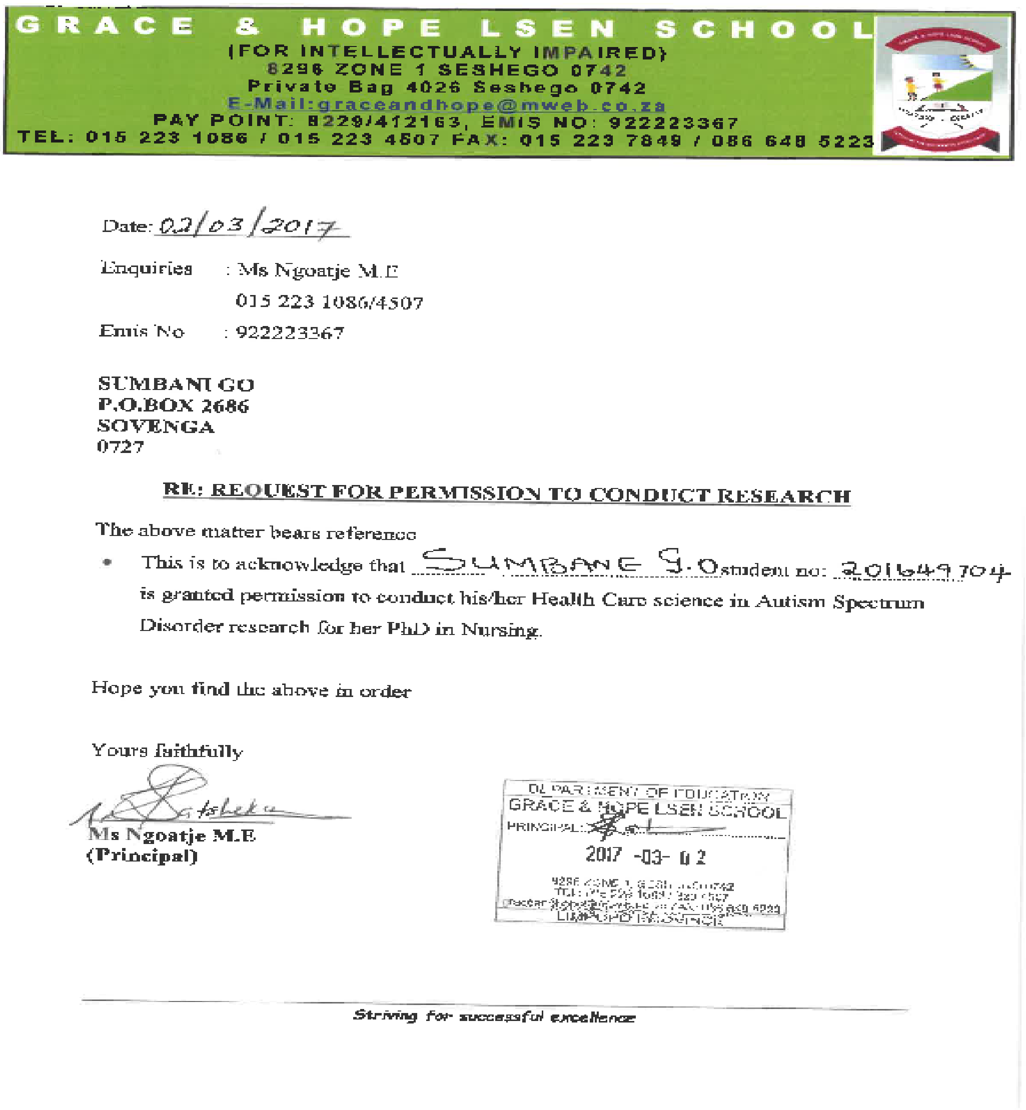
3.2 Arrangements should be made with the Circuit Office and the schools concerned.

3.3 The conduct of research should not anyhow disrupt the academic programs at the schools

3.4 The research should not be conducted during the time of Examinations especially the fourth term.

3.5 During the study, applicable research ethics should be adhered to; in particular the principle of voluntary participation (the people involved should be respected).

ANNEXURE D: Special school A permission to collect data



GRACE & HOPE LSEN SCHOOL
(FOR INTELLECTUALLY IMPAIRED)
8296 ZONE 1 SESHEGO 0742
Private Bag 4026 Seshego 0742
E-Mail:graceandhope@mweb.co.za
PAY POINT: 8229/412163, EMIS NO: 922223367
TEL: 015 223 1086 / 015 223 4507 FAX: 015 223 7849 / 086 648 5223

Date: 02/03/2017

Enquiries : Ms Ngoatje M.E
015 223 1086/4507
Emis No : 922223367

SUMBANI GO
P.O.BOX 2686
SOVENGA
0727

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH

The above matter bears reference

- This is to acknowledge that SUMBANE G.O student no: 201649704 is granted permission to conduct his/her Health Care science in Autism Spectrum Disorder research for her PhD in Nursing.

Hope you find the above in order

Yours faithfully

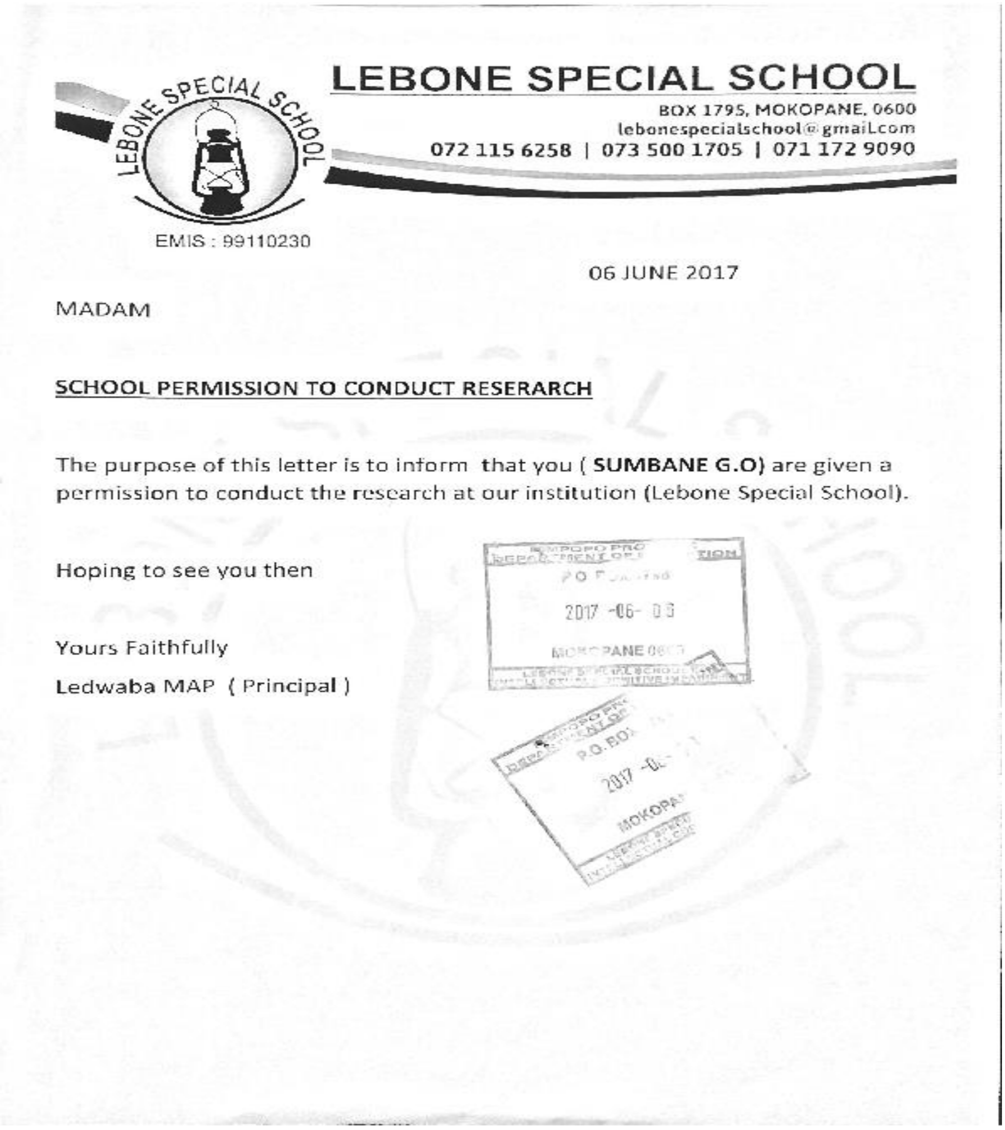
Ngoatjeh Ratsheku

Ms Ngoatje M.E
(Principal)

DEPARTMENT OF EDUCATION
GRACE & HOPE LSEN SCHOOL
PRINCIPAL:
2017 -03- 02
8296 ZONE 1 SESHEGO 0742
TEL: 015 223 1086 / 223 4507
[illegible] FAX: 086 648 5223
LIMPOPO PROVINCE

Striving for successful excellence

ANNEXURE E: Special school B permission to collect data



LEBONE SPECIAL SCHOOL
BOX 1795, MOKOPANE, 0600
lebonespecialschool@gmaiLcom
072 115 6258 | 073 500 1705 | 071 172 9090
EMIS : 99110230

06 JUNE 2017

MADAM

SCHOOL PERMISSION TO CONDUCT RESERARCH

The purpose of this letter is to inform that you (**SUMBANE G.O)** are given a permission to conduct the research at our institution (Lebone Special School).

