

**CAREGIVERS' EXPECTATIONS OF THEIR NON-VERBAL CHILDREN WHO  
PRESENT WITH AUTISM SPECTRUM DISORDER IN RURAL KWAZULU-NATAL**

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SUBMITTED IN FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE

MASTER OF SPEECH-LANGUAGE THERAPY

BY

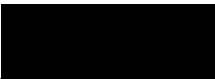
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## **Dedication**

I dedicate my Masters study to my beloved uncle Mohamed Younus Limalia, who taught me the true value of helping others.

May he be blessed with the highest stages of Paradise.

*'Indeed we belong to God and indeed to Him we will return'*

- Quran 2:156

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### **Abstract**

Caregiver expectations have been shown to have an effect on child outcomes. There is limited research regarding caregivers of individuals with non-verbal Autism Spectrum Disorder particularly in rural South Africa. The aim of this study was to explore caregivers' expectations for their non-verbal child with Autism Spectrum Disorder in rural KwaZulu-Natal. Individuals with ASD form part of a larger environment, which they may influence and in turn impacts them. Caregivers form part of this environment. Bronfenbrenner's ecological and bioecological systems theory framed the study and allowed these environments to be understood through implementing a qualitative study design. Eleven participants, who were caregivers of non-verbal children with ASD, aged from 5 to 7 were purposefully selected. Data were collected via semi-structured interviews and analysed thematically. Ten themes included caregivers, journey to diagnosis, feelings regarding diagnosis, caregivers understanding of ASD, caregivers' experiences raising a child with ASD, communication, education, social participation and employment, therapy and societal responses. Caregivers had varied expectations of their non-verbal children with ASD. The microsystem was fluid and changed regularly with grandparents often being the primary caregivers. Relationships within the mesosystem (caregiver and therapists) impacted how caregivers understood the diagnosis, this in turn affected their feelings and expectations which also changed over time (chronosystem). Education was the predominant expectation for most caregivers, taking precedence over communication and social participation. However, limited resources within in the exosystem (limited schools) made viable schooling options difficult. Communication was less of a priority in comparison to education and toileting. There is need for caregiver counselling regarding non-verbal ASD in rural South Africa, a need for more (special) education options and caregiver support groups. No participant who had a child with ASD in the 8-18 year old age-range was a study limitation.

*Keywords: Autism Spectrum Disorder, expectations, caregivers, communication, speech-language therapy, rural, education.*

## Glossary

**Autism Spectrum Disorder-** “pervasive neurodevelopmental disorder characterised by impairments in social communication and restricted, repetitive patterns of behaviour, interests or activities” (American Psychiatric Association [APA], 2013, p. 18).

**Caregiver-** A person who cares for, nurtures, loves and looks after one or more children, the role is similar to that of a parent’ (Department of Social Development & UNICEF, 2008, p.11). The word caregiver was used in this study for individuals whose role in the family was to care for the children with ASD.

**Expectation-** ‘The feeling or belief that something will or should happen’ (Cambridge Dictionary, 2021, para 1.). In the current study expectation referred to caregivers feelings regarding the future of their children with ASD in many areas.

**Rural-** Rurality is considered to be more than geography, it also refers to “the structure, state and quality of life of people living in sparsely settled places away from the direct influence of large cities and towns” (Duncan, Sherry & Watson, 2011, p. 30). For the purpose of this study, districts that fell out of a metropolitan were considered rural (Gaede & Versteeg, 2011). Whilst caregivers may have accessed services for their children at the regional hospitals, most had to travel distances to access this.

**Non-Verbal-** For this study, children were considered non-verbal if they use less than 10 functional words. The level of 10 words was used as it is an average between the studies consulted (Yoder & Stone, 2006; Freeman & Jahroni, 2008; Koegel, Shiratova & Koegel, 2009; Springer, Laughton & Kidd, 2013).

### **List of Abbreviations**

ASD: Autism Spectrum Disorder

CG: Caregiver

ID: Intellectual disability

KZN: KwaZulu-Natal

CWASD: Child with ASD



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## Chapter One: Introduction

### 1.1. Background

This study explored caregivers' expectations of their non-verbal child with Autism Spectrum Disorder (ASD) in rural KwaZulu-Natal (KZN). This area of study is important to speech-language therapists (SLTs) as it will assist with assessment and treatment planning for non-verbal children with ASD by considering the views of their caregivers and provide the caregivers with appropriate counselling.

*'He'll talk when he's ten'*

During my community service year i.e. a mandatory year of work at a government hospital or clinic for most health sciences graduates, I was placed in the iLembe District of KwaZulu-Natal with a significant rural population. I was fortunate during this year, to have worked with many cases of ASD, both newly diagnosed and those who had been diagnosed earlier. I observed that caregivers of children with ASD, specifically non-verbal children, had been provided with very little information to aid in understanding the disorder and its implications. They had varied expectations regarding their child's development and intervention. For some, this included expecting their child to begin speaking at a landmark age that they had set themselves, e.g. at ten years old or when they began school. Some of the caregivers felt that their child would never communicate, and intervention would be futile. The Speech-Language Therapist (SLT) did not know about parents' expectations unless they asked. This experience inspired the research question: "What are caregivers' expectations of their non-verbal child who presents with an ASD in rural KwaZulu-Natal?" This has not been explored in previous research.

This chapter is an introduction to this study. It presents the lack of support reported by South African parents of children with ASD and the indicators used to define an area as 'rural' in South Africa. It discusses the definition of non-verbal, the prevalence of ASD and the hybrid theory that was utilised to guide the current study and a rationale for the study.

## **Problem Statement**

There is a direct link between caregivers' expectations of different aspects of their children's lives and the development of these outcomes (Thomas, King, Mendelson, & O Nelson-Gray, 2018). Parents of children with ASD in South Africa reported a lack of social support, practical assistance, information about ASD, and uncertainty regarding their child's prognosis (Fewster & Gurayah, 2015). All these variables are related to expectations. Caregivers reported that they are not appropriately informed regarding the characteristics of ASD (Fewster & Gurayah, 2015). They also reported that health care practitioners often did not fully understand the disorder themselves and did not provide appropriate counselling and information (Fewster & Gurayah, 2015). There has been research regarding families' perspectives on ASD internationally, however, there is a lack of research in South Africa (Franz, Chambers, von Isenburg, & de Vries, 2017). According to Statistics South Africa (Stats SA) (2017), 82 out of 100 South Africans fall out of the medical aid net (approximately 45 million) and access public healthcare. In 2015, the recorded rate of child poverty in KZN was 75%, with about 4 million children under the age of six living in the poorest 40% of households (Ilifa Labantwana, 2019). Approximately 43% of South Africa's children reside in rural households (Hall, 2018).

In South Africa, there is no standard definition of rural (Gaede & Versteeg, 2011). The definition of 'rural' is based on several indicators including if a particular area falls under a traditional authority, if it is located outside of a metro and whether the area lacks 'urban qualities' like the availability of amenities and infrastructure (Gaede & Versteeg, 2011). Rurality is considered to be more than geography, it also refers to "the structure, state and quality of life of people living in sparsely settled places away from the direct influence of large cities and towns" (Duncan, Sherry & Watson, 2011, p. 30). Individuals with disabilities who reside in rural areas are faced with difficulties due to their geographical and social position (Duncan et al., 2011). The Rural Health Advocacy Project (2013), defines rural in relation to access to health care services and classifies an area as rural if it encompasses certain characteristics i.e. geographical remoteness, topographical features that hamper access to healthcare like hilly landscapes and poor roads, areas that are sparsely populated, a population that is financially deprived, increased cost of service delivery due to poorer economies



of scale and difficulty recruiting and retaining health care professionals (HCPs) due to limited amenities for example, shopping malls. Even when health care is free, the cost and time taken to travel to local clinics could be a barrier for the population which, in turn, could lead to poorer health (McLaren, Ardington and Liebbrandt, 2013). Individuals who live in geographically isolated areas which are underdeveloped and often under-resourced have difficulties overcoming the limitations associated with their disability (Duncan et al., 2011). A report on urbanisation and migration by Kok and Collinson (2006) stated that 43.7% of South Africa's population is classified as rural with 55% of KZN's population classified as rural. Due to a majority rural population in KZN, the current study will focus on caregivers who access public healthcare for their children, in rural areas. Due to the aforementioned factors such as poor access to services, inconsistent care and even community members, rural caregiver's perception of ASD may be different to that of caregiver in urban areas.

According to the Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition (DSM-5) (APA, 2013), ASD is described as a range of disorders with deficits in two key areas, social communication and restrictive and repetitive behaviours. The nature and severity of ASD have an impact on the individual's life and those around them (Karst & Van Hecke, 2012). The deficits in the two key areas mentioned above have implications for aspects of the individual's life like education and social functioning, all of which will affect their caregivers' expectations. The DSM-5 (APA, 2013) categorises the severity of ASD into 3 levels i.e. level 3- requiring very substantial support, level 2- requiring substantial support and level 1- requiring support. These levels are broken down according to the DSM-5's diagnostic criteria for ASD (social communication and restrictive and repetitive behaviours). Non-verbal individuals with ASD are often placed at a level 3 on the severity rating, as they require substantial support.

The statistics regarding how many children with ASD are considered non-verbal vary. Anderson et al. (2007) report that approximately 25-30% of individuals with ASD do not acquire verbal language, whilst the Centres for Disease Control and Prevention (CDC, 2019) reports this number to be about 40%. Children with ASD rarely develop functional verbal communication after the age of five (Pickett, Pullara, O'Grady & Gordan, 2009). There is no standard definition of non-verbal. Ronski et al. (2010) defined non-verbal as children whose Mullen expressive language test (Mullen, 1995) scores revealed their language to be under 12 months and who had less than ten

intelligible words. The Mullen Expressive Language test is a subsection of the Mullen Scales of Early Learning, which measures cognitive functioning of children from birth to sixty-eight months (Mullen, 1995). A study by Yoder and Stone (2006) considered their participants as non-verbal if they had used less than 20 different words across three different language samples. Kasari, Paparella, Freeman and Jahroni (2008) defined 'low-verbal' children aged 3-4 as having less than 5 words and Koegel, Shirotova and Koegel (2009) defined children in their study as non-verbal should they have no functional words and no object-label correspondence. A study by Springer, Laughton, and Kidd (2013) defined a child as non-verbal if they used less than ten words. For this study, children will be considered non-verbal if they use less than 10 functional words. The level of 10 words will be used as it is an average between the studies above. Non-verbal children have poorer outcomes in comparison to children with ASD who have verbal language (Patten, Ausderau, Watson and Baranek, 2013).

Development of speech predicts aspects of the individual's life like educational outcomes, employment, social relationships and if they can live independently. Although non-verbal individuals make up a substantial portion of individuals with ASD, there is limited research regarding why these children do not acquire verbal language (Brignell et al., 2016). A study by Patten et al., (2013) discussed difficulties faced by individuals with ASD when processing stimuli in the environment (like auditory and visual information relayed by communication partners) as a possible underlying factor in impaired functional verbal communication. Other studies refer to individuals with ASD who do not acquire speech as being minimally verbal and report that the terms non-verbal and minimally verbal are used interchangeably in research (Tager-Flusberg & Kasari, 2013). For this study, the term non-verbal will be used as this term is used in studies and practice in Africa (Bakere & Munir, 2011; Belhadj, Mrad & Hayalem, 2006; Mankoski et al., 2006). Studies regarding ASD in Africa have reported a high percentage of non-verbal individuals who present with ASD (Bakare & Munir, 2011). A Tunisian study by Belhadj et al. (2006) reported that 51.2% of their participants were non-verbal, whilst a study by Mankoski et al. (2006) in Tanzania reported 71% of their cases as non-verbal. It was concluded that this higher proportion could be due to local Tanzanian diagnostic practices. In the study by Belhadj et al. (2006), over 60% of non-verbal cases presented with co-morbid intellectual disability. Non-verbal individuals with ASD are categorised as 'requiring very substantial

support', which is the most severe category according to the DSM-5 (APA, 2013 p.18). Therefore, focusing my study on the non-verbal population will provide insight into a significant population within those who present with ASD.

Approximately 1 in 160 individuals across the globe live with ASD (World Health Organisation [WHO], 2018). About 1 in 59 individuals in the USA are diagnosed with ASD (Baio, et al., 2018). Autism is five times more common in boys than in girls (CDC, 2014). The prevalence of ASD in developing countries and African countries is still largely unknown (WHO, 2018). However, according to Autism South Africa (2015), there is no reason to believe that the prevalence of ASD in South Africa is any less or more than international figures. Incidence and prevalence figures of ASD are limited in South Africa (Malcolm-Smith, Hoogenhout, Ing, Thomas, & de Vries, 2013). Due to the recent increase in incidence and prevalence, there is a need to research ASD to improve service delivery to this population.

## **1.2. Theoretical Framework**

The ecological systems theory attempts to understand the development of a child through multiple contexts in their environment (Ettetal & Mahoney, 2017; Bronfenbrenner, 1979). This theory looks at how the inherent qualities of the child and the environment interact and how this influences their development (Bronfenbrenner, 1979) (Figure 1). The ecological systems theory structures the child's environment into four interrelated layers namely the microsystem, the mesosystem, the exosystem and the macrosystem with the chronosystem (Bronfenbrenner, 1979; Ettetal & Mahoney, 2017).

The microsystem refers to the structures that are closest to the child, with which they have direct contact. It includes the relationships that they have with individuals in their immediate environment (Ettetal & Mahoney, 2017). The microsystem includes parents or caregivers, siblings and schooling. Caregivers form part of the microsystem in the current study and therefore their child's diagnosis directly impacts their expectations.

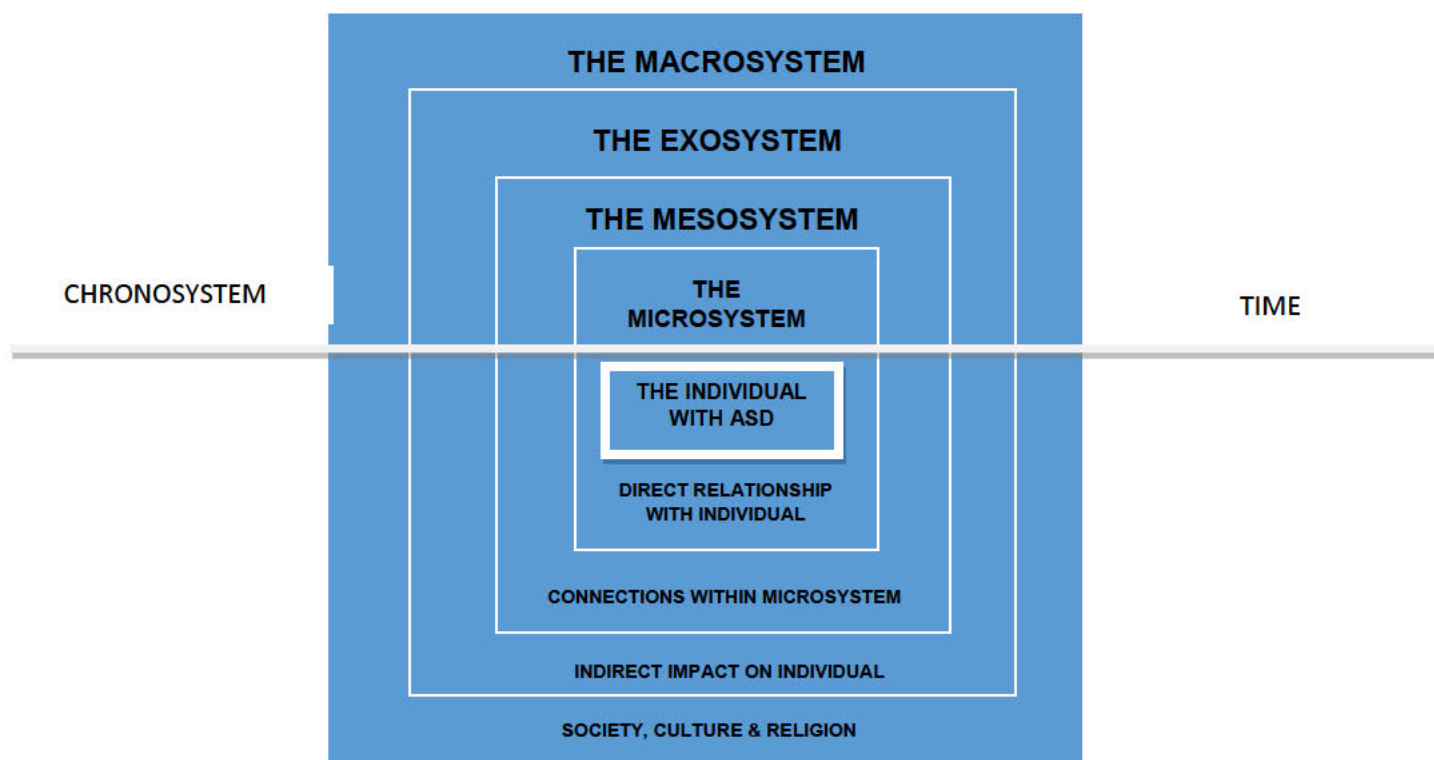
The mesosystem refers to the relationship between the different role-players in the microsystem (Bronfenbrenner, 1979) like the relationship between caregivers and the child's teacher. This layer highlights how factors in the microsystem have a bi-directional effect and can affect each other (Ettetal & Mahoney, 2017). An example of

this is when caregivers of individuals with ASD have interaction with their therapists. This relationship could have positive outcomes for both the caregiver and the child if the relationship between caregiver and professional is good (Wynaden & Ladzinski, 2006).