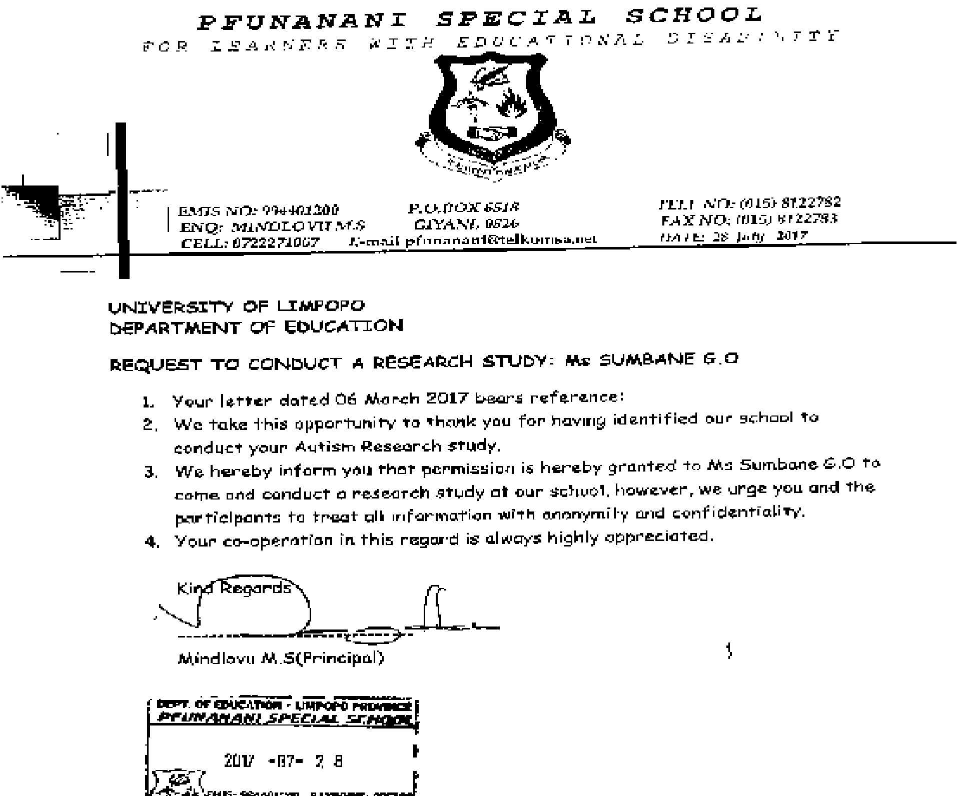
Hoping to see you then

Yours Faithfully

Ledwaba MAP (Principal)

2017 -06- 06
MOKOPANE

ANNEXURE F: Special school C permission to collect data



PFUNANANI SPECIAL SCHOOL
FOR LEARNERS WITH EDUCATIONAL DISABILITY

EMIS NO: 994401200
ENQ: MINDLOVU M.S
CELL: 0722271007

P.O.BOX 6518
GIYANI, 0826
E-mail pfunanani@telkomsa.net

TEL NO: (015) 8122782
FAX NO: (015) 8122783
DATE: 28 July 2017

UNIVERSITY OF LIMPOPO
DEPARTMENT OF EDUCATION

REQUEST TO CONDUCT A RESEARCH STUDY: Ms SUMBANE G.O

1. Your letter dated 06 March 2017 bears reference:
2. We take this opportunity to thank you for having identified our school to conduct your Autism Research study.
3. We hereby inform you that permission is hereby granted to Ms Sumbane G.O to come and conduct a research study at our school, however, we urge you and the participants to treat all information with anonymity and confidentiality.
4. Your co-operation in this regard is always highly appreciated.

Kind Regards

Mindlovu M.S(Principal)

DEPT. OF EDUCATION - LIMPOPO PROVINCE
PFUNANANI SPECIAL SCHOOL
2017 -07- 28

ANNEXURE G: Special school D permission to collect data

THUSANANG SPECIAL SCHOOL
SCHOOL FOR THE INTELLECTUALLY IMPAIRED

EMIS: 910131676
Enquiries: Mashishi M. E

27 March 2017
Reference: 201649704
Attention: Sumbane Gsakani
University of Limpopo
Turfloop

Madam

PERMISSION TO DO RESEARCH REPORT FOR DATA COLLECTION ON AUTISM SPECTRUM DISORDER: Yourself

1. This letter serves as confirmation that permission is hereby granted for the data collection on Autism Spectrum Disorder
2. This institution therefore has no objection to conduct your research studies as the Head of Department in Education is aware of your request and has granted permission for the conduction of research in Limpopo schools.
3. Wish you well in your studies

Yours faithfully

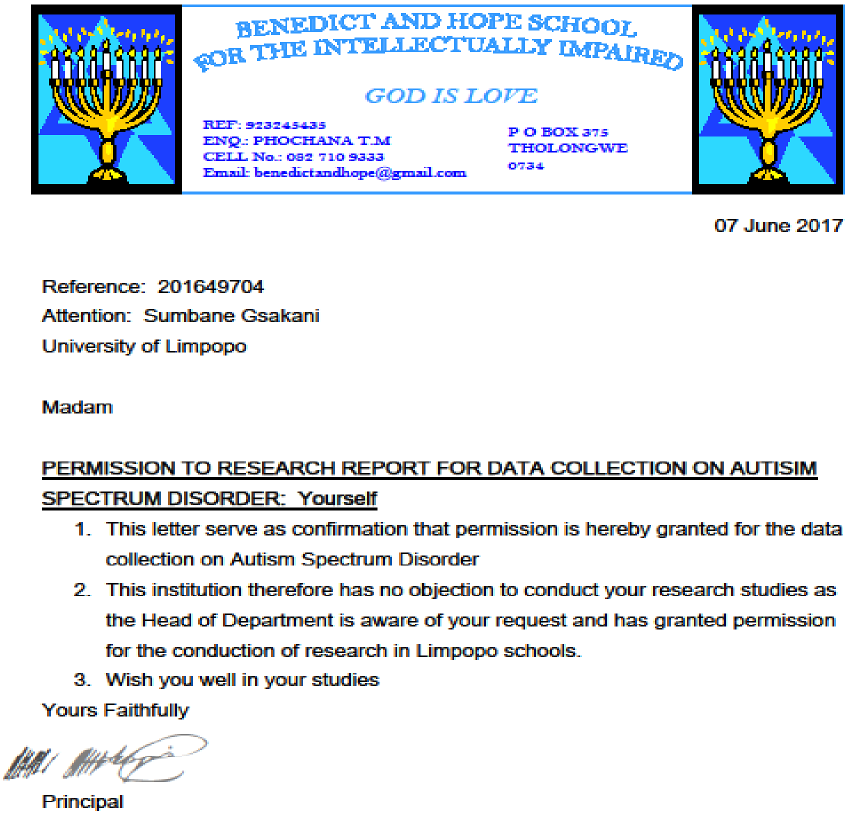
M. E Mashishi

Principal

DEPARTMENT OF EDUCATION
THUSANANG SPECIAL SCHOOL
2017 -03- 27
P.O BOX 2521
BELA-BELA 0480
TEL: 014 737 7746 | FAX: 014 737 7743
LIMPOPO PROVINCE

Box 2521,Bela-Bela, 0481. Tel: (014) 737 7746 Fax: (014) 737 7743
Email:thusanangschool@telkomsa.net

ANNEXURE H: Special school E permission to collect data



BENEDICT AND HOPE SCHOOL
FOR THE INTELLECTUALLY IMPAIRED

GOD IS LOVE

REF: 923245435
ENQ.: PHOCHANA T.M
CELL No.: 082 710 9333
Email: benedictandhope@gmail.com