The exosystem involves the larger social environment in which the child functions. The child often does not affect the role players in the exosystem, but they do influence the child, although it is indirect (Bronfenbrenner, 1979). For example, the resources available in the child's community will impact on the caregivers' knowledge of ASD and the support that they receive. This, in turn, would have an effect on the individual regarding intervention.

The macrosystem refers to the values, norms and beliefs of the society that the child belongs to (Ettekal & Mahoney, 2017). This could include the political and socio-economic climate of the country in which they reside, in this case, South Africa and its culture. This all impacts the child on some level. For example, the community that an individual belongs to may believe in spiritual intervention, which leaves the parent to decide whether to adopt only spiritual intervention or to consider including medical intervention. This would impact on the services that the individual receives.

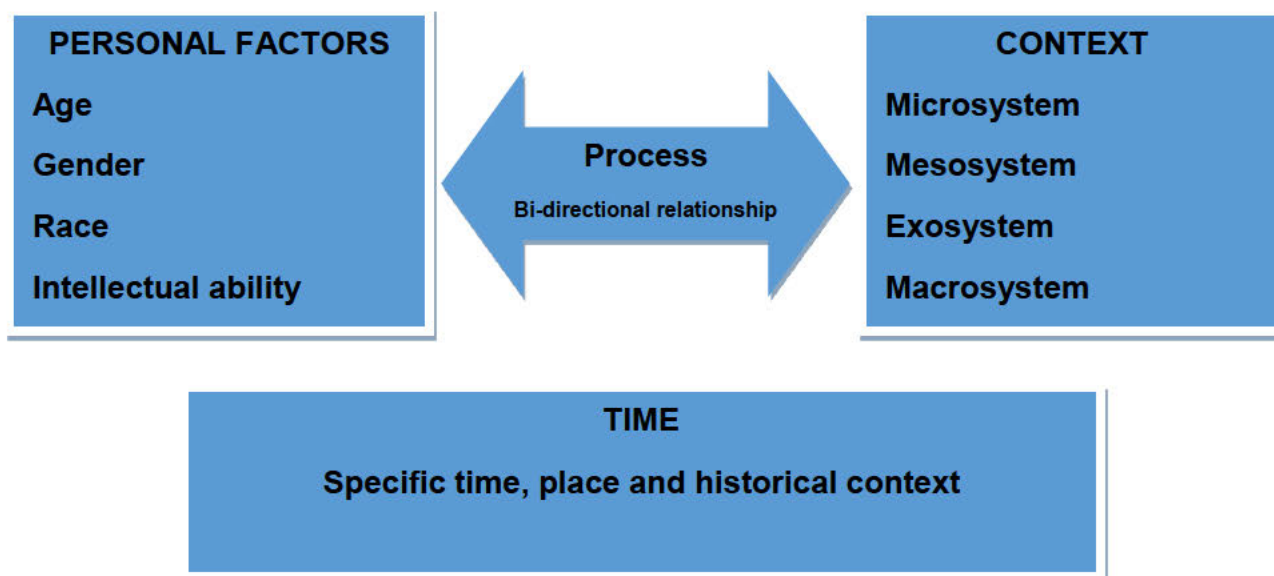
The final system mentioned, the chronosystem, refers to the time (Bronfenbrenner, 1979). Time influences all the other systems. For example, a caregiver's expectation of their child with ASD presently may be different from a caregiver's expectation of their child with ASD in the 1970s, or a caregiver of a child who was diagnosed with ASD five years ago may have different expectations to that of a caregiver whose child was diagnosed 6 months ago.



*Figure 1: Ecological Systems Theory (Bronfenbrenner, 1979)*

The revised bioecological model (Bronfenbrenner and Morris, 2006) aimed to focus more on the individual (personal factors). It was suggested that an individual's development is defined by four properties: person, context, process and time.

Person factors refer to defining characteristics of an individual like age, gender and intellectual functioning (Ettekal & Mahoney, 2017). These factors impact on the participation of the individual in their environment. The second aspect of the bioecological approach, context factors, includes the four systems of the ecological model (microsystem, mesosystem, exosystem and macrosystem) (Ettekal & Mahoney, 2017). The third factor, process factors, describes the complex bi-directional relationship between the first two factors i.e. personal factors and context factors, which is known as proximal processes. To understand the relationship between these factors the last factor is needed, which is time. Proximal processes occur in a specific time and historical or societal context. Time occurs within the chronosystem as mentioned above (Ettekal & Mahoney, 2017).



*Figure 2. The bioecological systems theory (Bronfenbrenner and Morris, 2006)*

The current study will utilize a hybrid of the two models put forward by Bronfenbrenner. It will include the personal factors from the bioecological model along with the contextual factors which are, in essence, the original ecological model. It will also merge the chronosystem from the ecological model and time from the bioecological model. Process factors will be included in the model as it is important to identify the links between the person and the context. In this study, the caregivers' expectations for their non-verbal child with ASD was explored considering the individual with ASD's diagnosis (personal factors) and the impact on their development, the various interactions of their surrounding environments and time.

The researcher used this model (figure 3) to identify and critically discuss caregivers' expectations. This allowed the researcher to gain an in-depth perspective of parents' expectations and how these expectations affect the different aspects of the individual with ASD's environment.



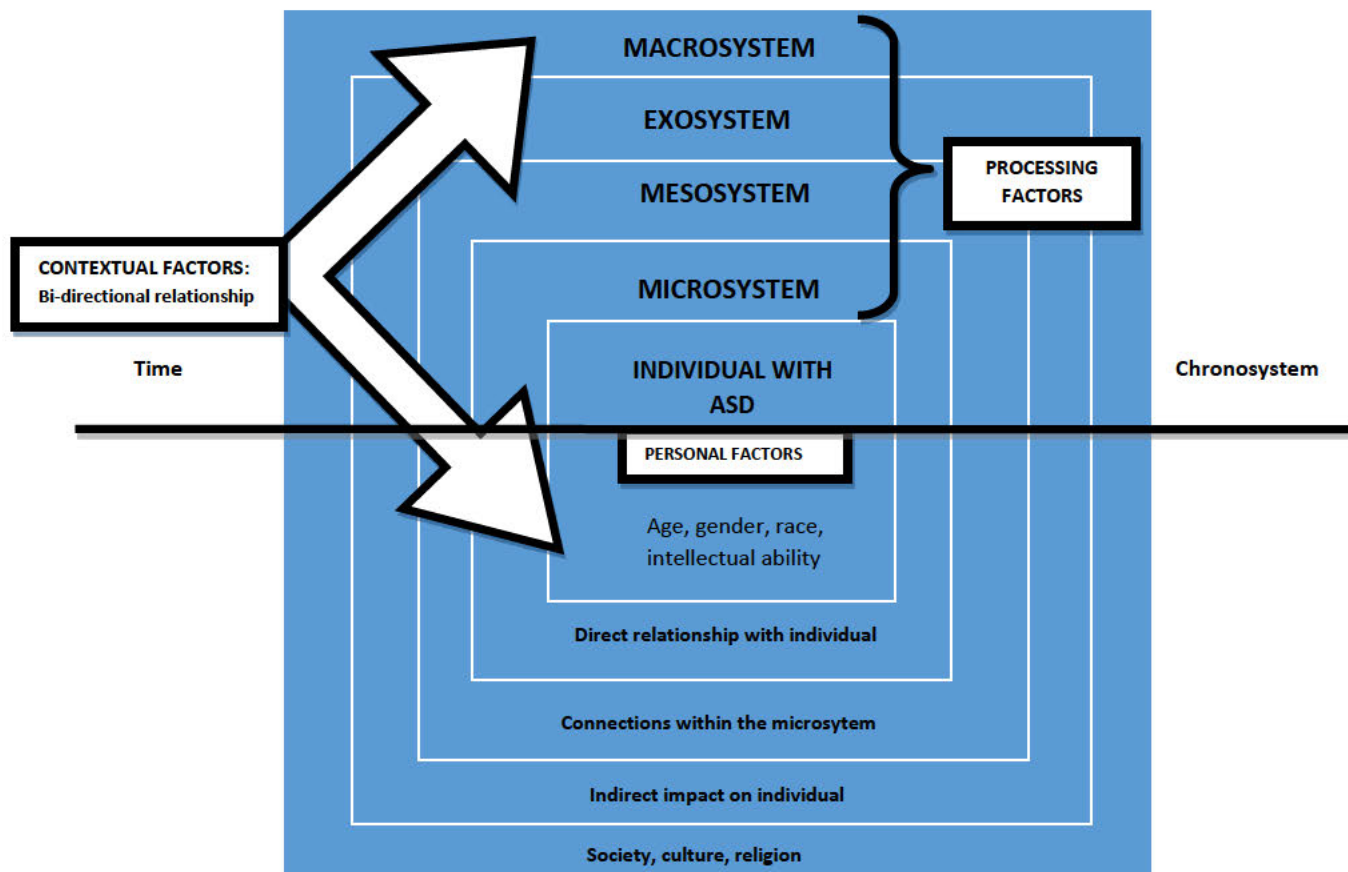


Figure 3. The hybrid model used in the current study (Bronfenbrenner, 1979; Bronfenbrenner and Morris, 2006)

### 1.3. Rationale

The literature presented in the review above indicates that there is a dearth of research on ASD in Africa (Bakare & Munir, 2011) and South Africa (Franz et al., 2017). Specifically, there is a paucity in research on caregivers' expectations of their non-verbal child with ASD. This study will contribute to research by exploring the rural context in KZN. The information from the study will enable SLTs in South Africa, more specifically rural KZN, to gain insight into what caregivers expect of their non-verbal children with ASD. A hybrid model of the ecological systems theory and the bioecological systems theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) was used to guide data analysis and interpretation. Personal factors like the individual with ASD's diagnosis will be explored and its impact on development, the interactions with their surrounding environments (microsystem, mesosystem, exosystem and chronosystem). The model will be used to critically discuss caregivers' expectations and gain perspective on how these expectations affect the different levels of the

individual with ASD's environment. This study will delve into identifying and understanding caregivers' expectations regarding various aspects of the child's life, like education, social implications, communication abilities and speech-language therapy. Parent reports indicate that information that caregivers provide regarding their child's development is invaluable (Miller et al., 2017), therefore being aware of the expectations will enable the SLT and other health care professionals to ensure that the needs of caregivers of non-verbal children with ASD and their children with ASD are met during intervention. It will enable the SLT to provide counselling to caregivers and help them to manage their expectations.

#### **1.4. Outline of Chapters**

**Chapter One** provides a background to the study, the problem statement, the theoretical framework and the rationale of the study.

**Chapter Two** is a review of the literature, it defines ASD and includes the diagnostic criteria, severity, prevalence, aetiology and evaluates various medical, speech, language and literacy characteristics associated with ASD. It discusses caregivers' experiences raising a child with ASD, defines and evaluates caregivers' expectations with regards to education, social participation, employment, view of therapy and societal responses.

**Chapter Three** outlines the methodology of the study. The aims, objectives, study design, study population and sampling are discussed. It includes the data collection procedure, analysis, trustworthiness and ethical considerations.

**Chapter Four** contains the results of the study, the analysis of this study in which the data is grouped into themes and subthemes and the interpretation. The results are described thematically with the hybrid theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) and literature being used to interpret these findings.

**Chapter Five** includes the conclusion deduced from the study, the limitations of the study, suggestions for future research and implications for clinical practice.



## Chapter Two: Literature Review

In this chapter ASD is defined, the diagnostic criteria are explained, and the levels of severity are outlined. The characteristics and communication profile of individuals with ASD are discussed with a focus on non-verbal individuals with ASD. Literature regarding caregivers' experiences is reviewed including information on their expectations regarding various aspects of life like education, social participation, employment, therapy and societal responses.

ASD is defined as a "pervasive neurodevelopmental disorder characterised by impairments in social communication and restricted, repetitive patterns of behaviour, interests or activities" (American Psychiatric Association [APA], 2013, p. 18). ASD is considered a life-long disorder by parents and clinicians (Levy & Perry, 2011; Fewster & Gurayah, 2015). Therefore, caregivers face challenges raising a child with ASD. The DSM 5 characterises and allows for diagnosing ASD in a medically and scientifically accurate and useful manner (APA, 2013). Table 1 describes the DSM 5's diagnostic criteria for ASD.

Table 1

*The Diagnostic Criteria for ASD according to the DSM 5 (APA, 2013)*

Must meet the criteria of A, B, C and D (currently or historically)
<b>A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by all 3 of the following criteria:</b> <ol style="list-style-type: none"> <li>1. Deficits in social-emotional reciprocity.</li> <li>2. Deficits in non-verbal communicative behaviours used for social interaction.</li> <li>3. Deficits in understanding, developing and maintaining relationships.</li> </ol>
<b>B. Restricted, repetitive patterns of behaviours, interests or activities as manifested by at least two of the following criteria:</b> <ol style="list-style-type: none"> <li>1. Stereotyped or repetitive speech, motor movements or use of objects.</li> <li>2. Rigid adherence to routine or ritualised patterns of non-verbal and verbal behaviour.</li> <li>3. Highly restricted, fixated interests that are abnormal in focus or intensity.</li> <li>4. Hyper or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment.</li> </ol>

<p><b>C. Symptoms must be present in early development</b> (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).</p>
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<p><b>D. Symptoms cause clinically significant impairment in considerable areas of functioning.</b></p>
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<p><b>E. These disturbances are not better explained by intellectual disability</b> (intellectual developmental disorder) or global developmental delay.</p>
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The severity of ASD characteristics differs from case to case (American Speech, Language and Hearing Association [ASHA], 2019). Individuals with ASD vary in their abilities, some may present with superior language and cognitive abilities whilst others present with significant impairments in these areas e.g. non-verbal (ASHA, 2019; APA, 2013). However, there are core characteristics that individuals with ASD present with (ASHA, 2019; APA; 2013).

The severity of the child with ASD's characteristics affects the level of their caregiver's stress, which affects caregiver's behaviours (Pastor, Fernandez, & Tarragía-Minguez, 2015). Therefore, the severity of symptoms with which the child with ASD presents may affect the expectations that their caregiver has of them. For example, a caregiver of a child with a level 3 severity (requiring very substantial support) may expect their child to become verbal whilst a caregiver of a child with level 1 severity (requiring support) may expect marriage for their child. A non-verbal child with ASD (using 10 words or less) will be classified as level 3 severity i.e. requiring very substantial support. Therefore, this could indicate increased stress levels for their caregivers and in turn affect caregivers' behaviours and expectations (Pastor et al., 2015). Described below in Table 2 are the levels of severity of ASD according to the level of support needed as outlined by the APA (2013).

Table 2

*The Levels of Severity of ASD According to DSM 5 (APA, 2013)*

	<b>Social communication</b>	<b>Restrictive, and repetitive behaviours</b>
Level 3 'requiring very substantial support'	<ul style="list-style-type: none"> <li>- Severe difficulties in verbal and non-verbal social communication skills which affect functioning severely</li> <li>- Limited initiation of social interaction</li> <li>- Minimal or abnormal responses to social overtures by others</li> </ul>	<ul style="list-style-type: none"> <li>- Reduced flexibility of behaviour</li> <li>- Extreme difficulty coping with change</li> <li>- Great distress or difficulty changing focus or behaviours</li> <li>- Restricted and repetitive greatly interfere with functioning.</li> </ul>
Level 2 requiring substantial support	<ul style="list-style-type: none"> <li>- Noticeable difficulties in verbal and non-verbal social communication; social impairments which are apparent even with support.</li> <li>- Limited initiation of social interaction</li> <li>- Minimal or abnormal response to social overtures by others</li> </ul>	<ul style="list-style-type: none"> <li>- Reduced flexibility of behaviour</li> <li>- Difficulty coping with change and other restricted/repetitive behaviours appearing often enough to be noticed by a casual observer and interfere with functioning in a variety of contexts.</li> <li>- Distress and/or difficulty changing focus or action.</li> </ul>
Level 1 Requiring support	<ul style="list-style-type: none"> <li>- Difficulty in social interaction causes noticeable impairments when there are no supports in place.</li> <li>- Problems initiating social interactions and clear examples of atypical or unsuccessful responses to social overtures of others</li> <li>- May present with decreased interest in social interaction</li> </ul>	<ul style="list-style-type: none"> <li>- Inflexibility in behaviours cause significant interference in one or more contexts</li> <li>- Difficulty switching between activities.</li> <li>- Problems of organisation and planning affect independence.</li> </ul>

## 2.1. Aetiology

The exact cause of ASD is unknown (Moss & Howlin, 2009). In the 1950s, ASD was thought to be caused by neglectful parenting, more specifically 'cold' parenting by mothers (Farrugia, 2009). In the 1960s, Dr Andrew Wakefield claimed that Measles, Mumps and Rubella (MMR) vaccinations caused ASD; this has since been refuted (Godlee, Smith, & Marcovitch, 2011). There has been significant research indicating that ASD has biological and genetic causes, with possible environmental contributors (Abrahams & Geschwind, 2008). In middle to low-income countries, links have been made between developmental disorders and malnutrition (Hume-Nixon & Kuper, 2018). The causes of ASD among African children include a post-encephalitic infection or sepsis before the onset of ASD symptoms (Mankoski, et al., 2006). Autoimmune and genetic factors were also reported as possible causes within the ASD population in Africa (Mostafa, El-Sayed, El-Aziz, & El-Sayed, 2008).

Different cultural groups have different perceptions regarding the cause of ASD (Gona, et al., 2015). ASD is often viewed from a Western lens and does not consider how non-Western cultures understand the cause, symptoms and treatments (Cohen, 2012). A Nigerian study found that 43% of healthcare workers interviewed believed that ASD is caused by supernatural factors (Bakare, et al., 2009). A study by Gona et al. (2015), done in Kenya found that witchcraft, evil spirits and curses were identified as possible causes of ASD by parents and professionals

As the aetiology of ASD is unknown, caregivers are often left to come up with their own beliefs regarding the origin of the disorder. Caregivers' beliefs are important as this can influence their beliefs and attitudes regarding treatment, their child's beliefs and attitudes, guide their actions and have an impact on the caregivers themselves (Vaughn et al., 2011). If caregivers believe that their child's characteristics are due to supernatural factors, this could lead the children to believe this about themselves. Some studies looked at the parental belief of causation concerning mental health, some parents blamed themselves for their child's ASD and therefore had poor mental health. Parents who believed that ASD was God's will and due to fate were less stressed than those that believed it was due to hereditary, pregnancy or environmental factors (Herbert & Koulouglioti, 2010). These findings highlight the presence of both spiritual and medical beliefs regarding ASD in Africa.

## **2.2. Characteristics of ASD**

Individuals with ASD present with a range of characteristics. Children who present with ASD generally have behavioural and emotional difficulties like temper tantrums, hostility, physical aggression and self-harm behaviours (Tiernan, Healy, Leader, & Mannion, 2011). This could be secondary to their difficulties in communication and social reciprocity (ASHA, 2019) and a high rate of psychiatric disorders and characteristics (approximately 69%) (Buck, et al., 2014). Individuals with ASD may also present with epileptic seizures (Buckley & Holmes, 2016) and disturbed sleep patterns (Devnani & Hedge, 2015).

About one-third of individuals with ASD experience a regression in milestones during their pre-school years (Al Backer, 2015). Regression refers to the loss of a skill that was previously acquired, including language (Stefanatos, 2008). Regression occurs more in ASD than in any other idiopathic developmental disorder. Language regression refers to the loss of verbalisation and is the most commonly reported area of regression in children with ASD (Al Backer, 2015). Language regression can co-occur with social regression (a regression of social behaviours) (Al Backer, 2015). Parents often note a regression when their child is between the ages of two and three (Oslejskova, Dusek, Makovska & Pejcochova, 2008). Non-verbal individuals with ASD may have initially spoken a few words and thereafter regressed (Rogers, 2004). Caregivers' expectations may be affected by this regression as they may expect their non-verbal child with ASD to become verbal again.

Individuals with ASD may also present with sensory and feeding difficulties (ASHA, 2019; APA, 2013). Sensory difficulties may involve the under-responsiveness, over-responsiveness or mixed responsiveness to various environmental stimuli for example, touch, light or sounds (ASHA, 2019; APA, 2013). Individuals with ASD are reported to have unusual eating habits and may be overly-selective, and have aversions to specific colours, textures, temperatures and smells and prefer specific brands of foods (Bandini et al., 2010).

### **2.2.1. Communication profile.**

Communication is often considered the main problem faced by individuals with ASD and their families (Papageorgiou & Kalyva, 2010; ASHA, 2019). Communication difficulties are usually noted in early childhood and persist into adulthood (Moh & Magiati, 2012). Individuals with ASD face difficulties with social communication, namely social reciprocity, joint attention and social cognition (APA, 2013). Mostly, children with ASD have receptive an

d expressive language impairments but language profiles vary with age and level of development (Mody & Belliveau, 2013).

A significant population of individuals with ASD are non-verbal (ASHA, 2019). According to Anderson et al. (2007), 30% of children with ASD do not acquire functional language. An extensive epidemiological study is needed to verify the large population of individuals with ASD who are considered non-verbal (Bakare & Munir, 2011). Language abilities are closely related to later prognosis (Mawhood, Howlin & Rutter, 2000). Individuals with ASD that are classified as level three severity according to the DSM 5 (APA, 2013) present with severe communication deficits (Maljaars, Noens, Scholte & van Berckelaer-Onnes, 2012). Therefore, a non-verbal individual with ASD may present with a poorer prognosis compared to a verbal individual with ASD. The discussion below details the different components of language and the features with which individuals with ASD present.

#### *2.2.1.1. Receptive Language.*

Children with ASD generally produce more language than they comprehend (Barneveld, Swaab, van Engeland, & de Sonnevile, 2014). In terms of receptive language, children with ASD present with a lack of orientation to speech or their names by 6 to 12 months (Saint-Georges, et al., 2010). They also face difficulties comprehending verbal and non-verbal communication (ASHA, 2019). Non-verbal individuals with ASD have a difficulty understanding the symbolic nature of pictures (Maljaars et al., 2012). Individuals with ASD have semantic (the meaning of language) deficits like idiosyncratic expressive word use, continuous literal interpretation of statements and neologisms (Vogindroukas & Vostanis, 2003). Individuals with ASD who are classified as level three according to the DSM 5 often show more severe delays relative to their non-verbal cognitive level.

### *2.2.1.2. Expressive Language.*

Syntax refers to the study of processes and principles by which sentences are constructed in a particular language (Chomsky, 2002). There are particular syntactic features that individuals with ASD present with, including a reversal of pronouns e.g. saying 'me' for 'you' (Durrleman, Hippolyte, Zufferey, Iglesias, & Hadjikhani, 2015), difficulty using conjunctions and articles (Eigsti & Bennetto, 2009), errors in verb tense marking (Eigsti & Bennetto, 2009), less negation and question utterances (Happé & Frith, 1996) and reduced sensitivity to grammatical errors (Minshew & Williams, 2007). Syntax in ASD is generally affected in ways that cannot be explained only by the accompanying total language delay (Omnya, Azzam, Khattab, & El-Sady, 2018). Non-verbal children with ASD often fail to compensate for their lack of verbal communication with other modalities like gestures (Mundy, Sigman, & Kasari, 1994). Lack of functional language can lead to challenging behaviour (Maljaars et al., 2012). Therefore, caregivers of non-verbal children with ASD's face a great deal of stress caring for their child with ASD.

Individuals with ASD also have a persistent difficulty in pragmatics i.e. the use of language (Schuh, Eigsti, & Mirman, 2016). They present with difficulties taking turns in conversation, poor topic development, sudden topic changes and stereotyped language (Simmons, Paul, & Volkmar, 2014). They have difficulties understanding non-literal language (Vulchanova, Saldaña, Chahboun, & Vulchanov, 2015), non-verbal social-communicative behaviours like facial expressions, eye gaze and gestures (Silverman, Eigsti, & Bennetto, 2017).

Individuals with ASD may also present with echolalia, which is a form of verbal imitation and is one of the most common communication impairments; it is considered to be one of the 'restricted and repetitive behaviours' that characterises ASD (Gernsbacher, Morson & Grace, 2016). Echolalia is considered a bridge to self-generated, meaningful speech with the intent to communicate (Prelock & Nelson, 2012).

#### 2.2.1.3. *Literacy.*

Literacy and executive functioning are also areas of difficulty for individuals with ASD (ASHA, 2019). As ASD is a spectrum, literacy and reading skills vary among individuals with ASD (Whalon & Hart, 2010). Individuals with ASD may have difficulty mastering decoding which is needed for reading (Whalon & Hart, 2010). They have good word-recognition skills, but severely impaired reading comprehension skills and often present with hyperlexia (the extreme profile of word recognition skills that develops in advance of comprehension skills). Individuals with ASD may have an unusual preoccupation with words. It is unknown how oral language abilities contribute to success in reading (Lanter & Watson, 2008). More research is needed to understand how individuals with ASD engage in reading (Whalon & Hart, 2010). There is limited research on the development of writing skills (Whitby & Mancil, 2009). Many individuals with ASD present with difficulties in written expression and graphomotor skills (Whitby & Mancil, 2009). A study by Fuentes, Mostofsky and Bastian (2009), reported that individuals with ASD write less and at a slower rate than their typically developing peers. There have been cases in which non-verbal children with ASD read and write meaningfully despite the absence of spoken language (Fleischmann & Fleischmann, 2012).

#### 2.2.1.4. *Executive functioning.*

Individuals with ASD often have deficits in executive functioning (Hill, 2004). Executive functioning deficits can predict future achievement (Diamond, 2013). It is proposed that executive functioning has a link to impairments associated with ASD in areas like (i) social impairment and social cognition (Leung, Vagan. Powell, Anagnostou & Taylor, 2016), (ii) the theory of mind (Pellicano, 2007), and (iii) restrictive and repetitive behaviours (Mostert-Kerckhoff, Stall, Houben & Jonge, 2015). There has been evidence to suggest that difficulties with inhibition could be an underlying cause for restrictive and repetitive behaviours (Schmitz et al., 2006). Individuals with ASD present with (i) weakness in cognitive flexibility, (ii) planning and organising (Geurts & Bringmann, 2010), (iii) working memory (Habib, Harris, Pollick & Melville, 2019), and (iv) have reduced adaptive functioning (Rosenthal et al., 2013).



### **2.3. Co-occurring conditions**

A study by Gurney, McPheeters, and Davis (2006), found that children with ASD are more likely than children without ASD to have medical and psychiatric conditions. Children with ASD usually present with developmental, neurological and psychiatric disorders (Close, Lee, Kaufmann, & Zimmerman, 2012). It has been reported that children with ASD often present with epilepsy, anxiety disorders, Obsessive-Compulsive Disorder (OCD), gastrointestinal difficulties, and food and skin allergies (Kogan, et al., 2008). Individuals with ASD present with irregular and disrupted patterns of sleep (Glazzard & Overall, 2012). ASD can also co-occur with genetic or developmental disorders like Down syndrome and Rett syndrome (Moss & Howlin, 2009), both of which have defining characteristics and symptoms which could compound the symptoms characterized by ASD.

ASD often co-occurs with Intellectual Disability (ID), which is defined as “a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem-solving) and in adaptive behaviour, which covers a range of everyday social and practical skills. This disability originates before the age of 18” (American Association of Intellectual and Developmental Disabilities para.1, 2019). Approximately 10% of individuals with Intellectual Disability present with ASD (Car Autism Roadmap, 2016). The percentage of individuals who present with ASD that have an ID, however, is considerably higher (Car Autism Roadmap, 2016). ASD in Africa is rarely diagnosed without ID (Bakare & Munir, 2011). This could be due to individuals presenting with less severe symptoms seeking intervention from spiritual leaders and traditional healers (Grinker, et al., 2012). Therefore, according to the CDC (2014), 50% of individuals with ASD present with ID. Springer et al., (2013) suggests that this number could be higher. This increased percentage could be due to referral bias (Matson & Shoemaker, 2009). ASD can co-occur with other syndromes like Rett syndrome and Fragile X syndrome (Moss, Howlin, & Oliver, 2011). Individuals with ASD who present with co-morbid ID have reduced independence and functioning (Swaminathan, 2015).

#### **2.4. Caregivers' experiences raising a child with ASD**

Caregivers generally go through pregnancy and the early stages of their child's life planning for their futures, wondering about the schools they will attend, the friends that they will make and whom they will marry. A caregiver, however, is rarely prepared for their child to be diagnosed with a developmental disorder like ASD.

Due to the nature of ASD, caregivers face unique challenges. As ASD is a lifelong condition, individuals with ASD rely on their caregivers, often living with them well into adulthood (Poon et al., 2013). Caregivers frequently feel a host of emotions upon their child receiving a diagnosis of ASD. Grief and distress are the two most common reactions, with the feeling of grief generally greater in caregivers who had recently received a diagnosis (Wayment & Brookshire, 2018). Caregivers have expressed feelings of denial, anger, shock and devastation upon receiving the diagnosis whilst others felt relief and vindication in finally gaining answers regarding their child's behaviour (Altiere & von Kluge, 2008).

A British study by Glazzard and Overall (2012), found that caregivers felt that they were not supported by their local authorities. Female caregivers of children with ASD often reported that they put their careers on hold to care for their children with ASD (Gray, 2003), leaving fathers to be the sole earners for the family. Raising a child with ASD is more of a burden on mothers as compared to fathers as mothers are often in charge of the day-to-day raising of their children (Herring, et al., 2006). Picardi et al., (2018) confirmed this by stating that mothers reported more subjective burden than fathers, whilst a Canadian study by Rivard, Terroux, Parent-Bousier and Mercier, (2014) found that fathers feel even more stressed than mothers. A study by Bourke-Taylor, Howey, and Law (2010), found that mothers of individuals with disabilities who have a job reported better health-related quality of life than mothers of disabled children who are unable to work. This may be due to the mothers who work feeling a sense of independence financially and enjoying the social interaction (Parish, 2006), thereby reducing stress and improving health related outcomes. Caregivers also experienced financial challenges with raising a child with ASD due to expensive treatments and the loss of income (Altiere & von Kluge, 2008). In South Africa, over

40% of families are headed by single parents (Department of Social Development, 2012), which places a significant strain on families financially and emotionally. Although all caregivers face difficulties accessing quality services for their child with ASD, greater difficulty accessing services is faced by caregivers in rural areas (Vergunst et al., 2017). Caregivers in rural areas report poor access to services and the services that are accessed as being less effective (Chen, Liu, Su, Huang, & Lin, 2007). Another challenge experienced was balancing the time spent with their child with ASD and time spent with their typically developing children (Aylaz, Yilmaz, & Polat, 2012; Ilias, Cornish, Park, Toran & Golden, 2019).

Caregivers of children with ASD are more likely to experience psychiatric conditions as compared to caregivers of typically developing children (Hodge, Hoffman, & Sweeney, 2011; Glazzard & Overall, 2012) and are likely to experience more stress than caregivers of children with other developmental disorders like Fragile X syndrome, Down syndrome and Cerebral Palsy (Blacher & McIntyre, 2006). Deficits in social communication and odd ritualistic and rigid behaviours associated with ASD are stressful for caregivers (Hayes & Watson, 2013). Some caregivers feel stressed due to their inability to understand the needs and wants of their child with ASD who is unable to communicate effectively (Sukmak & Sangsuk, 2018). The stress placed on the caregivers increases with the severity of the symptoms of ASD (Glazzard & Overall, 2012). Caregiver stress is associated with negative caregiver-child interaction, child behavioural problems, harsh parenting and ineffective intervention (Van Ijzendoorn, et al., 2007). Caregivers also experience a decrease in social and leisure activities, and limited time with their partners/ spouses and for themselves resulting in constant fatigue (Mitchell & Holdt, 2014). However, a study by Ilias et al., (2019) reported that 50% of parents in their study felt that having a child with ASD improved understanding between them and their spouse and they felt that they could rely on each other more. In a study done in rural Thailand, caregivers reported feeling sorrow, anger, distress and uncertainty about the challenges of caring to a child with ASD (Sukmak & Sangsuk, 2018). Caregivers may also perceive their child's diagnosis as a loss and feel 'cheated'. These feelings may persist for years post-diagnosis (Wayment & Brookshire, 2017). Caregivers, who choose to look at raising a child with ASD positively, generally have less stress than those that view it negatively. Some

caregivers have reported increased personal growth and maturity since caring for a child with ASD (Glazzard & Overall, 2012).

## **2.5. Defining caregivers' expectations**

Caregivers' expectations are a telling predictor for a child's future accomplishments (Thomas et al., 2018). Upon receiving the diagnosis of ASD, caregivers often feel a loss of expectations that they had for a typically developing child and are faced with misgivings regarding their child's future in aspects like marriage, education and having children of their own and the future of their family (Hock, Timm, & Ramisch, 2012). These expectations impact their child and have potential implications for treatment in terms of supporting the family and developing good relationships between the child and their caregivers. This may be more important for families where a child has a chronic illness or disability (Smith & Cheater, 2013) like ASD. Matenge (2000) found that parents often did not have specific expectations; rather they felt uncertain about their child's future. Poon et al., (2013) reported that parents of children with ASD and ID valued certain things for their children like marriage and having children but felt that the likelihood of this happening was minimal. A Malaysian study by Ilias et al., (2019) found that the majority of parents reported feelings of anxiety about their child's future from when they learned of the diagnosis. However, most parents found that after some time they readjusted their beliefs and thoughts about their child's future and diagnosis.

A study done in Australia by Wong and Heriot (2007), looked at the expectations of 22 parents of children (aged between five and twelve) with ASD had regarding their child's future by looking at 'vicarious futurity', that is the hope and despair that one feels for the future. Compared to parents of typically developing children, 80% of parents had high despair and low hope. Uncertainty about their child's prognosis lowered parents' expectations. In another study done by Dale, Jahoda and Knott, (2006) sixteen parents of children with ASD were interviewed regarding the course of ASD. Five parents felt positive about their child's future, two felt that interventions will improve with future research and therefore their child would significantly improve, one parent felt that their child would 'outgrow the disorder', another two participants felt that society would become more accepting of children with ASD and two parents felt that their children would not change or improve and therefore feared the future. Most parents had mixed

feelings; they anticipated some progress from their child but were aware that they would still have limitations.

Parent expectations have an impact on various aspects of their and their child's lives. Parents who expected vaccinations to be a cause for ASD were sceptical to vaccinate their children with ASD or their siblings further (Dale et al., 2006). Those who believed that it is caused by genetics were hesitant to have more children (Selkirk, McCarthy Veach, Lian, Schimmenti, & LeRoy, 2009).

## **2.6. Caregivers' expectations regarding education**

Parental expectations are a telling predictor of both parent actions and child educational outcomes (Thomas et al., 2018). What caregivers expect regarding education affects if and how they access education for their child with ASD. Education is regarded as a key element in maximum personal development and gaining equal status in society for individuals with ASD (Autism Task Force, 2001). Parental expectations of educational achievements were directly related to their child's cognitive abilities (Bush, Eisenhower, Cohen, & Blacher, 2017) and their previous educational achievements. Children with ID whose parents felt that education was a futile endeavour had poorer educational outcomes than children of those caregivers who accessed education for their child with ID (Mutua, 2001).