P O BOX 375
THOLONGWE
0734

07 June 2017

Reference: 201649704
Attention: Sumbane Gsakani
University of Limpopo

Madam

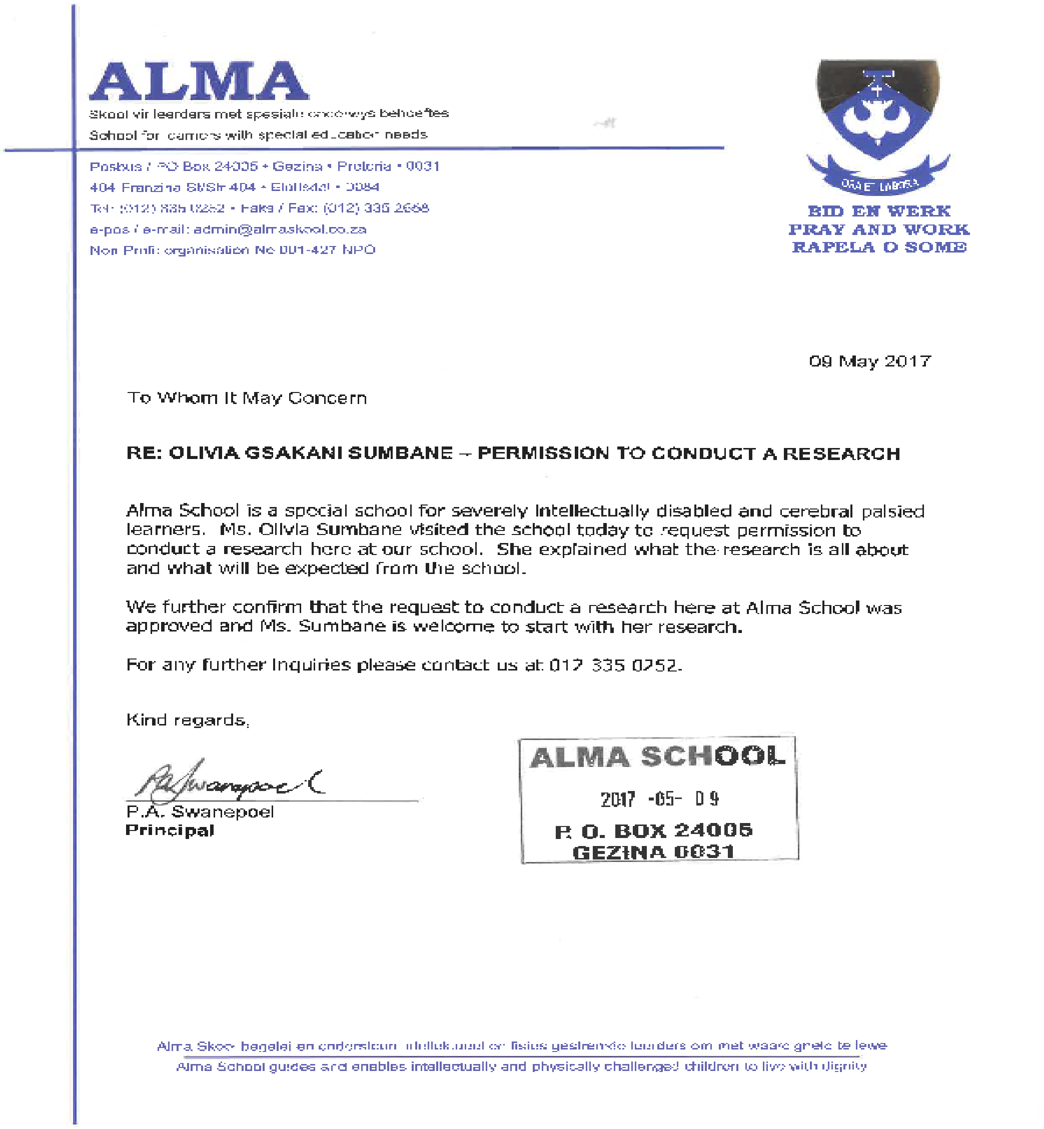
<u>PERMISSION TO RESEARCH REPORT FOR DATA COLLECTION ON AUTISIM SPECTRUM DISORDER: **Yourself**</u>

1. This letter serve as confirmation that permission is hereby granted for the data collection on Autism Spectrum Disorder
2. This institution therefore has no objection to conduct your research studies as the Head of Department is aware of your request and has granted permission for the conduction of research in Limpopo schools.
3. Wish you well in your studies

Yours Faithfully

Principal

ANNEXURE I: Special school F permission to collect data



ALMA
Skool vir leerders met spesiale onderwysbehoeftes
School for learners with special education needs

Posbus / PO Box 24005 • Gezina • Pretoria • 0031
404 Franzina St/Str 404 • Eloffsdal • 0084
Tel: (012) 335 0252 • Faks / Fax: (012) 335 2668
e-pos / e-mail: admin@almaskool.co.za
Non Profit organisation No 001-427 NPO

ORA ET LABORA
BID EN WERK
PRAY AND WORK
RAPELA O SOME

09 May 2017

To Whom It May Concern

RE: OLIVIA GSAKANI SUMBANE – PERMISSION TO CONDUCT A RESEARCH

Alma School is a special school for severely intellectually disabled and cerebral palsied learners. Ms. Olivia Sumbane visited the school today to request permission to conduct a research here at our school. She explained what the research is all about and what will be expected from the school.

We further confirm that the request to conduct a research here at Alma School was approved and Ms. Sumbane is welcome to start with her research.

For any further Inquiries please contact us at 017 335 0252.

Kind regards,

PA Swanepoel
P.A. Swanepoel
Principal

ALMA SCHOOL
2017 -05- 09
P. O. BOX 24005
GEZINA 0031

Alma Skool begelei en ondersteun intellektueel en fisies gestremde leerders om met waardigheid te lewe
Alma School guides and enables intellectually and physically challenged children to live with dignity

ANNEXURE J: Special school G permission to collect data

SEDIBA SA BOPHELO

BANA BA THARI SCHOOL FOR LEARNERS
WITH INTELLECTUAL IMPAIRMENTS
Enq: Marishane L.M.
Tel: 081 468 5653
Cell: 083 957 6063

P.O. Box 638
Sovenga
0727

EMIS NO.923242552

10 March 2017

Mrs Sumbane Gsakani
P O.BOX 7686
Sovenga
0727

Madam

PERMISSION TO CONDUCT RESEARCH AT BANA BA THARI SPECIAL SCHOOL

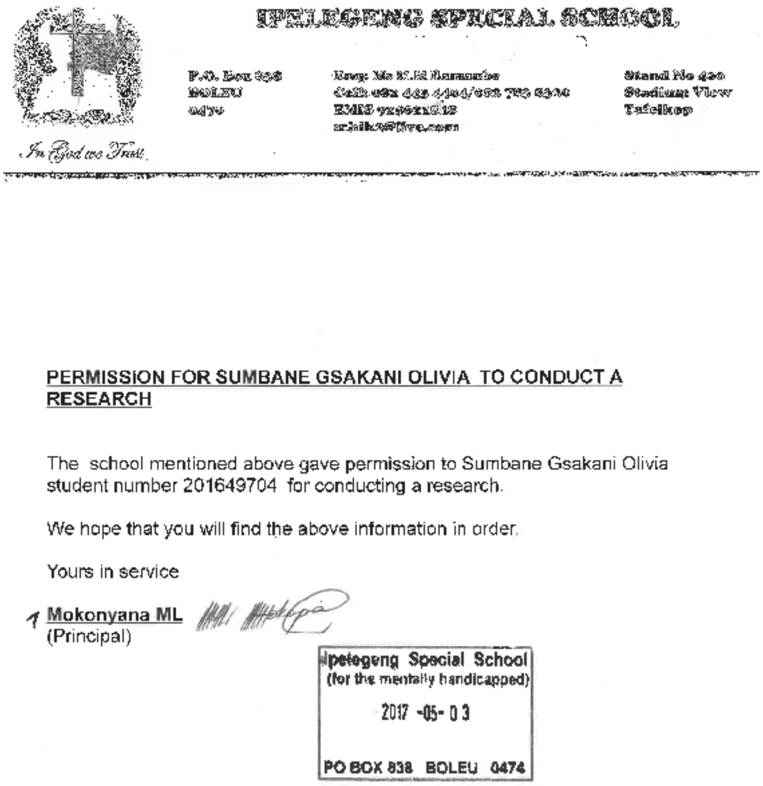
1.The above bears reference.
2.We received your application to conduct a research at our Institution.
3.Therefore,we would like to inform you that the School has granted you permission to proceed with your research project titled:**DEVELOPMENT AND VALIDATION OF A SUPPORT MODEL FOR FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN GAUTENG AND LIMPOPO PROVINCES OF SOUTH AFRICA.**

4.Hoping that you will get the necessary assistance you need from our staff members

Marishane Lm
Principal

DEPARTMENT OF EDUCATION
BANA BA THARI SPECIAL SCHOOL
FOR LEARNERS WITH INTELLECTUAL
2017 -03- 10
AND COGNITIVE IMPAIRMENTS
[illegible]
[illegible]
LIMPOPO PROVINCE

ANNEXURE K: Special school H permission to collect data



IPELEGENG SPECIAL SCHOOL

P.O. Box 838
BOLEU
0474

Enq: Ms [illegible]
Cell: [illegible]
EMIS [illegible]
[illegible]

Stand No [illegible]
Stadium View
Tafelkop

In God we Trust

PERMISSION FOR SUMBANE GSAKANI OLIVIA TO CONDUCT A RESEARCH

The school mentioned above gave permission to Sumbane Gsakani Olivia student number 201649704 for conducting a research.