There has been very little attention placed on caregivers' expectations for their young children with ASD as they transition into early schooling (Bush, Eisenhower, Cohen & Blacher, 2017). Difficulties regarding education are more common in 'low functioning' individuals with ASD, and those who do not attend special schools or inclusion classes. Finding an educational institution for children with ASD is challenging (Sukmak & Sangsuk, 2018). A study was done in the United Kingdom (U.K) by Parsons, Lewis and Ellis, (2009) found that caregivers of children with ASD were dissatisfied with the choices available to them regarding a school for their child as compared to caregivers of typically developing children. Caregivers worry that their child with ASD may have difficulties socialising and integrating into mainstream schools and that the mainstream school may not cater to their child's needs (Sukmak & Sangsuk, 2018). A study done in Malaysia reported that 45.5.% of the participants in their study described logistical issues for people who reside in the outskirts of the city or in rural areas as there is limited access to schools and limited resources for

interventions (Ilias et al., 2019). Family and parent characteristics also influence educational expectations (Bush, Eisenhower, Cohen & Blacher, 2017). Caregivers of individuals with ASD face unique barriers that impede the formation of positive expectations of schooling. Caregivers and therapists may have differing views regarding what is realistic. This may hinder the child's ability to maximise their potential and create strained relationships between caregivers and teachers (Bush, Eisenhower, Cohen & Blacher, 2017).

### **2.7. Caregivers expectations regarding social participation and employment**

Social skills are a frequently reported difficulty by caregivers after communication (Papageorgiou & Kalyva, 2010). A study by Poon et al., (2013) reported that caregivers of individuals with ASD rated social activities like getting married, having children and buying a house as least important for their children with ASD. Safety, happiness and satisfaction were rated the highest. This could be due to parents setting realistic expectations for their children (Poon et al., 2013). According to Stazmari, Bryson, Boyle, Streiner, and Duku (2003), early language and verbal skills are a telling predictor for communication and socialisation. Therefore, non-verbal individuals with ASD often have poorer social outcomes than those with increased language and non-verbal skills. Adults with ASD have persistent difficulties with social relationships, employment and academic performance (Mao, 2012). There is little research regarding caregivers' expectations for their non-verbal child with ASD concerning social participation.

As their child with ASD becomes older, caregivers' concerns change (Papageorgiou & Kalyva, 2010). They begin to accept the communication and social deficits that their child has and focus more on other aspects of their child's life like self-help skills and occupation. Individuals with ASD often have deficits in areas that potential employees consider a skill (Wilczynski, Trammell, & Clarke, 2013) such as communication. Family plays an important role in employment for individuals with ASD (Dudley, Nicholas & Zwicker, 2015). They are significant role-players in seeking vocational support by advocating for job placements (Nicolas et al., 2018) and assistance with navigating the services currently available (Hillier and Galizzi, 2014). Individuals with ASD who are classified as level three on the severity index have reduced job opportunities due

to an increase in co-morbid conditions and behavioural challenges (Swaminathan, 2015).

## **2.8. Caregivers' view of therapy**

Therapy refers to speech-language therapy, occupational therapy, physiotherapy and other rehabilitation that is offered at public health care facilities in South Africa. There is a paucity of research regarding caregivers' knowledge, views and satisfaction of treatment for children who present with ASD in South Africa (Wetherston, et al., 2017).

Caregivers of individuals with ASD believe that treatments are often inaccessible and costly. The majority of the South African population access healthcare via government-run clinics and hospitals (Mahlathi & Dlamini, 2015). The lack of trained professionals in the area of ASD impacts parents' views of treatment negatively (Dymond, Gilson, & Myran, 2007). The lack of government support and the long waiting times to access services also negatively impact caregivers' views of therapy.

As previously mentioned in caregiver experiences of raising a child with ASD (P. 20), treatment and therapy for ASD can be a financial burden on caregivers; therefore, some caregivers are unable to access all the services that the individual with ASD may require like speech-language therapy, occupational therapy and psychology. Many caregivers of individuals with ASD reported negative relationships with their healthcare professionals (Cimera & Cowan, 2009). This could be due to caregivers and therapists having differing views on realistic goals for the individual with ASD and the lack of information that caregivers with children with ASD are given. It could also be due to therapists not understanding certain cultural factors. Culture is extremely important as it impacts results and clinical decision making, it is important to make culturally appropriate assessment tools (Nordhal-Hansen, Hart & Øien, 2018). Caregivers may choose to remove their child from therapy should they perceive no progress (Lanners & Mombaerts, 2000)

In South Africa, individuals with ASD are often not provided with the treatment that they require (Bowker, Hicks, D'Angelo, & Wells, 2010). In a study by Wetherston et al. (2017), speech-language therapy was noted to be the most recognised therapy by caregivers of individuals with ASD. This could be due to communication being a core deficit in ASD. Other treatments recognised were occupational therapy,

physiotherapy, social stories and parent involvement. Parents often felt that therapists themselves do not have enough information regarding the different treatments available (Wetherston, et al., 2017).

Caregivers reported that they had difficulty finding therapists that specialise in ASD and travelled long distances to access services (Wetherston, et al., 2017). The majority of the population in South Africa access public health care services (Mahlathi & Dlamini, 2015), which provides therapy once a month; this could impact caregivers' views of the effectiveness of therapy.

A study by Shepard, Landon and Goedeke, (2018) looked at how caregivers chose interventions for their child with ASD. The study found that health care professionals like paediatricians influence parents' choices regarding interventions. Another important factor that is considered by parents is what their child needs specifically, therefore, it is important for therapists to keep parents up to date regarding new interventions (Shepard et al., 2018). For many health care professionals, it would be ideal to address the core characteristics of ASD via early intervention, however, it is important to remember that it is the child, their caregivers and families who face the effects of an intervention. Therefore, it is extremely important to identify what child outcomes caregivers of children with ASD value the most (Nordhal-Hansen et al., 2018).

A study by Fernández-Alcántara, et al., (2016) done in Spain reported that there is a need for health care professionals to help caregivers emotionally during the time of diagnosis and to answer any questions that the caregiver may have regarding the diagnosis including facilitating the access to resources that are available to these parents in their area.

## **2.9. ASD and societal responses**

Research has shown that typically developing children view children with ASD negatively (Campbell, Ferguson, Herzinger, Jackson, & Marino, 2005). These negative perceptions persist into adulthood (Butler & Gillis, 2011). Parents of individuals are also stigmatised due to the perception that they cannot manage their children's behaviour (Sarris, 2015). Stigmatization of ASD is present in most aspects of the individual with ASD's life including employment (Shcherbakov, 2016). In a study



by Werner (2011), female students in fields that work with individuals with ASD described working with these individuals as challenging, frustrating and difficult albeit rewarding and important. This highlights a negative attitude towards ASD amongst some professionals. Caregivers of individuals with ASD may feel affiliate stigma, which refers to internalized stigma for a family member of a stigmatized individual (Mak & Cheung, 2008). The caregiver or family member may feel ashamed or embarrassed of the individual with ASD due to others' reactions and perceptions of their family member with ASD. Caregivers of individuals with ASD may also be exposed to courtesy stigma; this may involve the blame being placed on the caregivers for the onset of ASD and the expectation that caregivers would be ashamed (Vidojevic, Gligorović, & Dragojevic, 2012).

A reason for parental stress is the public stigmatisation of ASD (Kinnear, Link, Ballan, & Fischbach, 2015). A study by Harandi and Fischbach, (2016) found that parents reported individuals using hurtful words to describe their children with ASD like 'weird', 'stupid', 'strange', 'freak', 'aggressive', 'brat' and 'retard'. Parents reported that their child with ASD is often left out of activities and avoided by other children. A study by Sukmak and Sangsuk (2018) found that stigma along with the child's ASD related behaviours are the most significant factors that make parenting a child with ASD challenging.

An Ethiopian study was done by Tilahun, et al. (2016) regarding caregivers of children with developmental disorders found that 43.1% of parents reported being worried about being treated differently and 45.1% felt ashamed about their child's condition. Stigma was reported to be higher in caregivers who sought traditional help and who provided supernatural explanations for their child's condition.

Most caregivers of children with ASD (95%) feel that children with ASD face stigma. Caregivers feel excluded and isolated from friends and family. Parents believe the difficulties that they face due to stigma can be attributed to rejection, exclusion and stereotyping (Kinnear et al., 2016). Children's behaviours are important in determining how they are perceived by others. Educating the public regarding the behaviours associated with ASD should increase public tolerance, understanding and acceptance (Harandi & Fischbach, 2016).

### **2.10. Summary of chapter two**

Chapter two contained a review of the literature and includes the diagnostic criteria, levels of severity, prevalence and aetiology and the characteristics of ASD, including the communication profile regarding non-verbal ASD. It focused on the main themes of the research i.e. Caregivers' expectations regarding education, social participation, employment, therapy and societal responses.

## **CHAPTER THREE: METHODOLOGY**

### **3.1. Aim**

The study aimed to explore caregivers' expectations for their non-verbal child with ASD in rural KwaZulu-Natal.

### **3.2. Objectives**

3.2.1. To explore caregivers' expectations regarding communication for their non-verbal child with ASD.

3.2.2. To explore caregivers' expectations regarding the education of their non-verbal child with ASD.

3.2.3. To explore caregivers' views regarding the social implications of having a non-verbal child with ASD.

3.2.4. To explore caregivers' expectations regarding speech-language therapy.

### **3.3. Study Design**

A descriptive, qualitative, phenomenological, case study design was utilized in this study. Qualitative research focuses on phenomena that take place in the 'real world' (natural settings) (Leedy & Omrod, 2013). Qualitative studies are not simply descriptive studies but are based on robust theoretical traditions (Hammer, 2011). It is used to understand the attitudes and experiences of the participants (Bricki & Green, 2007). Qualitative research aims to recognise the complexity of the issue and portray it in its multifaceted form (Leedy & Omrod, 2013). It seeks to understand and illuminate phenomena, in this case, caregivers' expectations of their non-verbal child with ASD (Golafshani, 2003). The benefits of qualitative research in the health sciences is becoming increasingly recognised by clinicians and academics (Marshall, 1996; Baxter & Jack, 2008). This research design was used for the current study as qualitative research provides valuable information in fields like speech-language therapy (Hammer, 2011). As qualitative research is used to describe phenomena richly within authentic contexts, it can help fill a gap in terms of description and interpretation of the complexity of communication disorders. Due to our diverse society, we have to understand the impact that different cultures, experiences and languages have on our clients and participants. As qualitative research aims to address these issues in other

fields like anthropology, education and sociology, it can be used to gain information on the impact of these differences on techniques used in treatment for individuals from diverse backgrounds like caregivers of non-verbal children with ASD and their children.

The phenomenological study design was used to attempt to describe and explore the participants' perspectives, understanding and perceptions (Leedy & Omrod, 2013) regarding their non-verbal child with ASD. Phenomenological methods are effective in highlighting these experiences from the participants' point of view, therefore challenging normative and structural assumptions. Phenomenological studies can be used to question, support or inform policy and action and therefore will be appropriate as the current study aims to gather data that will be useful for health care professionals and be useful when counselling and providing intervention (Lester, 1999), in this case, to caregivers of non-verbal children with ASD in rural KZN. Phenomenology aims to identify the 'essence' of human experience (Creswell, 2003). Therefore, this study design was appropriate as it explored the experiences and expectations of the caregivers of non-verbal children with ASD.

Case study designs are useful for learning about poorly understood and little-known situations (Leedy & Omrod, 2013), it is flexible, versatile and manageable (Rule & John, 2011). There is a dearth of research on non-verbal ASD and caregivers' expectations in general, therefore this design was appropriate for the current study.

### **3.4. Study Population**

The study population are caregivers of non-verbal children with ASD that reside in rural KwaZulu-Natal.

#### **3.4.1. Sampling technique.**

A non-probability, purposive sampling technique was used in this study. For non-probability sampling, units are chosen deliberately to show specific features of the sampled population and characteristics of the population are used as the basis of selection (Ritchie & Lewis, 2003). Therefore, this approach is well suited to small-scale, in-depth studies (Ritchie & Lewis, 2003) such as the current study. The idea behind qualitative research is to select participants or sites purposefully that will help the researcher to answer the research question (Creswell, 2009). Caregivers of non-

verbal children with ASD in rural KwaZulu-Natal were recruited due to their ability to answer the research question (Rule & John, 2011). The participants were recruited via speech-language therapists at rural hospitals. Purposive sampling was appropriate for the current study as the goal of this sampling method is to gain insight into a phenomenon by purposefully selecting individuals and settings that will maximise the understanding of the phenomenon as they are rich in information, therefore being a good choice for qualitative research (Omona, 2013).

### **3.4.2. Sample size and setting.**

Eleven caregivers of non-verbal children with ASD who reside in rural KwaZulu-Natal were recruited as participants for this study. This sample size was sufficient, as it provided the researcher with adequate insight into the expectations of the participants, therefore allowing the research question to be answered (Creswell, 2013). Concerning sample size, data saturation was another factor that was considered. Data saturation is reached when there is enough information to replicate the study when there is no new data, no new themes and no new codes (Guest, Bunce & Johnson, 2006). Saturation can be reached from as little as six interviews (Guest et al., 2006). Data saturation is not about the number of interviews but rather the depth of the information (Burmeister & Aitken, 2012). Data saturation was reached after ten interviews in the current study, as no new themes emerged between the ninth and tenth interview.

### **3.4.3. Participant Selection Criteria.**

Participants had to be:

- The primary caregiver of a non-verbal child with ASD. Non-verbal refers to a child “using less than 10 words” (Springer et al., 2013, p. 11) and a primary caregiver refers to a ‘person who cares for, nurtures, loves and looks after one or more children, the role is similar to that of a parent’ (Department of Social Development & UNICEF, 2008 p.11). Primary caregivers were included in the study as they spend the most time with the child and are the ones that access services and attend appointments with the child.
- The caregiver of a child between the ages of 5-18 years. This provided a range of expectations of the children at different ages and an insight into how caregivers’ expectations change over time.

- Residing in rural KZN as the focus of the study was to explore the expectations of caregivers of non-verbal children with ASD in rural KwaZulu-Natal. "Rural" refers to areas that are outside of a metro (Gaede & Versteeg, 2011).
- Currently accessing or have previously accessed therapy for their child with ASD (speech-language therapy, occupational therapy, physical therapy and other rehabilitation services).
- Caregivers of non-verbal children with ASD who do not have any co-occurring syndromes (e.g. Down syndrome, Rett syndrome, Fragile X syndrome), as the characteristics of these syndromes could compound the symptoms of ASD and therefore may not be a true reflection of ASD.

#### **3.4.4. Description of participants.**

Twelve potential participants from five districts of KZN (Zululand, Ugu, UmGungundlovu, Amajuba and iLembe) responded. All of these individuals met the selection criteria and completed the consent form. One participant (from Zululand) was included in the pilot study.

The main study included ten interviews with eleven participants (two participants cared for the same child). Two participants were from iLembe, three from Ugu, two from umGungundlovu and two from Amajuba. Participants included ten females and one male with an age range of 23 to 67. The age range of the children with ASD was 5 to 7. Five interviews were conducted in English and five were conducted in isiZulu (the two participants who cared for the same child were interviewed together). Ten participants were Black and one was Coloured. Four participants were the grandmothers of the child with ASD, with six being their mothers and one being an uncle. Regarding participants' employment status, three participants were employed full-time, one participant was employed on a part time basis and two participants were pensioners. The other three participants were unemployed. A description of participants is provided in table 3.

Table 3

*Description of participants*

<b>Participant Code</b>	<b>Code for child with ASD</b>	<b>Age</b>	<b>Sex</b>	<b>Race</b>	<b>Employment status</b>	<b>Language of interview</b>	<b>Relationship to child with ASD</b>	<b>Age of child with ASD</b>	<b>Schooling</b>	<b>District of KZN</b>
CGP	CWAP	76	F	Black	Pensioner	isiZulu	Grandmother	7	Mainstream	Zululand
CG1	CWA1	31	F	Black	Employed	English	Mother	7	Special Education	iLembe
CG2	CWA2	44	F	Black	Employed	English	Mother	5	Not attending	Ugu
CG3	CWA3	30	F	Black	Unemployed	isiZulu	Mother	5	Not attending	iLembe
CG4	CWA4	60	F	Coloured	Employed	English	Grandmother	5	Mainstream	Amajuba
CG5	CWA5	41	F	Black	Unemployed	isiZulu	Mother	9	Not attending	Amajuba
CG6	CWA6	57	F	Black	Unemployed	isiZulu	Grandmother	5	Mainstream	Amajuba
CG7		33	M	Black	Unemployed		Uncle			
CG8	CWA8	43	F	Black	Unemployed	English	Mother	7	Not attending	Ugu

CG9	CWA9	57	F	Black	Part-time employment	isiZulu	Grandmother	7	Not attending	Ugu
CG10	CWA10	23	F	Black	Student	English	Mother	5	Mainstream	umGungundlovu
CG11	CWA11	67	F	Black	Pensioner	isiZulu	Grandmother	5	Not attending	umGungundlovu

Notes: CG= caregiver

CWA= Child with ASD

CGP= caregiver pilot

CWAP= child with ASD pilot



### **3.5. Data Collection Method**

#### **3.5.1. Recruitment log.**

The researcher used a recruitment log to keep track of participants. The log was also used to record the dates and times that participants were approached if they met the criteria for the study and if they provided consent (Marczyc, DeMatteo, & Festinger, 2005). Their language of choice was also recorded.

#### **3.5.2. Interview.**

In-depth, semi-structured interviews were conducted to obtain data from the participants. Interviews offer more extensive and richer data as compared to surveys (Yin, 2012). The interviews allowed the researcher to study how the participants construct reality and view situations (Yin, 2012), in this case caregivers of non-verbal children with ASD and how they experience their world (Brinkmann, 2018). Semi-structured interviews were used as it allowed for more flexibility whilst still focusing the conversation on issues that are regarded as important to the study (Brinkmann, 2018). Interviews allowed the researcher to clarify ambiguity and seek follow-up information when necessary (Leedy & Omrod, 2013). Face to face interviews allowed the researcher to build a rapport with the participants and therefore yielded the best response (Leedy & Omrod, 2013). The duration of each interview was an hour to an hour and a half, with the average interview being an hour and fifteen minutes.

The interviews were conducted in either English or isiZulu, depending on the preference of the participant. An interpreter was used when the participant requested the interview to be conducted in isiZulu. An interpreter provides an oral translation service during the interaction of a minimum of two people (Hole, 2007) during an interview or focus group (Squires, 2009). Using an interpreter to assist with interviewing individuals of a different ethnic or linguistic group allows the researcher to gain rich and meaningful information for their study and is an important aspect of a cross-linguistic research process (Squires, 2009). The interpreters were first language isiZulu speakers who were either qualified speech-language therapists (or senior students of speech-language pathology) and familiar with the research procedure and

ASD. A total of three interpreters was used due to availability and logistics such as the geographical location of the interviews. Working with multiple interpreters could lead to challenges such as interpreters having differing understanding of the aims of the study or different priorities when relaying information (Plumridge, et al., 2012). This was mitigated in the current study by a detailed briefing prior to interviews as well as having all interviews back translated by the same person to ensure that the information presented was accurate. The interpreter was considered as the interviewer for the study as this allowed the interview to flow better (Farooq & Fear, 2003). The researcher briefed the interpreter on how to conduct the interview and the aims of the study beforehand (Langdon & Cheng, 2002). The participants provided verbal consent for the use of an interpreter during their interview. The interpreter used the interview schedule to ask the questions. Once the participant had answered, the interpreter translated the answer for the researcher, the researcher probed when needed and this was translated by the interpreter.

The researcher liaised with the participant to set a date and time for the interview. The interviews took place in a quiet space at the hospitals where the participants seek services for their child with ASD. Permission from the participants was gained to record the interview via audio recording and taking notes (Creswell 2003; Creswell, 2012). The interview was audio-recorded on two high-quality dictaphones (Panasonic IC recorder RR-XS350) by the researcher. The researcher began the interview by reminding the participant of the purpose of the interview and the research aim, confidentiality was assured (Sansoti, Lavik & Sansoti, 2012). The interviewing technique was reproducible (another individual could use the same topical guidelines and gain similar results), systematic (caregivers of non-verbal with ASD were chosen so that they provided the most unbiased ideas rather than reflecting a specific idea) and credible (the questions had enough clarity to generate truthful responses) (Bricki & Green, 2007).

### **3.5.3. Data Collection Instrument.**

An interview schedule was the main instrument used in this study (Appendix E). The questions used in this study were written in English and translated into isiZulu with the help of an interpreter. The translated interview schedule (Appendix F) was used when the participant elected to be interviewed in isiZulu. The interview protocol included

sections such as interview details (including place, date, interviewer, interviewee), instructions for the interviewer to follow so that standard procedure was followed during all interviews, key research questions and probes to follow these questions (Creswell, 2012). The interview was divided into three stages, a briefing or introduction, content gathering and debriefing (Neumann et al., 2009). A space for recording comments and a space to record the interviewer's reflective notes was included. A thank you statement was included at the end of the interview to acknowledge the time that the participant had taken to participate in the interview (Creswell, 2009).

Open-ended questions were used to gain in-depth information. The questions were developed according to the aims and objectives of this study and thematically organised using core literature (ASHA, 2019; Bokare & Munir, 2010; Car Autism Roadmap, 2014; Poon et al., 2013; Glazzard & Overall, 2012; Bush, Eisenhower, Cohen & Blacher, 2017; Papageorgiou & Kalyva, 2010; Wetherston et al., 2017). The themes included in the interview schedule and the motivation for their inclusion are included in table 4.

Table 4

*Themes included in the interview schedule and the motivation for their inclusion*

THEMES	MOTIVATION
Introduction and background information	Questions in this area were included to build rapport with participants and create a comfortable ambience for the interview process. It also provided the researcher with valuable information regarding the participants' background and day to day life which aided in the understanding and interpretation of results (Creswell, 2012).
Caregivers' experiences of raising a child with ASD	Questions included in this section helped the researcher to gain information on the types of experiences that caregivers have raising a child with ASD. Due to ASD being a lifelong condition, individuals with ASD often live with their caregivers well into adulthood (Poon et al., 2013). Therefore, it is important to understand the experiences that the caregivers face and their expectations. Caregivers'

THEMES	MOTIVATION
	past experiences could shape their future expectations.
Identifying caregivers' expectations	Parents' expectations are a telling predictor for their child's future accomplishments (Thomas et al., 2018). Upon receiving diagnosis parents often feel a loss of the expectations that they had for a typically developing child and are faced with misgivings regarding their child's future (Hock et al., 2012). Therefore, this theme enabled the researcher to identify caregivers' expectations for their non-verbal child with ASD in rural KZN.
Caregivers' expectations regarding education	Children of caregivers who felt that education was a futile endeavour had poorer outcomes than children with ID whose caregivers did access education for their children (Mutua, 2001). Therefore, gaining a perspective on what caregivers of non-verbal children with ASD in rural KZN expect regarding education is important as it could impact on the child's outcomes.
Caregivers' expectations regarding social participation and employment	A study by Poon, Koh & Magiati (2013), reported that caregivers of individuals with ASD rated social activities like getting married, having children and buying a house as least important for their children with ASD. Therefore, important information could be gained from participants regarding what they expect from their children in terms of social participation and employment, specifically in rural KZN.
Caregivers' views and expectations of therapy	Therapy refers to speech-language therapy, occupational therapy, physiotherapy and other therapies offered at the public hospitals. There is a paucity of research regarding caregivers' knowledge, views of and satisfaction with treatment for children who present with SD in South Africa (Wetherston et al., 2017). Therefore, it is important to gain information regarding what caregivers of non-verbal children with ASD in rural KZN expect from therapy and how they view it.
ASD and societal responses	Parents of individuals with ASD are stigmatised due to the perception that they cannot manage their children's' behaviour (Sarris, 2015). Caregivers of

THEMES	MOTIVATION
	children with ASD may feel affiliate stigma i.e. internalised stigma of a stigmatised individual (in this case the individual with ASD) (Mak & Cheung, 2008). It is important to understand how caregivers deal with stigma particularly in rural KZN, as this has not been explored before.

### 3.5.4. Data Collection Procedure

The following steps were carried out before, during and after the data collection process:

1. The researcher obtained ethical clearance from the UKZN Biomedical Research Ethics Committee (BREC), (Ethical clearance number: 00000096/2019) (Appendix I).
2. The researcher obtained a letter of support from the programme manager at the KZN Department of Health Research (Appendix J).
3. The researcher then obtained permission from the KZN Department of Health to access public hospitals (Appendix K).
4. The researcher recruited participants by contacting public hospitals in KZN which were located in areas that are classified as rural, that is, areas out of a metro (Gaede & Versteeg, 2011) where assessment and therapy services are offered for individuals with ASD. This was conducted via a letter (Appendix D) and a telephonic follow-up. The researcher explained the study and requested permission to send potential participants a letter requesting participation in the study.
5. Potential participants were identified by the resident speech-language therapists at the hospitals that the caregivers visit to access services for their child with ASD.
6. Letters requesting participation were sent to potential participants (Appendix B) via the resident speech-language therapist. Information documents requesting a convenient place and time to interview in English and isiZulu were included.

7. The researcher gained consent from the participants. Participants were only included in the study once consent has been obtained (Appendix C).
8. Participants were then contacted via phone to set a date and time for the interview, any questions were answered over the phone.
9. The pilot study interview was scheduled.
10. The study interviews then took place at scheduled times and at specified locations at the hospital where the participants access services for their children.
11. The interviews were audio-recorded and then transcribed verbatim with the English portion transcribed by the researcher and the isiZulu done by the interpreter, a separate interpreter then 'back' translated the isiZulu into English for analysis.
12. The data was analysed and interpreted thematically.
13. The final report was compiled and submitted.

### **3.6. Issues of Trustworthiness**

Concerning trustworthiness, the issues of dependability, credibility, transferability and confirmability were considered. Credibility refers to the researcher ensuring that the results reported accurately reflect the information shared by the participant (Creswell, 2009), in this case, the caregiver of the non-verbal child with ASD. This was ensured by recording the interviews on two, high-quality audio-recorders, which provided the researcher with two clear recordings of each interview (Modaff & Modaff, 2000).

The researcher conducted member-checking by checking important data with the caregivers of the individual with ASD before, during and after each interview to ensure that data is accurately understood (Tracy, 2010). Member checking strengthens the data (Korstjens & Moser, 2018). Transferability refers to the degree to which the results of the study can be transferred to other contexts (Lincoln & Guba, 1985).

Transferability was ensured by thick description, which refers to describing not just the experiences and behaviours of the caregivers of the individual with ASD but their contexts as well, thereby making the experiences and behaviours understood by an outsider and providing enough detail for other researchers who may want to transfer the results to other studies (Tracy, 2010).

Confirmability refers to the degree to which the findings of the study could be confirmed by other researchers (Lincoln & Guba, 1985). This is to ensure that the findings and interpretations are derived directly from the data. Dependability was ensured during the data collection and analysis i.e. if the study was to be repeated, the same results would be obtained (Creswell, 2009). Confirmability and dependability were ensured via an audit trail (Tracy, 2010). An audit trail refers to the transparency of the research process by documenting and describing the steps taken from the beginning of the research project to the end and keeping records of this throughout the study (Lincoln & Guba, 1985).

### 3.7. Ethical considerations

Ethical behaviour includes acting in a way that includes the correct principles of behaviour and conduct (Marczyc et al., 2005). During this study, the researcher followed the fundamental ethical principles of respect for persons (autonomy), beneficence, and confidentiality and not harm (Marczyc et al., 2005). The researcher also followed the principles of the Declaration of Helsinki, which was developed by the World Medical Association and governs medical professionals when researching with human participants (World Medical Association, 2018).

**Respect for persons (autonomy)** refers to the participants having the right to decide if they choose to be a part of the study or not, and how involved they wish to be (Marczyc et al., 2005). An important aspect of the study is enabling the participant to make an informed decision regarding their participation. To ensure this, the researcher provided the participants with the necessary information on the study so that they were able to make an informed decision (Marczyc et al., 2005).

**Beneficence** refers to 'no harm'. The study should not harm the participants in any way. Benefits should be maximised, and risk should be minimised (Marczyc et al., 2005). The researcher ensured this by providing valid information with regards to the study (Marczyc et al., 2005). The researcher treated the participants with understanding and respect.

**Informed consent** refers to the voluntary agreement to participate in research in which the participant understands. The researcher obtained consent from the

caregivers of non-verbal children with ASD to interview them. Informed consent was gained by describing the study explicitly to potential participants. This allowed the participant to make an informed decision regarding their participation (Marczyc et al., 2005). The participants were asked to complete a consent form (in English or isiZulu) as a requirement of participation (Marczyc et al., 2005). Gaining informed consent involves informing the potential participant about their rights, the nature and purpose of the study, the procedures to be undergone and the potential benefits and risks, and how the results will be published and used (Hoeyer, Dahlager, & Lynöe, 2006). The process of informed consent is on-going and the potential participant can opt-out at any time, even after the informed consent documents have been signed. Proxy consent was applied. If the participant was unable to read the documents, the study was explained to them in detail via an interpreter. This ensured that the participant understood the information presented before they participated in the study (Marczyc et al., 2005). The participants were compensated for their transportation to and from the hospital as a token of appreciation by the researcher, it was made clear before the interview that they would be compensated regardless of the views that they express. It was also made clear that the researcher would not be able to provide any help regarding therapy or a disability grant as this was brought up by the participant of the pilot study.

The researcher is responsible for maintaining **confidentiality**. The researcher and interpreters did not divulge any personal details about the participants. This was assured by assigning each participant a code when referring to them (Refer to Table 3) as well as ensuring that interpreters understood the sensitive nature of the research. The researcher had prepared a list of psychologists and social workers available in the participant's area should they have a negative emotional reaction to the interview (due to the sensitive nature of the topic). This was not necessary for the current study. Two participants who became emotional during the interviews, were provided with the details of the hospital's social work department.



### 3.8. Pilot Study

A way to ensure the trustworthiness of the research study is to conduct a pilot study (Leedy & Omrod, 2013). A pilot study is a brief exploratory investigation. It is used to trial procedures, data collection instruments and methods of analysis (Leedy & Omrod, 2013). It is a good way to determine how feasible the study is (Janghorban, Roudsari, & Taghipour, 2014). It is used to test the study for weaknesses and then modify it if necessary (Janghorban, Roudsari & Taghipour, 2014). Table 5 contains the aims of the pilot study with motivation.

Table 5

#### *Aims of the pilot study*

<b>Aims</b>	<b>Motivation</b>
To evaluate the sample of participants (inclusion and exclusion criteria)	The pilot study allowed the researcher to locate and explore potential participants for the study (Schreiber, 2008). It enabled the researcher to determine the appropriateness of the inclusion and exclusion criteria (Drummond, 2017)
To assess the trustworthiness of the data collection tool developed i.e. interview schedule	The pilot study enabled the researcher to identify if any changes needed to be made to the tool before use in the main study (Leedy & Omrod, 2013).
To assess the appropriateness of the interview questions	This is done to determine if the wording and sequence of the questions would yield a rich response and answer the research question and adapting the questions that need to be adapted (Leedy & Omrod, 2013).
To determine logistical issues like time taken per interview and potential cost.	This is to ensure that finances and time are managed efficiently throughout the

	data collection process (Schreiber, 2008).
To evaluate the use of an interpreter	The pilot study enabled the researcher to identify any changes that needed to be made in terms of the dynamic between the researcher, interpreter and participant and how the questions were asked and translated.

### 3.9. Pilot Sample profile and size

The pilot study consisted of one participant i.e. one caregiver of a non-verbal child aged between five and eighteen with ASD in rural KZN. The first potential participant that responded to the researcher's request to participate in the research was chosen for the pilot study (Refer to table 4 for participant description). The participant met the proposed inclusion and exclusion criteria for this study (refer to pp. 22-23). Since changes to the data collection tool and method occurred, the data gathered from the pilot study was not included in the main study as it had implications on the standardisation of the data collected.

Table 6

*Description of pilot study participants*

Caregiver (relationship to child)	Gender	Age	Language	Employment status	Age of child with ASD	Schooling	District of KZN
Grandmother	F	78	IsiZulu	Pensioner	7	Mainstream	Zululand

The participant of the pilot study was questioned after the interview for the researcher to gain feedback on the data collection process and instrument. The participant was asked about the nature and phrasing of questions and if the participant was able to understand the questions and the length of the interview. These responses helped to determine the feasibility and test the study for weaknesses. The feedback and data received allowed the researcher to practice the research process and analysis and check if the questions asked gained enough relevant data (Schreiber, 2008). Minor changes were made to the data collection tool and the manner of interviewing based on listening to the audio recording. The changes made are in Table 7.

Table 7

*Description of changes made following the pilot study interview*

<b>Area of focus</b>	<b>Feedback from a pilot participant and researcher</b>	<b>Action taken</b>
Gaining consent from facilities	The researcher found it extremely difficult to gain permission from individual hospitals. There was no response to emails and hospitals would give numerous email addresses to re-send documents to.	The number of phone calls and e-mails was increased. E-mails were re-sent
Travelling to and from the pilot	The researcher and interpreter needed to be punctual as they flew with Air Mercy Services to the hospital.	The researcher reiterated the need to be on time.
The inclusion and exclusion criteria	The researcher noted that these were appropriate.	No action necessary
The use of an interpreter	The researcher noted that it was difficult to interpret the questions directly during the interviews and the	The interview schedule was translated into isiZulu before the interview to make it

Area of focus	Feedback from a pilot participant and researcher	Action taken
	<p>interpreter may have been summarising the responses rather than translating verbatim</p>	<p>easier for the interpreter during the interview.</p> <p>The isiZulu portion of the study was transcribed and thereafter translated by a different interpreter to ensure that the questions and answers match that of the English.</p>
<p>Consent and biographical information forms</p>	<p>The participant had limited literacy and therefore the study was explained verbally. The participant signed a cross next to her name as this what she does to all documentation. The age of diagnosis could be added into the interview schedule.</p> <p>The consent and information forms do not include details of individuals that they may contact for any questions that they may have regarding grants and therapy at the particular institution.</p>	<p>A script was added to the start of the interview schedule (Appendix G &amp; E, p. 1) with a verbal explanation of the study the section including the date of diagnosis was added in.</p> <p>Information regarding individuals that they may contact was added to the information forms.</p>
<p>Quality of audio-recording</p>	<p>The audio-recording was clear and could easily be transcribed</p>	<p>No action necessary</p>
<p>Length of interview</p>	<p>The interview lasted 1 hour and 5 minutes. The participant did mention that the interview was a</p>	<p>The participant was offered a five -minute break halfway through the interview. The</p>

Area of focus	Feedback from a pilot participant and researcher	Action taken
	bit long and that she was tired	researcher made the length of the interview more explicit to the participant at the start of the interview and offered refreshments during the interview to make the process more comfortable.
Questions in the data collection instrument	<p>The participant said that the questions asked were acceptable.</p> <p>The researcher noted that not enough information regarding the participant's living conditions/contexts was gained during questioning. It was noted that there were some gaps in information.</p>	<p>A question and probe were added to gain more context.</p> <p>Questions 3, 19 and 28 were added</p> <p>Probes were added to questions 2, 8, 11, 14, 22</p>
The wording of the questions	The participant reported that the questions were easy to understand. She required certain questions to be repeated. Once they were repeated, she understood and answered appropriately	No changes were necessary
Researcher's manner during the interview	The participant reported that both the researcher and interpreter were easy to speak to.	No changes were necessary

### **3.10. Data Analysis**

#### **3.10.1. Transcription.**

Transcription refers to the close observation of data through repeated listening (Bailey, 2008). It allows the researcher to change the audio recordings into data in the form of text (Creswell, 2012). The transcription was verbatim to avoid bias (Lacey & Luff, 2009). The transcription also included non-verbal aspects of the interviews as non-verbal cues like hand gestures, expressions and tone could add meaning to the spoken words (Lacey & Luff, 2009). The researcher transcribed all utterances by the interviewer and the participant as this allowed the researcher to capture details of the interview like speed, tone, emphasis, pauses and timing which impacts on analysis and interpretation (Bailey, 2008; Creswell, 2012). Transcription was done in English and/or isiZulu depending on the language/s used by the participants. The interviews that were conducted in isiZulu were transcribed by the interpreter, with the isiZulu portion transcribed by the interpreter. The isiZulu transcript was then sent to another interpreter to translate back into English to ensure that the responses were consistent.