We hope that you will find the above information in order.

Yours in service

Mokonyana ML
(Principal)

Ipelegeng Special School
(for the mentally handicapped)
2017 -05- 03
PO BOX 838 BOLEU 0474

ANNEXURE L: Special school I permission to collect data

UNICA SCHOOL FOR CHILDREN WITH AUTISM

4 May 2017

Mrs Sumbane GO
Student number: 201649704
PhD in Nursing Science
University of Limpopo

Dear Ms. Sumbane GO,

Project title: *Development and validation of a support model for families of children with Autism Spectrum Disorders in Gauteng and Limpopo Provinces of South Africa*

Permission is hereby granted for the use of participants from UNICA School for Autism, in Pretoria.

It is noted that you will be constituting your sample by Interviews with teachers, teacher assistants and parents of children with Autism.

Data collected must be treated with due confidentiality and anonymity.

Yours faithfully

……………………………
Mrs Perumal
Principal of UNICA school

UNICA SCHOOL
Menlo Park

ANNEXURE M: Co-Cording certificate

Private Bag X1290, Potchefstroom
South Africa 2520

Tel: 018 299-1111/2222
Fax: 018 299-4910
Web: http://www.nwu.ac.za

School of Nursing Science
Tel: 0182991833
Fax: 018299182
Email: Belinda.Scrooby@nwu.ac.za

Sumbane Gsakani Olivia
Student number 201649704

18 June 2019

Dear Sumbane Gsakani Olivia

CO-CODING COMPLETED FOR DATA

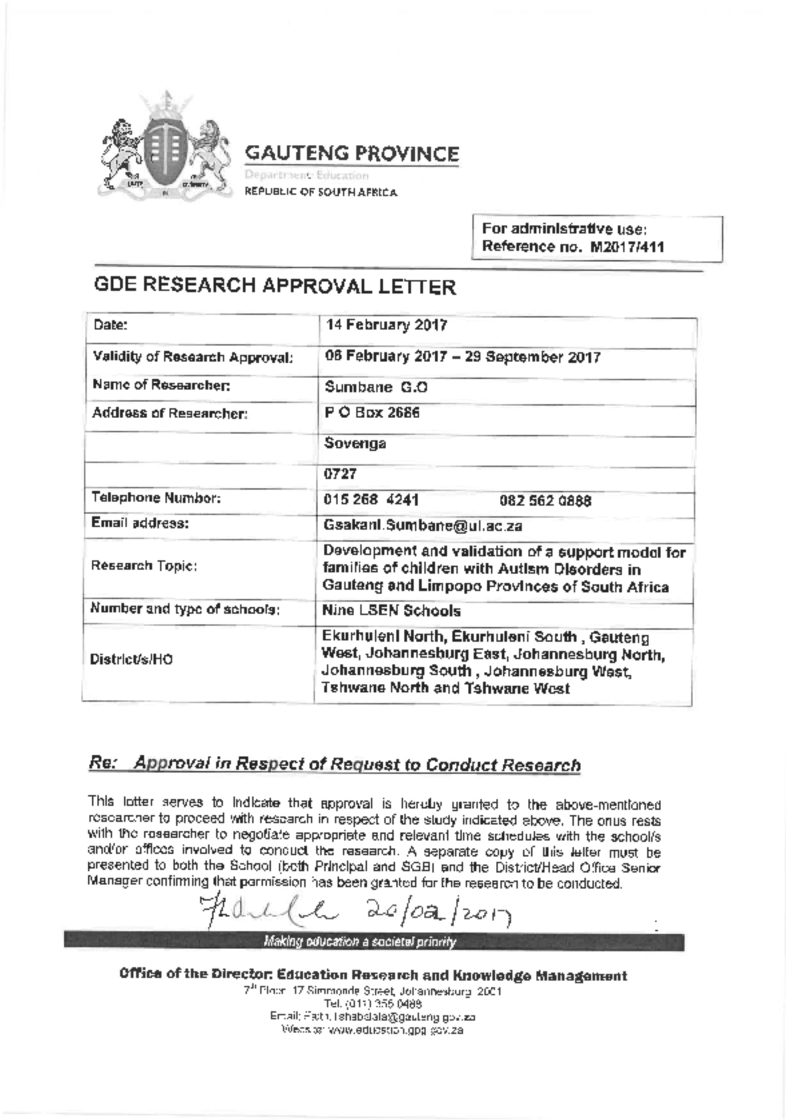
I hereby confirmed that data were co-coded by myself for student Olivia Gsakani Sumbane with student number 201649704.

Yours sincerely

Dr Belinda Scrooby
Senior lecturer: Anatomy

Original details: (12335746) C:\Users\NWUUser\Desktop\Co-coding\Co-coding completed for data Sumbane.docm
18 June 2019

ANNEXURE N: Gauteng province Department of basic Education approval



GAUTENG PROVINCE
Department: Education
REPUBLIC OF SOUTH AFRICA

For administrative use:
Reference no. M2017/411

GDE RESEARCH APPROVAL LETTER

Date:	14 February 2017
Validity of Research Approval:	06 February 2017 – 29 September 2017
Name of Researcher:	Sumbane G.O
Address of Researcher:	P O Box 2686
	Sovenga
	0727
Telephone Number:	015 268 4241 082 562 0888
Email address:	Gsakani.Sumbane@ul.ac.za
Research Topic:	Development and validation of a support model for families of children with Autism Disorders in Gauteng and Limpopo Provinces of South Africa
Number and type of schools:	Nine LSEN Schools
District/s/HO	Ekurhuleni North, Ekurhuleni South , Gauteng West, Johannesburg East, Johannesburg North, Johannesburg South , Johannesburg West, Tshwane North and Tshwane West

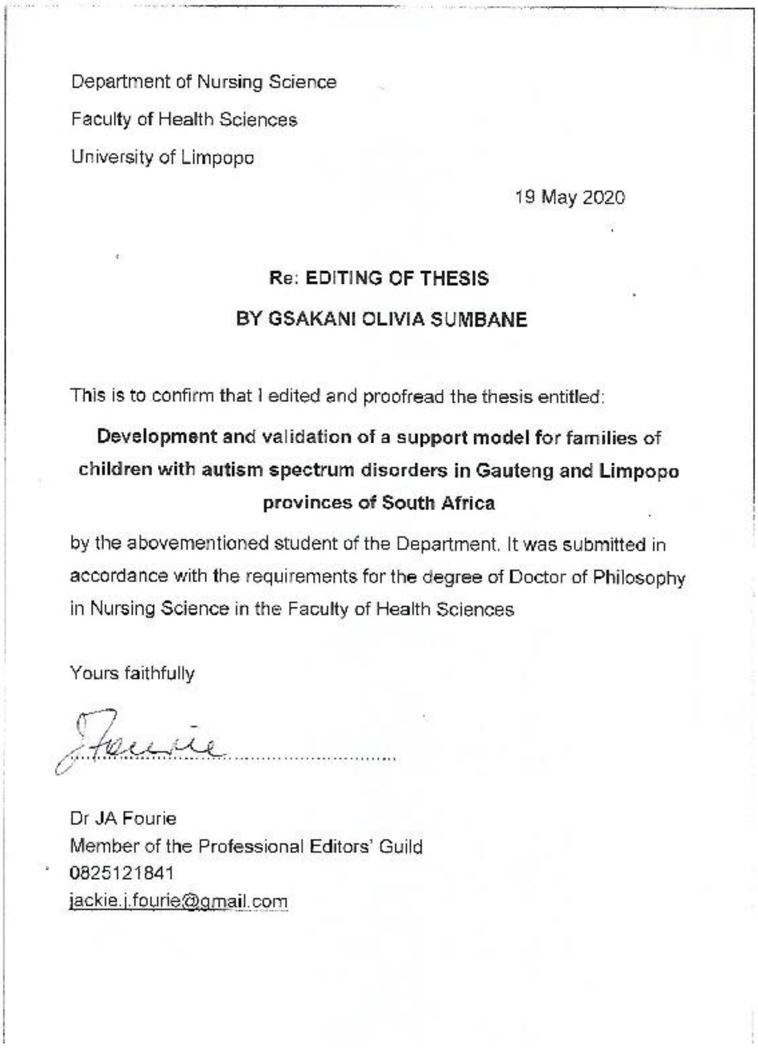
Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

20/02/2017

Making education a societal priority

ANNEXURE O: Language editing certificate



Department of Nursing Science
Faculty of Health Sciences
University of Limpopo

19 May 2020

Re: EDITING OF THESIS
BY GSAKANI OLIVIA SUMBANE

This is to confirm that I edited and proofread the thesis entitled:

Development and validation of a support model for families of children with autism spectrum disorders in Gauteng and Limpopo provinces of South Africa

by the abovementioned student of the Department. It was submitted in accordance with the requirements for the degree of Doctor of Philosophy in Nursing Science in the Faculty of Health Sciences

Yours faithfully

J Fourie

Dr JA Fourie
Member of the Professional Editors' Guild
0825121841
jackie.j.fourie@gmail.com

ANNEXURE P: Interview guide

Interview guide for the primary caregivers

Central question

- Describe in detail your experiences regarding caring for a child with ASD?