#### **3.10.2. Organisation.**

The organisation of data collected from an interview is critical, it must be systematic as interviews generally yield a vast amount of data (Creswell, 2012). The researcher kept track of and organised data by incorporating data into a table of sources. This table was organised according to types of data e.g. interviews, forms filled, documents and/or other (Creswell, 2012). The data was organised further according to age, gender, location and education of the non-verbal children with ASD in rural KZN (Creswell, 2012). The data was organised according to categories of the sources of information received (Creswell, 2012).

#### **3.10.3. Analysis.**

A *preliminary, exploratory analysis* (Creswell, 2012) was conducted by the researcher. This allowed the researcher to develop an idea of the data collected by writing concepts, short phrases and ideas on the margins of the transcripts (Creswell, 2012). Coding refers to using labels to highlight different themes in the data (Rule & John, 2011). Choices made during coding impact the reporting and interpreting of the data. Coding provides a great opportunity to get close to the data (Rule & John, 2011). The

codes follow themes that were found in the literature review (Creswell, 2012). The researcher analysed the data by colour coding the information to narrow the data into themes and form descriptions (Creswell, 2012). Themes were decided via inductive thematic analysis, which aided in organising the data into increasingly more abstract and detailed themes (Creswell, 2007). The researcher worked closely with the existing themes that were identified in the literature review and the data to establish a comprehensive list of themes (Creswell, 2007). The process of coding allows important information to be highlighted and information that lacks evidence to be incorporated (Creswell, 2012). The themes identified during the coding process are often used to guide the findings and reporting of results (Creswell, 2012).

The final step in data analysis is *interpretation* (Creswell, 2012). The interpretation of the study refers to the understanding that is gained from the data (Creswell, 2012) and the lessons that could be learned from it (Lincoln & Guba, 1985). It is the meaning that is derived from a comparison of the findings of the research to the literature and theories (Creswell, 2003). The researcher used the hybrid theory to interpret the data collected during the interviews with the caregivers of the non-verbal children with ASD and further understand it. The researcher interpreted the data by seeking and considering as much evidence as possible, the interpretation should leave no loose ends, as it may then be vulnerable to alternate interpretations (Yin, 2009). The interpretation also acknowledged contradictory research (if there is any) and provided possible explanations for the differences in the findings (Yin, 2009). The interpretation was used to demonstrate the researcher's awareness and current thinking regarding the research topic (Yin, 2009) i.e. the caregivers' expectations of their non-verbal children with ASD in rural KZN. Interpretation is the essence of research, without reaching the inherent meaning of the data, no resolution of the research problem could be found (Leedy & Omrod, 2013). The interpretation could either confirm information from the past found in the literature regarding caregivers' expectations of their non-verbal children with ASD or deviate from it and will lead to new questions that were not foreseen by the researcher before the study (Creswell, 2003). Interpretation formed from the data could initiate a call for change and reform of policy (Creswell, 2003)

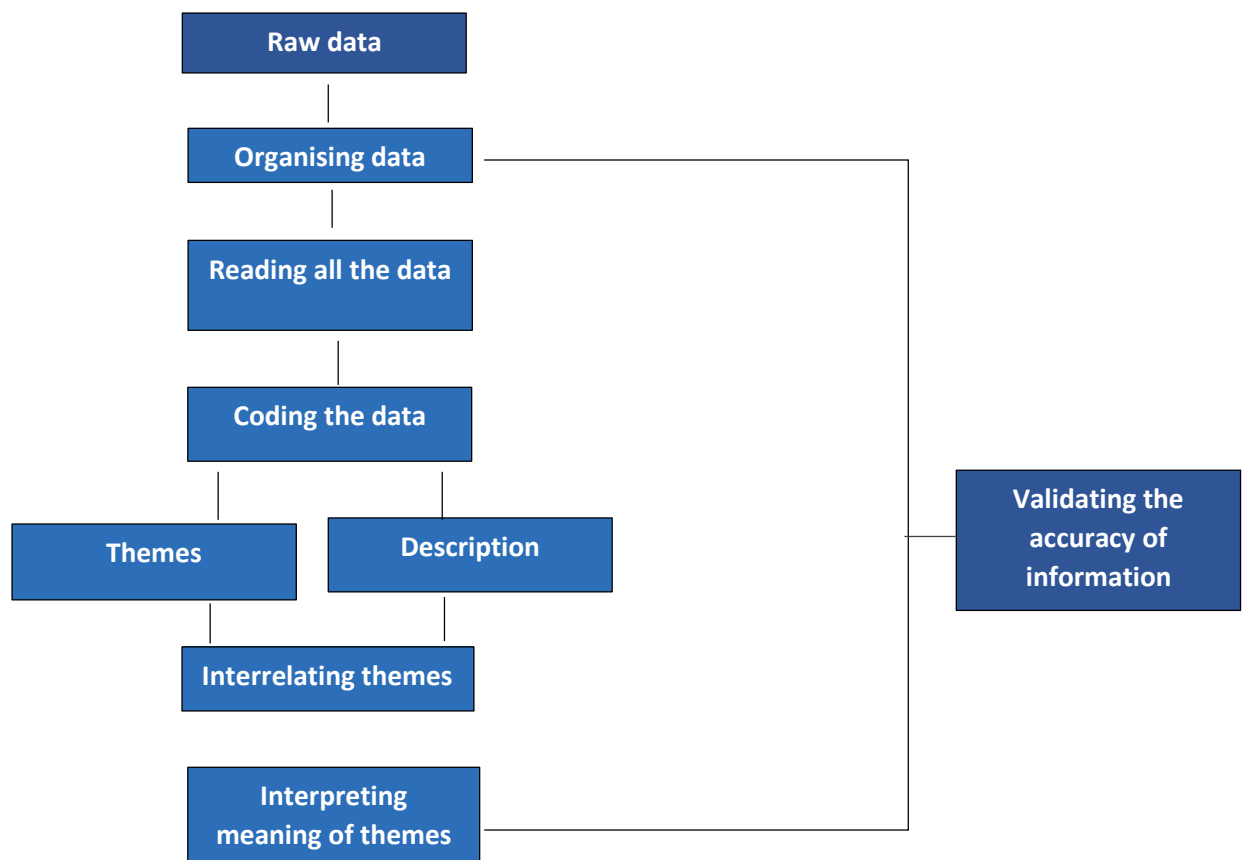


Figure 4. The data analysis process (Creswell, 2013)

### 3.11. Representing and reporting findings

The researcher used a comparison table to display her findings visually. This table enabled the researcher to identify and draw comparisons and similarities between the expectations that caregivers of non-verbal children with ASD have, under the relevant themes (Creswell, 2012). A narrative discussion was used to report the findings of the study (Creswell, 2012). This allowed the researcher to develop detailed descriptions of the findings, which is used with the results described under the relevant themes (Creswell, 2012). Literature that was reviewed, together with the data from the current study was used to interpret the results.

### 3.12. Data management

All electronic data were stored on the researcher's laptop in password-protected files, allowing only the researcher and her supervisors to access. All printed and written



material will be stored in a locked filing cabinet in the Discipline of Speech-Language Pathology at the UKZN Westville Campus, where it will remain for five years. All confidential documents will be shredded and destroyed after five years of storage (Creswell, 2013).

### **3.13. Dissemination of results**

For the research study to have an impact on the population that it is studying, the researcher should share the results with the said population and professionals in the field and the results must be made public (Marczyc et al., 2005). The researcher will notify the participants about the results of the study via letters to the hospital that their respective interviews took place.

The researcher will share the research with Action in Autism and other advocacy groups that work with individuals with ASD and who can make the results public. The results will also be shared with the relevant individuals who aided in the recruitment process and with the KwaZulu-Natal Department of Health. The researcher will make the research available to other SLTs by publication and presentation at conferences.

## Chapter Four: Results and Discussion

This study aimed to explore caregivers' expectations of their non-verbal children with ASD in rural KZN. The participants in this study included 11 caregivers of non-verbal children with ASD from 4 districts (iLembe, Amajuba, Ugu and Umgungundlovu) in rural KZN. The caregivers included 10 females and one male, with four caregivers being grandparents to the child with ASD. Both English and isiZulu participants were included (refer to Table 3), therefore interviews were transcribed according to the language of interview with the isiZulu interviews being back-translated. Caregivers and their children with ASD were given numbered codes (e.g. Caregiver 1 is CG1 and Child with ASD 1 is CWA1). The results are presented and discussed according to the themes and subthemes that emerged during the data analysis and in relation to the relevant literature as well as in relation to the hybrid theory that frames the study (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). Direct excerpts from the interviews are presented in the language of the interviews and translated into English for the isiZulu interviews. This aided in ensuring that the content of the interviews were not changed. The thematic content analysis yielded 10 themes and 28 subthemes. The themes and subthemes are presented in Figure 5. The themes and subthemes in relation to the hybrid theory are presented in Figure 6.

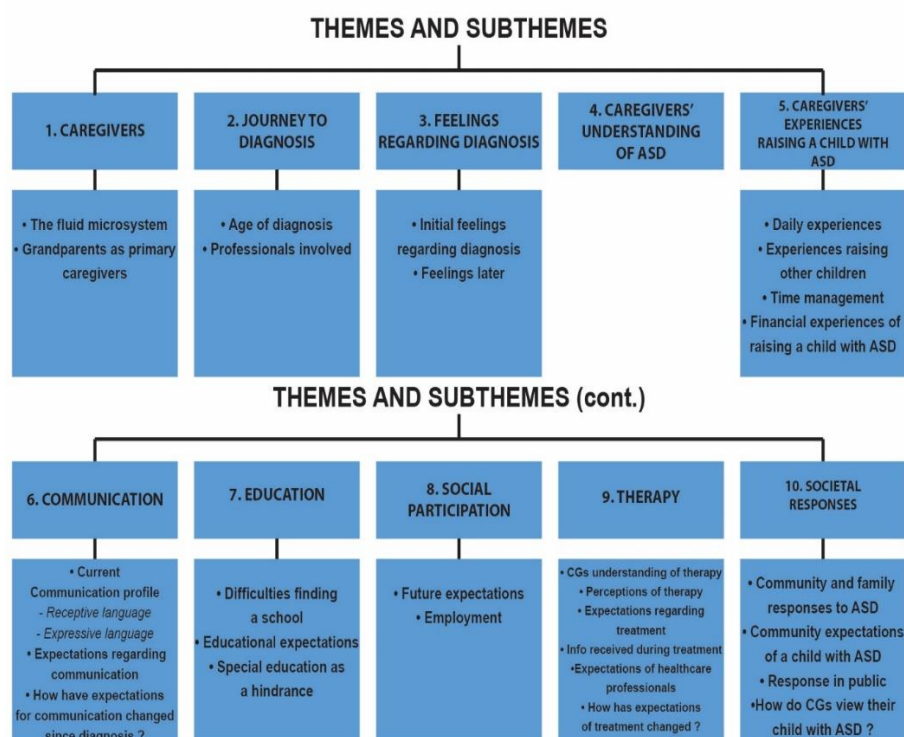


Figure 5. Themes and subthemes (CG refers to caregiver)

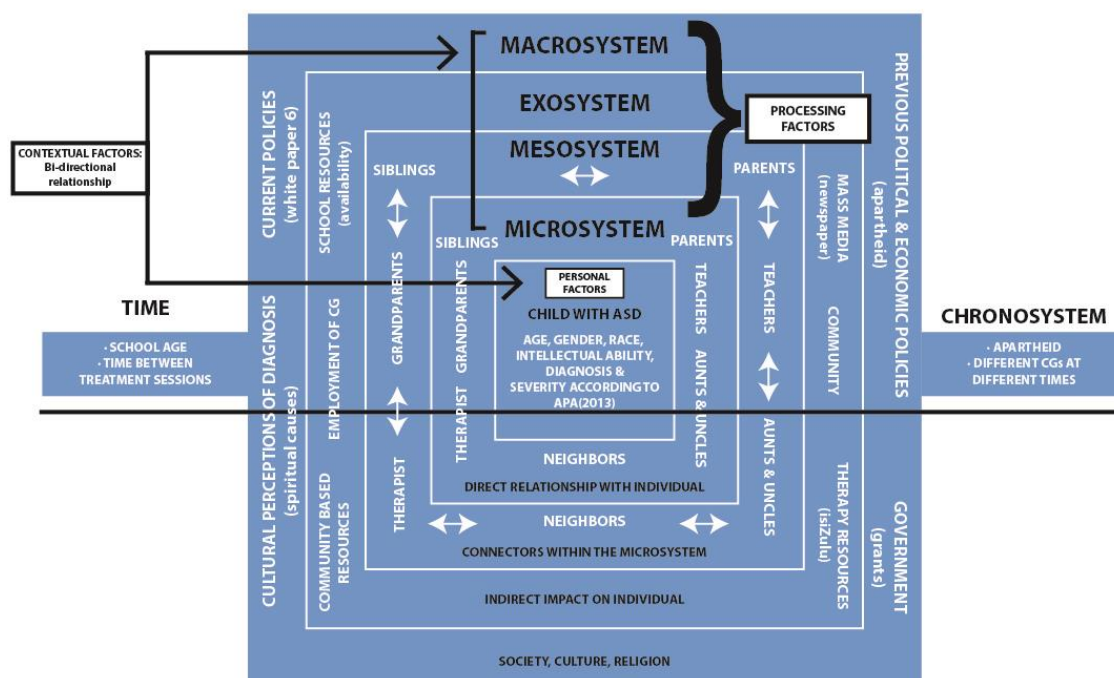


Figure 6. The hybrid theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) in relation to the current study. This figure illustrates the results of the study (in white font) framed by the components of the hybrid theory (in black font)

Caring for a child with ASD is a journey. Below is a composite story, created from the results of this study that illustrates the journey of caregivers of children with non-verbal ASD in rural KwaZulu-Natal and its reality.

***A day in the life of...***

The sun is about to rise on another day in iLembe. A young mother readies herself and her child for a long 70km journey including many taxis to the regional hospital<sup>1</sup>. Her child has been diagnosed with ASD. She is unsure about his future and does not know what to expect. She hopes that the therapists will help her understand the disorder and help her son to be like other children. She leaves her baby with her elderly grandmother and sets off on her journey.

Its midday in the Ugu district, a grandmother has been waiting for many hours in a line at the local hospital for her grandson's hospital card so that he may begin his appointments for the day. He is fidgeting and touching other people in the line who do not seem to enjoy it, she feels embarrassed and does not tell them of his diagnosis. She eventually gets his card and has four appointments for the day including the speech therapist, the occupational therapist, the dietician and the doctor. By the second appointment her grandson is exhausted, crying and does not want to participate. She leaves the hospital at 4pm with an unhappy child in tow, wondering if it's all worth it. Is it?

It is late afternoon in Zululand. A mother feels defeated after being on the phone with the local special needs school, she is trying to secure a place for her daughter but is worried about how she will afford it. R5000 excluding transport costs is a significant amount of money for them as her brother is the only one in the family who works. He earns R3000 per month which is usually stretched thin to support all seven members of their household. The school has informed her that they have a very long waiting list and thereafter will only admit her daughter if she is toilet-trained. She wonders how this will be possible as her daughter does not understand her or speak.

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<sup>1</sup> Often referred to as a provincial hospital, a regional hospital is highly differentiated and has 10 to 15 clinical specialities; with 200 to 800 beds (Hensher, Price & Adomakoh, 2006).

It is sunset in uMgungundlovu. A grandmother is preparing supper for her three grandchildren that she cares for. She thinks about her morning conversations with her friends when fetching water from the river. They were asking when her grandson will begin speaking and attending school like the other children in their community. She thinks back to a meeting with his doctor who tried explaining to her what his future could look like, she had difficulties understanding this information as some of the terms used were in English. Therefore, she does not know what to expect and worries for him as he gets older.

It is bed time in Ethekwini. A mother yearns for her son that she left behind with her mother in her village in the Ugu district. She is aware that he has ASD and worries how her mother is coping. She works in Ethekwini during the week and therefore is unavailable for his healthcare appointments. She tries to follow up with her mother regarding his progress but her mother reported that she sees no difference despite the therapists trying their best.