Probing questions

- What challenges do you experience when caring for an ASD child?
- What existing support services are in place to support ASD children?
- What are the support needs of the family of children with ASD?
- What are the coping strategies utilized by primary caregivers of children with ASD?
- What is your knowledge regarding ASD?

Interview guide for the teachers

Central question

- Describe in detail your experiences regarding teaching children with ASD?

Probing questions

- What challenges do you experience when teaching ASD children?
- What existing support services are in place to support ASD children?
- What are the support needs of the teachers of children with ASD?
- What are the coping strategies utilized by teachers of children with ASD?
- What is your knowledge regarding ASD?

ANNEXURE Q: Consent form

DEPARTMENT OF NURSING SCIENCE ENGLISH CONSENT FORM

Statement concerning participation in a Clinical Research Project*.

Name of Project / Study: **Development and validation of a support model for families of children with Autism Spectrum Disorders in Gauteng and Limpopo Provinces of South Africa.**

I have read the information and heard the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurized to participate in any way.

I know that sound recordings will be taken of me. I am aware that this material may be used in scientific publications which will be electronically available throughout the world. I consent to this provided that my name is not revealed.

I understand that participation in this Study / Project is completely voluntary and that I may withdraw from it at any time and without supplying reasons.

I know that this Study / Project has been approved by the Turfloop Research Ethics Committee (TREC). I am fully aware that the results of this Study / Project will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

Any questions that I may have regarding the research, or related matters, will be answered by the researcher/s.

If any medical problem is identified at any stage during the research, or when I am vetted for participation, such condition will be discussed with me in confidence by a qualified person and/or I will be referred to my doctor.

I indemnify the University of Limpopo and all persons involved with the above project from any liability that may arise from my participation in the above project or that may be related to it, for whatever reasons, including negligence on the part of the mentioned persons.

I hereby give consent to participate in this Study / Project.

Signature of researched person...................Signature of researcher……………………

Signed at……………………………..this…………day of………………..20

Contact NO: 082 562 0888

ANNEXURE R: Model validation instrument

SECTION A

The instrument for validation of the social support model

Please indicate your response to the following questions using the key below:

Yes;		No;

1. CLARITY OF THE STRUCTURE OF SOCIAL SUPPORT MODEL

No	Criteria	Yes	No	Remarks
	Sematic clarity and consistency			
1.1	Are major concepts of the model defined?			
1.2	Are significant concepts clearly defined?			
1.3	Is the amount of explanation appropriate and useful?			
1.4	Are definitions consistent with one another?			
1.5	Are assumptions and purposes compatible with other elements in the model			
	Structural clarity and consistency			
1.6	Is the context of the social support model clearly described?			
1.7	Is the goal of the social support model clearly set?			
1.8	Do all relationships fits within the structure of the model?			
1.9	Is the model graphically portrayed well in the form of a visual presentation?			
1.10	Do diagrams and structures provide support with one another			
1.11	Is there any interconnection between the concepts used in the model?			
1.12	Were related attributes guiding the interrelationships between concepts and components?			
1.13	Is there any evidence of logic coherence on the frame of reference of the model			

In your own words kindly describe how clear the structure of the social support model is?

____

____

____

____

____

____

2. SIMPLICITY OF THE SOCIAL SUPPORT MODEL

No	Criteria	Yes	No	Remarks
2.1	Is the social support model clear for easy reading?			
2.2	Is the social support model understandable?			
2.3	Are relationships directional			
2.4	Are relationships illustrated			
2.5	Are guidelines formulated for the operationalization of social support model relevant			

In your own words kindly describe the simplicity of the social support model:

____

____

____

____

____

____

3. GENERALITY AND IMPORTANCE OF SOCIAL SUPPORT MODEL

No	Criteria	Yes	No	Remarks
3.1	Is the social support model designed in broad implications to make it applicable in different disciplines?			
3.2	Does the model have the potential to influence mental health actions?			

3.3	Will application of social support model resolve families with ASD children problems			
3.4	Are the concepts within the domain of nursing			
3.5	Can the model be applied to other disciplines			
3.6	Is the social support model addressing the realities of the situation			
3.7	Is the outcome of the social support model achieved			

Based on the information provided on the description of the model, kindly describe in your own words the generality and importance the social support model is:

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Other comments:

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Thank you for your time in completing the model validation report

ANNEXURE S: Transcripts

Date: 15 March 2017

R: = Researcher

P: = Participant

Limpopo Province Teacher No: 6

Introduction: good morning teacher, how are you as I have already indicated I'm Sumbane GO a PhD student from the University of Limpopo. We are about to start with our interview, the questions that I will ask, there will be no right or wrong answer, please answer the questions according to your experience. I am here to investigate issues related to autistic children the first question will be: can you describe in detail your experiences when training or teaching these children in your class?

P: thank you, mam, for my experiences when teaching the learners with autism I'm also learning from them. They learn from me and I also learn from them. They teach something because I have to teach according to their needs, as we know that we are unique in life they are also unique. Even the program that we are using also needs individual education support that is what we are doing here. This type of learner can learn they only need someone with a big heart, patience because according to their disability they don't behave like any other normal learners, but we don't blame them because it is how God made them. So what I have learned since I have been teaching them is that they are trainable, eee… let say you are saying please sit down the learner will be able to sit down when coming to decision, when you said please stop it the learner will stop and another thing is that we are teaching them morning rise ………. They communicate with me, even some most of them are nonverbal with the help of the AAC method because we are using adopted hand signs and we are also using real objects. The adopted one let say please come here, please read here, those that they are having little speech they can read, according to that classroom list there is a name and picture if I ask who is this, those who are having little speech they can say this is so and so because they are looking at the picture. These are the AAC method because maybe if I can point on somebody they cannot remember but when the picture of someone they can say this is so and so. For me, they are trainable even though they are having so many challenges in life but some they can be educable because they differ according to their disabilities.

R: mmm, I heard you say they differ according to their disabilities, kindly share with us their behaviours in class.

P: their behaviours are so different, some behaviours are aloofness, aloofness we mean that the person does not want to be with other people but what to be alone eee… some of them don't want noise that is why they are putting the fingers on the ears, they don't like noise. The second behaviour is that when they do things they repeat like that learner was repeating words we call it echolalia if you say good morning he keeps on saying good morning. The third symptom is that they keep on a routine if you show him this is the door we are going out through this door, even if there is another door on the other side since you have shown him this site every time he wants to go out using this one even if this is locked, this person will stand there he doesn't want to use the other one even myself I learned from them. Those are their behaviours, their behaviours are different they need someone patient if you don't have patience you won't work with learners with autism.

R: mmm, how do you cope as a teacher of children with ASD?

P: The other thing that assisted me a lot is that I was also having a learner with autism, my blood daughter, she was also a part of the New Horizon, and she was here until the age of 21. Because they are leaving at the age of 21, but eee…. Unfortunately at the age of 22, she passed on because she was having epilepsy, she got sick when she was still very young at the age of 4 years. I think even with that thing encouraged I to help them because what I was doing to her I also do it in class, I'm a mother and a teacher and at the same time.

R: mmm, I heard you saying that these children experience different challenges what are they?

P: The challenges are that I don’t have a classroom, the classroom is the crucial one. Number two the classroom is not autism-friendly, as you can see that we are in a mobile class, in another way we can say infrastructure is not good for us if they move around the floor is shaking and we don’t have resources, some of the resources like water that is running in the classroom, we go outside as you come here you saw a learner with a bucket carrying water with a bucket, this is some of the challenges that I’m facing. Because this is educational, life skills I’m teaching them how to wash dishes eee…. I should have running water in the classroom so that I can assist them to teach as we wash like, but for me, it is very difficult. Even the learners are suffering from the noise caused by mobile class especially those who do not want the noise, you see the whole day that poor children close his ears with fingers. You know as their behaviour is exceptional that poor child keeps on doing like that because other children run around. Even the one that is so disruptive always run around. I have one child that is always bulling others so other learners are always afraid of him, if he comes near them they run around as they are afraid of him. This are the challenges that I’m facing. In a classroom in fact according to the method when teaching the learners with ASD they said 1 is to 6 with class assistant. But now I found myself 11 is to 1 without a class assistant really for me is so difficult to work with them. I’m not doing the work according to my expertise because of lack of class assistance is overcrowded. The other challenges are lack of resources. I don’t have adequate resources. Yes because some resources we are using the aided once and unaided resources. Really I have a lot of challenges as I have indicated infrastructure seeing this one is not friendly for them because most of them are having epilepsy. As you know that Autism is coupled with epilepsy, most of them are non-verbal. Only those that can utter words are two. The rest of them lack speech. According to the researchers they said Autism attack most of the boys than the girls that is why here I’m having only three girls and seven boys.

I forgot to mentioned that we don’t have a centre for autism, as they are exiting at the age of 21 years, they are kept at home and our hearts is so broken as educators because even the parents is a challenge to them because they don’t know where to take them.

R: mmm, can you explain more about aided and unaided resources?

P: unaided resources are the once that are to show that sit down and we adopt some of the sign like please sit down those are adopted, please bring the water by showing the bucket, please go to the toilet showing the picture that is unaided, is the one that you are not going to buy but to apply. With the aided once is the resources that maybe bought those eee… in AAC we should use apron as one of our resources, I must wear an apron here with a pockets to put words when I teach so that I will be able to move around with an apron showing them what is this, or match this with this like when I'm teaching colours, I can put different colours and words this side, so that the child can match, those are the aided once.

R: mmm, you have mentioned a lot of challenges, what do you think should be done to overcome the challenges?

P: I'm suggesting that if the department of education they can provide us with a centre for autism, they can provide us with a centre as is one part of the infrastructure at a school base level we must not be in a mobile class, really this is totally not allowed and again the bathrooms are far away from here, I don't have a class assistant, but I have to take them down there next to the junior class, and then some are slow, some are doing like this and then I cannot send them alone. It is my duty as a teacher to go with them. Some can go alone like this little one, when I open the door to say that now is the time for the toilet she will run like she is going to compete with someone, and then others you are still going to say please let us go to the toilet. Maybe if we were having a proper classroom that is having the toilet and the sink inside so that everything is accessible but really we don't have. I'm looking forward to the department to build a centre for autism and also at the school base we must also have a classrooms not a mobile classes. If we are having a proper classroom we are going to extent our support, teach them how to fix up their beds, maybe it will be divided, the other side be the bed site and the other side to be the kitchen site so that we can teach them even simple things like making a juice, simple things as they are trainable. With overcrowding is due to lack of classes if they can build us more classes as we have only two classes for ASD. So it is the duty of the department to see to it that they build and provide us with assistance teachers. According to the researchers a learner with autism his weight is equal to 10 learners because the way in which he learns the ability is weighing 10 learners in the mainstream. If you can count now as they are eleven how many learners do I have in this class?

The other thing that I suggest is that to develop a program for this learners it needs parents, Occupational Therapist, Head of Department, Physio therapist, Principal so many stakeholders. Parents want their children to learn so that they can be assisted for the future. But now I'm developing the program alone without the assistance of the parents and all the stakeholders. We must sit together with health people must also be part of us so that we can share ideas.

R: mmm, how is the parent's response?

P: Sometimes we invite them maybe once a year some they turn up some they don't turn up. But according to the educational program we should sit together as a group sharing ideas, the parents must be there, educators, class assistance and care givers at home as well. Because what I'm teaching here it must be continuous as well at home if they are not part of us really, what I taught them here it won't even practice at home, it is of my concern that they should be part of us.

R: mmm, how many health care practitioners do you have in your school?

P: We don't have any health care practitioners, I'm suggesting that if the department can look into this because I know that they know those that are at the head of department at this sector they know very well that all those stakeholders must be with us when we develop a teaching program but they don't come.

R: mmm, from what you have said it shows that you have experience with regards to ASD, is there anything that you still need to learn?

P: myself as an educator, I need a workshop, where a presenter of the workshop can also be trying to demonstrate with this learners, because in most cases when we attend the workshop is just a lecture and educator is not a practical thing. But for me I wanted the presenters to come and see the class of mine. When they said we must teach this and this we must be demonstrated, not just a theory, it is always a theory. Myself I just have to figure out what works for me or it can work to the child, they must do hands on demonstrations, like when I was in training for education other times lecturers were bringing the kids in the classroom, they call it demonstration they teach and then we observed how the kids were responding from there even for us it was so easy also to go and do as lecture, but now those once who are presenting those workshops they just do theoretical things, they don't come to our kids situation, in fact I want them to come to this school and take this to the hall so that they can demonstrate with them, not lie showing us the video no, for me is a little help but I want hands on is what I like.

R: mmm, have you attended enough workshops for ASD?

P: not enough because this year we are starting with AAC, we are going for training from tomorrow until Friday I will be attending a workshop on AAC and then they said it should be a semester thin, so will attend this semester and then the second semester next year January we are going to sit for an examination, what I have attended is not enough because it was one or two days workshops and always they don't bring our kids along they just said it in a theoretical point of view.

R: mmm, so far as I was listening is like they did on the job training for autism, will it be relevant that they can train a teacher fully in autism-like, for example, physiology, care, and everything, maybe a one year course.

P: the one that I'm talking about that I'm attending tomorrow is a certificate course we are going to learn more about AAC with UNISA, there are 100 educators do that are doing hands-on with.

R: mmm, who is paying for the course?

P: the Department of Education is a learner ship, not internship.

R: how are the children supporting each other in class?

P: they do support each other like this one does not want to wash hands, washing hands is part of our program so that before they can eat is our norm to wash hands first before we eat. The other one I will say so and so please take the other one to the basin to wash hands, they are supporting each other, even when we go for lunch those who are coming with school bags, and they are supporting one another. They are like any other person, only the different behavioural problem that they are having they can support one another.

R. mmm, how is the support from the parents?

P: is less because they only bring the kids here and just go home, and some they don't even pay for funds raising, in our school every Wednesday they are having a snoopy, the school is selling the snack, a packet of Simba's, chocolate, sweets, some of the parents they don't pay. It is the school program for funds raising but it is so painful to see other learners eating and others they don't eat. As a teacher, I always take from my pocket and buy for those learners because every class is given a portion to sell and we take back the money to the office. Some parents pay some they don't pay we keep on requesting money for snoopy some they don't give support.

R: mmm, is there anything that you want to add when it comes to supporting at your school?

P: sometimes this is the most vulnerable group at school because even some of the educators said these autistic learners you must just put a fence here so that the ASD learners can be aside, even educators they cannot cope with our learners, they don't support them. Even the children those that are intellectually impaired some of them can speak they can do this and that sometimes, they can even force our learners to the toilet to do fun things this is the most vulnerable group. Those who are doing hostel supervision they are so vigilante always. During break time two educators and support staff are outside to look the learners, even after school some educators are doing supervision. The clever once even if they are intellectually disabled as you know the degree is not the same they take advantage of them. Some they assault some they try to do eeee…sexual harassment those things are happening. So really we need more power here human resources are needed. When the teacher retires the Department of Education is not feeling that post they left like that. Other teachers are supposed to share the work of a retired teacher, even when somebody has passed on.

R: do you have a support group in your school:

P: it was three years back when we were having the support group, we were having a support group that was to meet once a month, but you know people outside becomes discouraged, we were meeting with one of the doctors here at Burger Street we were meeting there every month and then discussing with everyone. The parents were given the inputs, sometimes we make awareness in town at the park the one next to SABC but is three years back. Last year and two years back those groups never existed they didn't even call us.

R: mmm, do you have anything that you want to indicate or add related to autistic children?

P: what I want to talk about is about their diet we never said anything about the diet. ASD children always should follow their diet. Because sometimes they don't eat everything and another thing when you give them food they smell it and put aside but they differ some they eat everything, so to them diet is very much important. We are looking forward to the Department of Health to provide us with expertise concerning diet Dieticians. Because sometimes we just force to say take your food, the poor child will do like this. Secondly eee… in South Africa we are having few doctors who are knowledgeable about ASD specialists in ASD. With me no one told me that your child is autistic, they just treated epilepsy and then the teacher to my daughter before she was admitted here. Firstly she was at Grace and Hope and the lady who was working there is the one who told me that she sees autism signs and symptoms, because she is also having a son with autism. I was so frustrated because she was under a specialist and that specialist never told me that my child is having autism that is why I'm saying we are looking forward to South Africa to have doctors who will study more about ASD, not only doctors but including Dieticians and nurses. With my daughter they were concentrating on epilepsy, the teacher because was having the son she called me to come and visit the school by that time I was still working at the mainstream school. Then she said you see this child has autism.