## **4.1. Caregivers of Non-verbal children with ASD**

### **4.1.1. 'Maybe they told my sister' -The fluid microsystem.**

Caregivers of children with ASD in the current study form part of their child's microsystem. The microsystem is fluid i.e. their microsystem changes depending on circumstances. South African households are dynamic, with residents changing frequently in short time frames (Hall & Mokomane, 2018). In the current study, the children with ASD in rural areas had different primary caregivers in their lives mainly due to caregivers (mainly parents) finding employment in urban areas, leaving their children in the care of other family members who then assume the role of primary caregiver. This fluidity is exemplified in CG5. She found employment in Johannesburg and left CWA5 in the care of her sister, who then found employment and CG5 returned home, once again becoming CWA5's primary caregiver. In rural South Africa, there is a decrease in nuclear households (i.e. households with parents and their children only) due to the migratory pattern, particularly an increase in female migration behaviours (Camlin, Snow & Hosegood, 2014). According to Stats SA, (2017), extended families are the most common type of households in South Africa (36%), with 66% of Black South Africans living in extended families. CWA6 is cared for by his grandmother and uncle as his parents work out of the province. CG2 returns home on the weekends from her job to care for her daughter and CG11 is a university student in Durban, so her sisters and mother help with childcare when she is at university.

The fluid microsystem may be a result of factors in other components of the hybrid theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) such as the macrosystem and chronosystem. Participants had the need to seek employment out of their rural residential areas due to factors in the macrosystem and chronosystem i.e. the previous political and economic system of apartheid which forced many Black South Africans into the rural areas. Although apartheid ended in 1990, the rural areas were left underdeveloped and impoverished. Apartheid deliberately caused large social, psychological, economic and medical disparities between races (Bohman et al., 2007; BarRebarin & Richter, 2013).

The fluid nature of the microsystem may have an effect on caregivers' expectations as different caregivers of a child with ASD may present with varying levels of understanding of ASD or receive dissimilar information when taking their child to

healthcare appointments. How information is shared by healthcare professionals to caregivers of a dynamic household needs to be considered. The fluid microsystem may result in health care professionals liaising with multiple individuals regarding a child, which could affect the consistency of care that the child receives and provide challenges for health care professionals when providing health care information.

In the current study CG5 was unclear on the details of her child obtaining an ASD diagnosis as her sister took CWA5 to therapy for a period of time. Due to these factors within the framework in the current context, the communication between CG5 and her sister (which forms the mesosystem) may be difficult due to geographical, financial and educational factors. This highlights the challenges faced by CG5 in attaining and maintaining consistent health care for CWA5 which health care professionals may be unaware of. The gap in communication within the child's mesosystem has a negative effect on the child with ASD. CG5 being unaware of her child's diagnosis for a significant period of time may have impacted the support that CG5 and CWA5 received as early diagnosis and intervention have positive implications for the long-term quality of life for children with ASD (Elder, Krieder, Brasher, & Ansell, 2017).

*CG5: Mhlampe bamutshela usisi wami ukuthi une Autism kodwa akangabuza ukuthi yini yona lena. Mina kwakumele ngibuze ukuze ngiqonde ukuthi iyini. (Maybe they told my sister that she has Autism, but she didn't ask questions on what it is. I had to ask and understand on what it is.)*

#### **4.1.2. 'She did funny things and left me with the baby'- Grandparents as primary caregivers.**

Due to the fluidity of the microsystem, the younger individuals of families often having to leave home due to work. Grandparents become the primary caregivers to the children with ASD (Schatz & Ogunmefun, 2007). In South Africa, intergenerational family relationships are usual (Lloyd & Sherlock, 2000). Only one in three South African children live with their biological parents and 61% of these children who do not live with either of their parents live with a grandparent (South African Human Rights Commission and the United Nations Children's Fund (UNICEF), 2011). Similarly, in 2017, Statistics South Africa (STATS SA) reported that 65% of children live with their grandparents. Unemployment and low wages have led to parents being unable to

manage their financial responsibilities to their children and leaving their parents liable. In a time that the grandparents should be taken of, they are doing the caretaking (Mokone, 2006).

The grandparents in this study form part of the child with autism's microsystem (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) and their expectations influence their behaviours and actions, which have a direct impact on the child with autism and their future. In the current study four of the eleven caregivers interviewed were grandparents, specifically grandmothers. This was due to factors such as their children leaving home for work and death of a parent (CG4). Two participants (CG2 and CG3) leave their children in the care of their grandmothers when they are working. Therefore, a total of six of the ten children with ASD were primarily looked after by their grandmothers. CG9 and CG11 both cared for grandchildren from other offspring in addition to the grandchild with ASD. Grandparents as primary caregivers goes back to the apartheid system in South Africa which forced many of the country's Black citizens into rural areas forcing their children to leave home and travel into the urban areas to find jobs, leaving the older members of the family to look after their children (Hall & Posel, 2019). The apartheid system forms part of the macrosystem as it was a previous government policy, the remnants of which still have an indirect effect on the child with ASD and their families. As apartheid forms part of the history of South Africa it forms part of the chronosystem (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006).

*CG2 : Well actually I am staying inside the \_\_\_ so it's a single quarters, she stays with my mum and my sister but most of the time she is with my mum because she is always at home, my sister is always working...my mum has the responsibility.*

*CG4: His mother passed away...she had him in November and by December she was very sick... they said put her off the machines until she passed away.*

*CG7: He is my big brother's son, he is in the Eastern Cape, the mother of the child also lives there, they have broken up.*

*CG9: Kwakunzima. Umawakhe wayesamncane, uyazazi ke izingane, waya eskoleni wabanengane. Wenza izinto ezingaqondakali wangishiya nengane (It was difficult. His mother was young, you know young people she went to school and had a baby. She did funny things and left me with the baby.)*



*CG11: Nabantwana uma bethola amatoho baye bathumele imali. (If my children get part-time jobs, they're able to send money home.)*

One grandmother in the study (CG9) reported that raising a child with ASD coupled with financial strain led her to alcoholism. This correlates with research which suggests that raising their grandchildren affects grandparents negatively in areas such as physical health, psychological health and economic and social well-being (Kelley, Whitley & Campos, 2010). Poor physical health, less social and family support all have a negative effect on the psychological health of grandmothers looking after their grandchildren (Kelley, Whitley & Campos, 2010). Grandparents who are raising children with developmental disabilities face unique challenges (Lecavalier, Leone & Wiltz, 2006). The grandparents in this study reported feeling overwhelmed at their grandchild's diagnosis as they had raised other children who did not present with any developmental conditions. Research confirms this by suggesting that the stressors of taking on a parenting role later in life is compounded by raising a child with a disability (Conway, Jones & Speakes-Lewis, 2011).

*CG6: Kwabanzima angifuni ukuqamba amanga. Ngangiqala ukuzwa ngayo [ASD]. Nginabantwana abawu-5 kodwa akukaze kube khona ngisho noyedwa emundenini onalokhu [ASD]. Angikaze ngiyibone ndawo [ASD]. (It was very difficult, I won't lie to you. This is the first time I learnt about this [ASD], I've got 5 children and not even one in my family has this [ASD], I never saw it [ASD] anywhere.)*

Grandparents of children with disabilities have greater needs (Janicki, McCallion, Grant-Griffin & Kolomer, 2000). CG11 reported that she did not understand the diagnosis of ASD despite it being explained in her first language as she attended the healthcare meeting with the child's mother who received the information. The lack of understanding may be as a result of how information was presented to her during healthcare meetings. This may be due to the terminology or 'medical jargon' used by health care professionals. Gallagher, Kresak, and Rhodes (2010) looked at the needs of grandmothers who were the primary caregivers of children with disabilities and found that grandmothers had unique needs including information, strategies to deal

with matters regarding the disability and respite. In contrast, one caregiver (CG4) reported that she did not feel any stress in raising her grandson with ASD, which confirms research that suggests caregivers who viewed raising a child with ASD positively had less stress compared to those who view it negatively (Glazzard & Overall, 2012). This contradicts research that suggests that grandparents of children with disabilities experience more personal stress than grandparents raising children without disabilities (Kresak, Gallagher & Kelley, 2014).

*CG4: [Raising him is] wonderful, I would never say even with my own children I had sleepless nights, with this child I never had a sleepless night.*

*CG9: Eyi ngifuna ukukutshela into ebuhlungu (wathula waseyakhala) ngangingaphuzi, ngisebenza kodwa ngagcina ngiyeka ukusebenza ngenxa yokutholakala kwe-ASD. Ngagcina sengiyisigqila sotshwala (isidakwa), kodwa sengizizwa ngingcono manje. (I want to tell you something that hurt me, I wasn't drinking, I was working but then I stopped working [due to diagnosis] and I ended up an alcoholic, but now I feel better.)*

## **4.2. The Journey to Diagnosis**

The diagnosis of ASD is often a complicated and lengthy process (Nadel & Poss, 2007) and the journey to gaining a diagnosis for a child can often times be lonely, frustrating and confusing for caregivers (Fewster & Gurayah, 2015). Participants had varying experiences in obtaining a diagnosis for their child including age of diagnosis and the professionals involved.

### **4.2.1. 'I don't really know' -Age of diagnosis.**

Children in this study generally received their diagnosis between the ages of two and four. Literature suggests that an ASD diagnosis is usually made after the age of three, therefore, some children in this study were diagnosed early in comparison. This contradicts research in which South African caregivers reported delays in getting a diagnosis of ASD for their child (Mitchell & Holdt, 2014). The age of diagnosis is dependent on the age that a child presents with clinically significant characteristics to warrant a diagnosis (Volkmar, Paul & Cohen, 2005). The relative early diagnosis in the current study may be as a result of caregivers noting the severity of the child's communication difficulties, as seeking help for this was the catalyst that led to the diagnosis. Due to this early age of diagnosis, it appeared that caregivers expected their children to 'outgrow' their difficulties in the future and did not view ASD as a life-long disorder. The type of services accessed by caregivers is another consideration for early diagnosis. CWA1 was diagnosed at a private hospital by a paediatric neurologist at 18 months old, the earliest of all participants. The correlation between an early diagnosis and private healthcare was also found in a South African study by Reddy, Fewster and Guraya (2019).

Three caregivers in the current study were unsure of the exact age that their child was diagnosed. CG5 reported that perhaps her child was diagnosed at three years old. CG5 was working in Johannesburg at the time and her sister would take the child to appointments, however her sister had to stop due to finding a job. CG5 reported learning of the diagnosis when the child was 6 from the doctor. This links to the fluidity of the microsystem as it may be difficult for health information to be shared between caregivers.

CG5: Kwaze kwafika esigabeni sokuthi emtholampilo babuze ukuthi uyekeleni ukuza azolashwa. *Usisi wami wayeka ukumuhambisa ngoba esethole umsebenzi. Angazi ngempela ukuthi bekwenzakalani phakathi kwabo kanye nodokotela, mina ngazi manje ngoba kuyimina osemuhambisa ukuyolashwa. (It got to the point where the clinic would enquire about her not attending therapy, my sister stopped taking her because she got a job. I really don't know what was happening between them and the doctor, I only know now because I attend therapy with her.)*

#### 4.2.2. 'I read it on the card' -Professionals involved in diagnosis.

Many participants visited various health care professionals at their local primary health care facility and/or district hospital before attaining a diagnosis, as was found in a study done in KZN by Madlala (2012). In the South African context, nurses are usually the first healthcare professionals to whom caregivers of children with ASD express their concerns (Matenge, 2014). This was confirmed by the current study in which two participants noted delayed speech and brought this to the attention of nurses at immunisation appointments, who referred them to a speech-language therapist. In both cases, the speech-language therapist referred them to a psychologist who diagnosed them. In South Africa, there are limited services and access to information therefore, caregivers often rely on healthcare professionals to provide them with appropriate referrals (Matenge, 2014). There is a need for nurses to be educated regarding the characteristics of ASD so that the appropriate referrals can be made and early intervention can begin (Matenge, 2014). CG1 and CG9 were asked by their doctors to see an audiologist who after ruling out hearing difficulties, referred to a speech-language therapist. Three caregivers reported that the speech-language therapist was the first person from whom they had heard the word 'autism'.

CG6 reported that her husband had read about the symptoms of ASD in a newspaper and thereafter took her grandson to the doctor who confirmed the diagnosis. Newspapers are perceived as reliable and credible sources of information (Dutta-Bergman, 2004). Mass media outlets have been shown to increase the use of health-related services for various population and contexts of diseases (Young, Willis, Stemmler, & Rodgers, 2015). Even though health information is readily available online, traditional media such as newspapers are still important for disseminating

health information particularly in rural communities (Young, Willis, Stemmler, & Rodgers, 2015).

CG6: *UMkhulu uwumuntu ojwayele ukufunda amaphepha. Ephepheni iSolezwe wafunda ngezimpawu ezicishe zifane nalezi ezikhona Ku CWA6 wabe esesazisa. (Grandpa is a person who often reads newspapers, in the Isolezwe newspaper he read up on similar symptoms to those of CWA6's and informed us.)*

Two caregivers reported the child with ASD not receiving a diagnosis. CG4 reported that initially her grandson didn't receive a formal diagnosis of ASD from a doctor as a blood test done to test for ASD [sic] was negative. He was later diagnosed by a psychologist. Poor counselling and education by health care professionals regarding ASD in South Africa has been reported (Reddy et al., 2019).

*He was never diagnosed as autistic we just were like 'why is not talking at the age of two?' we took him to the paediatrician. The blood tests, the main one that was for autism, it came back negative.*

CG9 reported that she never officially received a diagnosis of ASD and that the study interview was the first time she heard the term, whilst CG11 did receive a diagnosis of ASD but she did not understand when the doctor explained it during a consultation as most of the terms used were in English. In South Africa, consultations are often done in the patient's second or third languages (Levin, 2014). The language barrier between caregivers and health care professionals is linked to the hybrid theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). Colonisation and later apartheid (the macrosystem and chronosystem) influenced the way in which universities provided education. Research was often done in English and Afrikaans, with African languages being completely disregarded therefore many professions (including health care) have limited information and resources in African languages, creating a continuous cycle of inequality (Pillay & Kathard, 2015). In the current study, although the doctor provided information in CG11's first language (isiZulu), the terms used were in English. This could be due to the lack of resources in isiZulu for counselling regarding a diagnosis such as ASD. The inability to properly communicate

with health care providers due to a language barrier adds to the patient's emotional distress, uncertainty and poor satisfaction with the service that they are receiving, which could delay them in obtaining necessary care and information on time (Hussey, 2012).

CG10 reported that the doctor never discussed her son's diagnosis with her and that she found out about it when she read his hospital card with the diagnosis written on it, thereafter she did some research to understand more about ASD. This correlates with research done by Reddy et al., (2019) which reported that in South Africa support and guidance provided by health care professionals post-diagnosis for children with ASD was limited. Receiving a diagnosis of ASD is a significant event in a caregiver's life, the way in which health care professionals communicate this information affects caregiver satisfaction, which affects how they function and therefore the care that they provide to their children (Reed & Osborne, 2012). Caregivers may form expectations based on how they received their child's diagnosis. For example, if a health care professional wrote the diagnosis down and did not explain it to caregivers thoroughly, caregivers may assume that the diagnosis is not serious enough to warrant an explanation and therefore expect their child to outgrow the disorder.

*CG10: Honestly the doctor, didn't really communicate anything with me, he write it down. I read it on the card. I read the diagnosis down on the card. He just told me that his milestones are delayed and when I read the card thoroughly, I see that there is ASD.*

### 4.3. Feelings regarding the Diagnosis

#### 4.3.1. 'I wished she could die' - Initial reaction to diagnosis.

Caregivers often feel a strong sense of emotion when hearing that their child has ASD. Many of these feelings have to do with losing the image of the 'perfect' child (Gentles, Nicholas, Jack, McKibbin & Szatmari, 2020). Caregivers in the current study initially felt upset, overwhelmed and stressed about the diagnosis. They had feelings of 'why me' and 'why my child'. This is consistent with research which suggests that an ASD diagnosis elicits many negative feelings in caregivers (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012). CG2 reported that upon learning of the diagnosis, she felt such a great loss that she would have preferred her daughter to have died. It is imperative for health care professionals to understand the stress that caregivers of children with ASD face as it directly impacts their expectations. If caregivers feel that death would be a better alternative to an ASD diagnosis they may not expect much from their children and this would impact their help-seeking behaviours which in turn affects the development of their children (Nik Adib et al., 2019).

*CG1: I was broken, I couldn't understand. I didn't understand why her, I couldn't understand why my child*

*CG2: I was so stressed, I am telling you I was so stressed in such a way that I wished she could die at least, she could die and I must just be by myself yeah. Ay I hated her.*

*CG11: Kwaba buhlungu kakhulu ngoba phela uma ubuza ukuthi lento izolapheka yini, bathi cha. (It was very painful because you ask if it's curable and they say no.)*

Two caregivers expressed feelings of denial upon hearing their child's diagnosis. Denial is a common reaction that caregivers of children with ASD experience immediately after diagnosis (Gentles et al., 2020). CG8 noted that the speech-language therapist had mentioned a possible ASD diagnosis when her son was three years old, but she was in denial and did not follow-up on the referral to the psychologist. CG8 attributed her denial to not understanding how her daughter could have a 'serious' diagnosis due to a lack of physical characteristics. This links to a general stereotype that disability is physical (Gorlin, 2019). CG8 then only obtained

an official diagnosis when he was seven years old and needed to attend school. This is consistent with research which suggests that caregivers often seek a diagnosis for their child when they are in need of a service such as schooling (Gentles et al., 2020). CG8 and CWA8 form part of each other's microsystem and have a bi-directional relationship. CWA8's diagnosis elicited negative emotions for CG8 which led her to stop accessing services for CWA8. This in turn affected CWA8 as he could have received a diagnosis and treatment earlier which may have benefited him as there is research to suggest that non-verbal children who start intervention during pre-school years are more likely to become verbal than those who are diagnosed after five (Koegel, 2000). A later diagnosis also has implications for education as school placement for children is difficult in South Africa (Donahue & Bornman, 2014).