Another addition is that when we start this school they said our sector is a small unit in a big unit. At first, they said they are going to turn this school into an autism school, but you know departmental issues, this is my 9th year being here nothing has happened. But because things are beyond our control we are a small unit in a big unit with only two classes for ASD.

For me, one more thing is that we should have more classes because now I'm having the middle and senior group together, even in the junior class there are middle and junior groups together. We need to have junior, middle and senior classes so that we would work according to their age.

Lastly, we should make the community aware of ASD because always we attend some awareness on HIV and cancer, but I have never heard of an autism awareness because they normally say our kids are mad. They label them so they must just be made aware to let South Africa know about autism. They must also remunerate us well because we are doing a good work …laugh…..

R: mmm, thank you very much for the additions, I have mentioned a lot of things about diet, how is the diet in your school do you have a menu?

P: yes, but some of the menus are not relevant to our kinds, those who do not want the food, the poor child will stay without eating but those who are day scholars are better because will go home and eat, but what about those that are staying in the hostel. It is as frustrating as a mother and a teacher we are so frustrated. As educators, we need counselling as we are working with different learners from different families we are always shocked, every day we are facing different challenges so we need counselling. There is no one even bothering coming to us and say are you coping what is it that we can do for you we need counselling, especially with over crowdedness. The management keeps on admitting, they will admit because they are in the office and you are struggling alone here they can’t see. Now you see that is why *naa* I said I did not want to be in a staff room, I said no let her come here in class so that when we talk you will also observe the behaviours. I hope now you can even write a book about your observation.

R: mmm, I understand that the challenges that you have frustrate you as the teacher, can you clarify more about your frustration.

P: it is demoralizing because we don’t have enough support from our department and our local place where we are working. Even the office they know that one is to 6 but they are bringing more kids what do they expect from me as an educator. I keep on saying you know that 1 is to 6 and I don’t have a class assistant but they keep on eeee… saying that there is a lot of waiting lists where do you think we can put the kids we have to admit but they are not supporting me with an assistant. If they can bring the assistant for me it will be much better. I’m alone like this sometimes I feel like eeee…. Counselling, sometimes I have my challenges at home coming here also is a challenge how do you cope with those two things together really is not a joke we need counselling.

Conclusion: thank you as the researcher you were giving us your mind you didn’t hide anything that is why we gave you time to give additions and also suggestions and you tried your level best to come up with what you think it’s important to for taking care of autistic children. This information we are going to analyse it and come up with the model and also will recommend your suggestions that there be a course or training course for teachers for autistic children.

R: thank you

TRANSCRIPT FOR FOCUS GROUP INTERVIEW

Date: 18 April 2017

Researcher = R

Participant = P

Participant (LPCG 19, 20, 21, 22)

Focus group 1

Introduction: Good afternoon once more we will start with our interview session, I am here to investigate issues related to autistic children the first question will be, there is no wrong or wright answer. We must give each other a chance to talk. Let us avoid using names during the interview, please feel free, the first question is: can you describe in detail all experiences you have with your autistic child with regard to care and support?

P19: this child was born being like this, but immediately after birth we did realize that the child was not normal, her mother breast fed her, after we realized that she was not normal we gave her formula feeds, when we call her she will just say hee, hee, with a saliva coming out of her mouth. The problems that I heard with this child was painful because she use to pass stools or urine whenever she wants any place, she was not toilet trained, when she finishes eating she use to vomit, but now is much better, this is her 3rd year for her being at school, before we never thought that we can take her to school, she started at Grace and Hope but I was not happy the way the elder aunt take care of him, she stays with her elder aunt for 10 years, the elder aunt refuses her to come and visit us at home, she even took her disability grant card, the one that I have is new, from there I removed her from that school, she stayed at home for four years before admitted in this school. When I went to the SASSA's office for renewal of the disability grant they said we would renew when she is 18 years. It is better is you register her for social grant, from there I register her and took her to this school. I do use to do everything for her even before I receive her social grant. When she is at home she don't do anything when she is at school she is a different person as she participate on the activities. I teach her how to wash plates at home I told her that she must have two bowls were she must put water and she must pour some soap on the other bowl she must wash with the water with soap, rise on the other bowl and dry it on the crate. But she always do the opposite. But I try by all means to teach her. The other problem is during the menstrual period because she is unable to bath herself, so I need to be there and assist her during bath time, if I told her to go and take a bath on her own she doesn't even take her clothes out. So I make sure that she I supervised her every day, instructing her to bath all the body parts, so I showed the position to maintain while washing her private parts. From there I'm there to supervise how to dress starting from the underwear, from the, she must come here hair and apply roll on. For me to hear about this school I was assisted by a certain lady in town who told me that there is a special school around Mokopane and she gave us the phone numbers. From there they gave us direction.

R: is she able to talk?

P19: yes, but not everything, she can even count up to 10, although she skips other numbers in between. Her mother is also intellectual disabled but it started at 12 years, and her grandmother is also mentally ill she was admitted at Weskoppies hospital, so I have got three people at home whom are mentally ill. Even her mother she is unable to do anything for herself I'm also supervising her to take a bath.

P20: with me I did not realised that my child is intellectual disabled, one of the lady alerted me that the child is intellectual disabled but I didn't took it serious, after a year the child was unable to sit or crawl, on the second year still the same thing she was not able to sit, crawl or walk is when that we realised that she has got a problem, he crawl and walk on the 4th year, we took her to chrech, just like any other child, from there to a normal school, at the school they called me and informed me that the child is not suitable for a normal school. I should take him to LSEN school, from there I took her to Grace and Hope, and she was not getting social grant and I was unable to pay the fees, so after two years I removed her as it was far. From there I took her to Dutch is a centre for children with disability.

From there I removed her again to this school. With the activities at home she is able to wash dishes, although she cannot do it properly, she wash her clothes, she is able to bath herself, and she can cook sometimes but not always.

P21: with me my child was born in 1993, he was delivered at home, all his milestones were delayed, sitting, standing, and walking she took time, she lacks speech, she has grown up now but she is unable to speak, when she plays he play with the young once, she eats each and every thing he eats even his clothes, when it has wholes she will tear it off, I buy her clothes every time. He even tear his blankets, she is able to fed himself, before he use to eat without being full, but now he is much better, when he wakes up she eats porridge first before tea. Each and everything she takes it to the mouth, whether is a plastic or what, luckily he doesn’t get sick often. She smells everything before he eat. She leaves like a baby, there must be someone with her always at home. When we are at home we lock all the doors because she will waste or sugar, oil, washing powder. So I took her to the hospital they gave her treatment, and then she was admitted here at this school, the problem is she needs to be taken care of more than any other child in the school. When this school opened the children were not many, so she was able to get the care that she needs, so when time goes on the children becomes more so asked my mother to take care of her at home. In 2000 she was getting her treatment at Groethoek, in 2007she was getting it at Mankweng hospital. At Mokopane hospital they said the only institution were my child should go is at eVuxakeni hospital at Giyani. The process was delayed up until gave up as I was going up and down with her from the doctors, magistrate, social workers sometimes when you go there were not there in the office. So now she is at home as she needs more care than others.

R: mmm, does she takes instructions?

P21: she can hear, when she is thirsty she is able to get some water by herself, but she doesn’t care whether the cup is clean or not. When she is hungry she will you the plate, when someone eats something and she want it she will just go and take a plate.

P22: what I have observed from my brothers son he is mentally ill, he is able to go out from home alone to a street to people whom he don't even know, he will just sit there and do nothing. I cannot say a lot as he is not my child and he did not grow up with me. He is unable to speak, but follow the instructions, he is unable to bath and dress himself, but he is able to feed himself.

R: how do you feel to have a child with autism?

P21: it is painful and difficult to stay with an adult who behaves as like baby, a person who can't bath herself or go to the toilet, who can't do anything for herself is very painful to stay with a baby for ever. I understand that she has got a problem on the head but I don't know what causes the problem, she is just a baby, … she cried ……… it is so painful when I start talking about her, even if is its long that she has been there but the situation is not simple to accept, is just like death is painful.

R: so what happened to that issue of taking her to eVuxakeni hospital?

P21: I gave up, my grandmother takes care of her as she is a pensioner, if she is not around her siblings takes over, but we are not staying in the same house but we are next to each other with my grandmother.

P20: I have accepted, this is the gift from god, I don't know what god's plan was when he gave me this child. I'm able to cope with the situation.

P19: with me I have accepted the three of them because there is no one who can take care of them more than me. Today as I came here there is no one to assist them, bread, electricity, and kettle is there but they won't be able to make tea for themselves, the grandmother has got an eyes problem due to high blood pressure, my sister she can't even try to make tea because one day she burned herself on the buttock, and she never told me that she has burned herself. When I asked what burned her she said is the kettle, so I don't allow her near the kettle anymore. I have accepted this is what god chose to give it to me, out of all this people I was chosen to be the one to take care of them, and I will continue to take care of them until death. When we take a bath, I put four bathing bowls for all of us, I undress first so that they do the same.

R: how is the support at home, school, neighbours and churches?

P21: with me I stay with my husband and my children, they support her, they don't have a problem, my first born was born is 1996 and the other one in 2000,so if I arrived home late, they will bath her. I don't allow her to get out of the yard, because if she is outside she need to have someone, I don't allow her to be on her own, our neighbours they don't like her they don't show any support, because her behaviour is unacceptable, if she can go to our neighbours she will open the refrigerator and eat each and everything which is inside for an example a bottle of mayonnaise, peanut butter, so people they don't allow such behaviour. That is why I bought a fence so that I will always lock the gate for her. She watch other children playing over the fence and she feels happy by seeing them running up and down. When someone that she knows arrives home she will run to her granny and laugh, so the granny knows that someone is coming. When we arrived she will give us a hug and she will laugh at us, to show that she is happy. That time when she was attending school the school mates where supporting her. When I took her for follow up I need to hire a private transport as she will touch everyone in the taxi and other people they don't like it. some other people will hurt you with their words, if I told them that she is intellectual disability they will say is not my fault that she is disabled so she mustn't touch me, and they don't understand how painful it is to have a child who has got challenges. At the hospital they provide her with treatment but as time goes on she does not respond any more. At church she is always up and down she can't sit still. I have never took her to my relatives.

P22: at home they are providing the necessary support and here at school.

P20: with me our neighbours are providing the necessary support, she plays with children younger than her. The support at home is good, even the relative's support is good, she is able to visit them during school holidays. The school support is good, to show that she enjoys being at school she don't want to be absent even when she is not feeling well.

P19: with me support at home is good, my children are able to give the three of them clothes, on Sundays we all go to church wearing our church uniform, and even at the church they understand them. The problem is when she visit the elder aunt at Bochum, our neighbours support is good. The problem is her mother who always fight with others, she sometimes fight with her daughter or the granny. One day she bits her daughter. School support is good she can even wear a school uniform without taking a bath, she likes school very much. One day she ran over her transport and she suffered a tissue injuries, since that day I told her that you stand still and call me when the transport arrives, when she arrives home from school she does not want to get off the transport.

P21: when she is angry she is aggressive,

R: what are the challenges that you experienced as the care givers of the children with autism?

P21: the challenge that I have is that I don’t have any other person who can assist with the care of my child, what will happen if my mother pass on, so I asked myself who is going to take of her as I am working. I think she need to be in an institution where they will be able to take care of her, because she cannot cope to live with other people who doesn’t have knowledge about her condition and she is on her own world. I just wish that one should answer my prayers. That is the only challenge that I have.

P20: with me I have got a question, are the school going to provide them with opportunities to work after 21 years or what? I am asking this because in other schools children like this once they teach them vocational skills like washing cars, sewing and gardening. What will happen to them when we die, because if we die they will experience a big problem on their own?

R: here at school they teach them vocational skills, so after 21 years they exit the school and they must go and do what they were doing at school there at the community, although is not simple for them to be employed and our government is doing nothing about that, they don’t accommodate them after 21 years. That is a serious challenge in SA that we are experiencing.

P19: my challenge is that what will happen to this people when I die as the elder aunt she is old too. But only god knows. The other thing is that as I have indicated that these people they are unable to take care of them during menstrual period, I am asking for pads and gloves, because I touch they blood with my bare hands, and they are having a heavy menstruation.

R: have you ever asked for gloves at the clinic, if not you can explain that to the sisters at the clinic and ask them how they can assist you. Is there any other challenges.

P19: no

R: are you able to attend social functions?

P19: yes, even last month I am from Moria, I even go and attend funerals one of my son is able to take care of them when I am not around, he will cook for them, give them water to bath, night prayers I don't attend as you cannot trust people, as they can raped them.

P20: I have got a fear because our children are females, I am just afraid of the adolescent stage as I don't know what will happened to them as they don't understand the consequences of sex.

P19: even the mother of this child she is still 41 years she is still young, and she still deserve to have a male partner but is a challenge as she will not be accountable and responsible for anything. So I don't allow them to go anywhere.

P21: with me if there is anyone who will take care of her, I don't attend any social function.

R: what is it that you know about autism?

P21: they told me that she is having autism plus hyperactivity, they said maybe it is caused by heredity and I told them that we don't have a history of autism at home, so they didn't know what the cause is. When she is angry she hit her head on the floor, so they told me that I must provide her with a pillow, when she runs she doesn’t care if it is safe or not so you need to provide a safe environment always.

P22: what I have heard is that he is having epilepsy, I don’t have any other information.

P19: the psychologist said that her mind is of a 2 years old baby, so I asked him how can we change her mind to her age level he said he don’t know, you know how they are. What assist me is the tea from the church *di tayelo*. The psychologist also said that I must teach them how to bath, I don’t even know what is wrong with her. I think is family history as they are three at home.

P20: they told me the same thing that the mind of my child is the same as the 2 years old baby, but they didn’t tell me what is it and what are the causes. They said at home we must teach them the daily activities.

R: what are your needs as the families of children with ASD?

P22: we are in a difficult situation, where I even don’t know what I need. I need a treatment that will control her behaviour properly, because at the present she is uncontrollable. I even gave up on the treatment, I don’t take her for follow ups anymore because it doesn’t assist her.

P19: maybe the government can give them something to improve their thinking or their minds from 2 years to their age, so that they will be able to take care of themselves may be it will be much better. Even if they can give us a sponge, or blankets and they don’t want to share their beds.

R: so how would you feel if your child can be admitted in a school with hostel?

P21: I want to see her every day, if it is in an institution like eVuxakeni I will leave her but if it is in a hostel no.

R: let me summarize what we have discussed, I will start with P3 her child behaves like a baby, she eats everything even her clothes, and she also tear her clothes and blankets, she is unable to speak, when she is angry she is aggressive, support at school and at home is good, but the neighbours they don’t like her, even to use a public transport is a challenged people they don't understand her condition, with the challenges you said if you can have someone who will assist if your mother passed on, with the coping mechanism you said it is painful and not simple to accept the situation, the knowledge about autism you said they told you that she is having autism and hyperactivity.

P20: mentioned that her child is able to speak, take a bath, wash he clothes and clean, she plays with younger children, her milestones were slow, she went to pre-school, normal school and then they told you that she won't cope in a normal school and they you take her to the special school, you have accepted her, you said is a gift from god, you also asked a question of what will happen to this children if you passed on are they going to be given an opportunity to work, with the knowledge you said they didn't tell you the name of her condition or either the courses, the only thing that they have told you is that her mind is like of a 2 years old baby.

P19: you said you are the aunt to the child, her mother and her grandmother are also mentally ill, so you are taking care of them all, you said she is having a slightly speech, you supervised her on everything, you have accepted them, the main challenges is during the menstrual period as they are unable to take care of themselves, so you need to be assisted with pads and gloves, with your knowledge on autism you said they said she has the mind of a two year old baby, the rest you don't know. The support at home, school and neighbours is good, the only person that worries you is the elder aunt.

R: is there anything that you want to add?

P22: my child she is untrainable, they told me to do toilet training but if I took her to the toilet after eating she won't pass anything, she will pass it at her own time, she is untrainable.

P20: when I said my daughter is able to clean, she doesn't clean the whole house she only clean her own house, she does not discard the water after washing dishes. But she do her own washing, and I'm using a washing machine for my clothes but she do her own washing with her hands.

R: how much are you paying for the transport?

P19: we are paying R350.00 and we can’t afford. But if whether you pay or not they won’t leave your child. Last time when the schools are closed we use to pay half but nowadays we pay full and we don’t afford, now winter is coming and we must buy them winter clothes and I am not working as I am taking care of them. My husband is a pensioner.

R: Is there any support group that you attend in your community or at school?

P19, P20, P21, P22: no

Conclusion: thank you as the researcher you were giving us your mind you didn’t hide anything that is why we gave you time to give additions and also suggestions and you tried your level best to come up with what you think it’s important to for taking care of autistic children. This information we are going to analyse it and come up with the model.

R: Thank you