*CG8: That word, was the first time me hearing the word autism. So I didn't even know what is that and I became too cross that you know this lady is saying that the child has a sickness when I can see that the child is completely fine, he just cannot talk. So for me it was like this lady you know... it took me time to even admit you know... to understand and admit you know yeah he is.*

Caregivers of children with ASD often feel a sense of guilt after receiving a diagnosis (Altiere & von Kluge, 2009; Desai, Divan, Wertz & Patel, 2012). CG5 felt that she was somehow to blame for her son's diagnosis until the psychologist explained that she was not at fault. A study by Da Paz, Siegal, Coccia, and Epel (2018) found that self-blame is moderately associated with caregiver burden.

*CG5: I felt so bad because I didn't understand why. The psychologist explained that it is not my fault. It is normal disease/condition.*

Caregivers are not always happy with the information that they receive about their child with ASD, which motivates them to gain more information about the diagnosis (Ludlow, Montgomery & Rohleder 2011; Lutz, Patterson & Klein 2012). Three caregivers in the current study did their own research upon receiving the diagnosis, with two caregivers attending support groups on at least one occasion for more information. The information that caregivers receive impacts their expectations of their



children. CG1 and CG10 did their own research online and therefore formed expectations based on this information.

Not all reactions to the diagnosis of ASD in this study were negative. CG4 reported a feeling of acceptance when she obtained a diagnosis for her grandson.

*CG4: I accepted it. I have an older sister (who says) 'oh nothing is wrong with the child'. I said look, I will do whatever the doctor says for him because I want him to have a future. After I am gone people will say look his granny did her best. No, I have accepted it.*

CG4's acceptance of the diagnosis may be due to her already knowing that her grandson had difficulties. Research suggests that caregivers who suspect a developmental delay have more positive reactions to an ASD diagnosis than caregivers who do not suspect that their child has difficulties (Nissenbaum, Tollefson & Reese, 2002). This is linked to their expectations, caregivers who suspect difficulties expect there to be an underlying reason and are therefore more accepting upon receiving a diagnosis for their child. None of the caregivers in the current study expressed relief at finally gaining a diagnosis as was found in other studies (van Tongerloo, van Wijngaarden-Cremers, Jan van der Gaag, & Lagro-Janssen, 2014). This could be due to them not expecting the diagnosis. Nissenbaum et al., (2002) reported that caregivers who were not expecting the diagnosis had negative reactions.

*CG4: When the psychologist told me that, at the back of my mind, I knew that he had a problem. I already knew and my expectations is that he won't be like a normal child.*

#### **4.3.2. 'I have accepted it' -After the shock: Feelings about diagnosis later.**

Despite initial negative reactions, many caregivers in this study reported that their feelings regarding the diagnosis have now improved. Three caregivers reported that speaking to other caregivers of children with ASD helped them to handle and understand their child's diagnosis better. CG1 and CG8 attended parent support groups. CG1 attended a support group meeting offered by a local organisation and

CG8 attended one support group offered by a special needs school in her area. As her son is still on the waitlist for that particular school, she was only able to attend one meeting. CG2 has a colleague with a child with ASD who has helped her to understand the diagnosis better. Gerber, (2014) reported that parent support groups provide information and emotional support for caregivers of children with ASD. It may be particularly helpful for those caregivers who are facing difficulties that could have a negative effect on their well-being. Caregiver support groups could be a cost-effective solution to assist caregivers in the current study who are facing difficulties in understanding and managing their expectations regarding raising their child with ASD and therefore may be a viable option for caregivers in rural areas. Caregiver support groups form part of resources that caregivers' access and therefore are part of the exosystem (Bronfenbrenner, 1979, Bronfenbrenner & Morris, 2006). CG8 had limited access to this resource due to it being associated with a school, therefore it indicates a need for more easily accessible support groups for caregivers of children with ASD in rural KZN.

*CG2: But as time goes by and talking to other mothers with the autistic children I became okay but ay I used to hate her.*

*CG8: They did call me for the parents what you call it? Group and I met a lot of ladies with children with the same condition and we were talking, it was an open meeting and we talked and I did get a lot of help from there.*

Some caregivers of children with ASD show psychological resilience (diminished psychological distress) after their children are diagnosed with a chronic disorder, they get over the initial impact of the diagnosis and accept it (Lloyd & Hastings, 2009). Acceptance of the diagnosis is seen to protect the caregivers of children with ASD from distress (Tomiya, et al., 2018). After receiving a diagnosis for their child, caregivers begin to understand the diagnosis, their children's behaviours and accept the diagnosis (Madlala, 2012). Three caregivers (CG3, CG6 & CG8) reported that although they have accepted the diagnosis, they still feel sadness when they see younger children surpass their children particularly with their speech milestones. This is consistent with research by Bravo-Benítez, Nieves Pérez-Marf, Román-Alegre, and Cruz-Quintana, (2019) which stated that the feelings of grief regarding raising a child

with ASD are cyclic with periods of happiness and acceptance and feelings of anguish and sadness thereafter.

CG6: Kubabuhlungu ngempela, kakhulukazi uma usubona izingane ezineminyaka ewu-2 sezikhuluma kodwa yena lutho. *(It hurts a lot, especially when you see 2-year olds talking but nothing comes from his mouth.)*

CG 8: CWA8 is a bit behind. It is hard, I love him too much but it's hard.

CG11: Lokhu kuyaqala ukwenzeka, manje kuyathusa kodwa sengamukelile. *(This is the first time this has happened so it's shocking, but I have accepted it.)*

Some caregivers still struggle with the diagnosis and feel emotional about it. CG9 feels upset that her grandson has difficulties as she is already over-burdened with childcare and finances and did not expect this to be compounded by raising a child with a disability. This indicates how factors in the child's mesosystem (their caregivers having to raise their siblings) and exosystem (caregivers' finances) complicates caregiver stress regarding their child's diagnosis (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). CG3 reported that she faces more difficulty accepting the diagnosis now in comparison to when she initially received it. These feelings changed due to her expectations relating to therapy being unmet after some time. Her feelings changing over time links to the chronosystem (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). This links to literature which states that caregivers of children with disabilities often create unconscious expectations of various service-providers, with these expectations changing based on what is accomplished (Russell, 2003).

CG3: Ekuqaleni ngangilindele ukuthi uzoshintsha. Ngangicabanga ukuthi bangakwazi ukuthi bamusize, afane njengezinye izingane eziphila kahle, ezinganankinga. *(In the beginning I expected that he would change. I thought that they [therapists] would be able to help him, so he could be like other normal children.)*

#### 4.4. 'something to do with the brain'- Caregivers' Understanding of ASD

Caregivers in the current study had varying levels of understanding regarding ASD. Most caregivers understood ASD based on information presented to them by their health care professionals. As mentioned above (p. 66), some caregivers formed an

understanding and opinion on ASD from their own research. Two caregivers mentioned it being a spectrum disorder. CG1 felt more at ease knowing that it was a spectrum as she felt that her daughter was high-functioning and has Asperger's syndrome based on her research. Lindsey and Barry (2018) found that more integrated knowledge regarding a disorder helped caregivers to accept the diagnosis. CG1 believing that her child is high-functioning impacts her expectations of her, she assumes that her daughter's symptoms are 'mild' and therefore expects her daughter to have limited challenges in the future.

Many caregivers described abnormalities in the brain when discussing their understanding of ASD. This may have been how ASD was explained by health care professionals during counselling.

*CG2: But I see it has something to do with the brain, that's what the psychologist told me, something is in the brain, when the brain is developing something went wrong.*

*CG3: Unegqondo okusengathi incane futhi akakwazi ukukhuluma. (His brain seems smaller and he can't talk).*

*CG5: According to the psychologist, she told me it's the condition of the mind. I think it something with the brain, just brain damage.*

The current study reflected that caregivers who were not proficient in English reported having a poorer understanding of ASD and its implications in comparison to participants who were proficient in English. This could be as a result of limited health information regarding ASD in isiZulu. It is known that there is no isiZulu term for ASD. Even in situations in which the health care professionals are proficient in the same language as the caregivers there is still miscommunication due to the difference in knowledge and educational level with regards to medical conditions (Jacobs, Shepard, Suaya, & Stone, 2004). In the current study, CG11 expressed that she is aware that her grandson has 'autism', but does not know what this term means as it is English.

In reference to the hybrid theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) that frames the study, caregivers and their children form part of each other's microsystems. Caregivers' understanding of the diagnosis impacts their expectations

of their child with ASD which affects how they access treatment for the child with ASD. For example, CG1 understands her daughter to be high-functioning based on her own research and as a result has higher expectations of her and places emphasis on therapy as she believes it will enable her daughter to live a more 'normal' life. The relationship between the caregiver and the healthcare professional (the mesosystem) is important in this context as caregivers rely heavily on health care professionals to help them understand their child's diagnosis. In this study caregivers linked their expectations of their child to outcomes described by health care professionals for example, CG6 reported that the health care professional explained that her grandson would lead a 'different' life. It was noted that whilst she hoped he would achieve certain things she did not necessarily expect it. The resources available in a community form part of the exosystem (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). The limited isiZulu resources available to health care professionals have an indirect effect on the child with ASD. The lack of appropriate information affects what the caregivers understand, their expectations and the types of services that they access or that they are aware of.

## 4.5. Experiences Raising a Child with ASD

### 4.5.1. 'I am his mind'- Daily experiences.

Most caregivers expressed that raising a child with ASD is challenging and stressful. Caregivers reported that their children's behaviours were difficult to understand and manage. This is consistent with the findings of a study by Ludlow et al., (2011) who reported that the challenging behaviours associated with ASD exacerbate caregiver burden. Two caregivers reported that raising their child with ASD is difficult as they are not toilet-trained, making finding schools and leaving them in the care of others difficult. CG6 and CG7 reported that CWA6 cannot be left in the care of others as he self-harms. They were counselled on how to manage their daily life difficulties by their health care professionals. Expectations were brought up by CG4 who explained that her grandson did not exhibit challenging behaviours when he was younger therefore his challenging behaviours are an unexpected experience.

*CG2: It was so stressful, even now yeah...because she doesn't go to school and the more stressing part is that she is still wearing nappies.*

*CG4: I wasn't expecting it [the challenging behaviours] because he was fine when he was younger.*

*CG5: It is a bit difficult, sometimes I don't understand her behaviour. Screaming and laughing for no reason.*

*CG6: Uma esecasukile uvele azishaye phansi ngekhandanda noma azishaye ngenqindi ekhandanda. Kodwa ke bake basitshela ukuthi uma enza njalo kumele senzenjani. Satshelwa ukuthi simubambe simuhage simutshela ukuthi siyamuthanda. Uma eseqalile uyeza kimina bese ngiyamubamba ngimtshela ukuthi ngiyakuthanda mntanomntanami bese eyathula. (When he is angry, he hits his head against the floor or hits his fists against his head. But they did tell us what to do in these situations. We were told to hold him, hug him and tell him we love him. Once he starts hurting himself, he comes to me, I hug him and tell him that I love you my grandchild, then he stops.)*

Non-verbal individuals with ASD are classified as 'severe' according to the APA (2013) and require immense support with activities of daily living. CG10 was the only participant who described communication as being the main difficulty with raising her son. She stated that he is non-verbal and this makes it difficult for her. This is surprising as communication was often what lead caregivers to seek help, yet communication was not reported as a primary challenge, rather behaviour and toileting appeared to take priority. This could be due to the emphasis placed on education by caregivers and these behaviours (especially toileting) impacts schooling options. This links to the chronosystem of the hybrid theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). What caregivers see as important at a specific time has an effect on their expectations. Schooling was important to most caregivers in the current study and many believed that education would lead to their children becoming better communicators and better at socialisation. As a result, many caregivers perhaps did not prioritise communication at that moment and therefore did not report it as a concern or expectation.

*CG10: I'd say that he is quite difficult to raise, because basically I am his mind, I have to think everything for him, I have to think no, he is hungry now, he should go to the toilet now.*

Three of the caregivers who were grandparents found raising a child with ASD to be challenging as they were different from other children that they raised. This was compounded by the worry of what would happen to the child when they pass away. CG6 and her husband raise their grandson with the help of their family. Bayat (2007), found that the diagnosis of ASD promoted family unity.

*CG6: Akukho okungakanani ngoba sibambisene. Sathi masithola ukuthi unje, sabambisana ukuze kuzoba lula. Angeke ngisho ukuthi bukhona ubunzima engibutholayo ngoba siyasizana njengomndeni. Uma ngingekho mina, khona umkhulu ozohlala naye amugade amushintshe namanabukeni. Yimina nomkhulu esikwazi ukumunakekela kahle ngoba siyazi ukuthi mele simuphathe kanjani. (There's nothing much to say because we're all supportive. When we found out that he is like this, we all decided to be supportive so that it could be easier. I can't speak on any difficulties because as a family, we all help each other out. If I'm not around, grandpa is around to take care of him and change nappies. Grandpa and I take care of him the most because we know how to handle him.)*

One grandparent in the current study reported that it was easy raising her grandchild despite him having ASD. As previously mentioned (initial feeling re, CG4 had already suspected that her grandson had some difficulties and therefore is more receptive to the diagnosis.

*CG4: [Raising CWA4 is] Wonderful, I would never say even with my own children I had sleepless nights, with this child I never had a sleepless night.*

#### **4.5.2. 'Her brother understands her'- Experiences of raising siblings of children with ASD.**

In the current study despite 10 of 11 caregivers looking after more than one child, none had experience in raising a child with ASD. CG1 reported that her son is protective of CWA1 and often understands her when others cannot. Some studies suggest that siblings of children with ASD are better adjusted than other children (Fisman, et al., 1996). Siblings form part of the child with autism's microsystem, and they share a bi-directional relationship, therefore siblings' behaviours impact each other (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006).

*CG1: Her brother understands her a lot better, so if she's getting frustrated and she's feeling that you are not getting her she will run and find her brother. He is very understanding, very supportive I think that when the cousins do not understand when they are going on holidays and all of that, they will say 'aah (CWA1) is this many years and she can't speak' and he will say 'so what?' He is the one who protects her. I think that it is things like that that help us become better because we know.*

The view of two caregivers was worry for their other children. CG8's younger daughter is cared for by her mother as CG8 has to take CWA8 to his appointments and CG11 worries that CWA11 will become a burden to his siblings when she passes away. As siblings grow older, they may need to become the primary caregivers of their siblings with ASD (Coyle, Kramer & Mutchler, 2014). Caregivers may expect their typically developing children to care for their sibling with ASD as there may be no alternatives.



Siblings may feel the burden of these expectations throughout their lives as taking responsibility for their sibling affects many decisions of their lives including where they live, who they marry and their careers (Seltzer, Orsmond & Esbenson, 2009). This is an illustration of the bi-directional relationship of the microsystem and how a sibling's diagnosis (personal factor) can directly impact a child without ASD in the family in the long term (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006).

*CG8: When I got the younger child I realised this child (CWA8) needs therapy so then I had to take him, because my mother is old. He's got dates [appointments] so it is better for my mum to stay with the one who doesn't have dates. So the younger one is with my mum.*

*CG11: Ayi, uma eyokwazi nje ukufunda asebenze, angabi umthwalo kwezinye izingane. (If CWA11 will be able to learn [attend school] and get a job then he will not be a burden to the other children.)*

CG8 was the only participant who mentioned a positive family history of ASD. Her nephew has ASD and she suspects that her late older brother may have had ASD, therefore she was worried about her youngest child having ASD. Younger siblings of children with ASD are at a higher risk of developmental problems as compared to the general population (Green, 2013). She reported during her interview that her daughter has been reaching her developmental milestones, including speech, therefore she feels at ease.

#### **4.5.3. 'It's easy'-Time management and raising a child with ASD.**

Due to the demanding nature of raising a child with ASD aspects of caregivers' personal lives such as careers, health and leisure time are affected (Ooi, Jong, Jacob & Khan, 2016). In the current study three caregivers (CG1, CG2 and GG4) were employed full-time, whilst two (CG3 and CG9) worked part-time. The other six participants were unemployed with one (CG10) being a full-time university student. Time management was not a challenge for most caregivers in the current study. This could be because they live with extended family and therefore have help with childcare, whilst others were unemployed and were therefore able to be full-time carers to their children. Two caregivers (CG3 and CG10) found managing their time

to be a challenge due to their children's' behaviour such as breaking objects and hyperactivity.

*CG1: I think for me it's never been really hard because like I said, I don't see it as a disability.*

*CG2: For me it is easy because I don't live with her everyday.*

*CG3: Ngoba nginaye ekhaya usuku lonke kumele ngiqiniseke ukuthi ngiyamugada. Engathatha ngisho nalengilazi ayiphihlize phansi noma agibele phezu kwamakhabethe akhiphe izinto. Ngike ngimunikeze umakhalekhukhwini ukuze akwazi ukuthi ahlale phansi nami ngikwazi ukwenza ezinye izinto. (Since I'm at home with him the whole day I have to make sure that I watch over him. He can even take this glass and smash it in on the floor or he could climb on cupboards and take stuff out. I often give him my cellphone so that he can sit down and then I'm able to do other things.)*

*CG4: It's not tiring, I can't complain. Some days if I had a hectic day at work I will say, I am tired today. Once I put off the TV he knows it's dark, he goes to sleep.*

*CG10: It's quite difficult and overwhelming, yeah. Running around all day, basically [laughs].*

#### **4.5.4. 'He doesn't eat anything'- Financial experiences of raising a child with ASD.**

There is a bidirectional link between disability and poverty (Pinilla-Roncancio, 2015). Autism is regarded as the most expensive disability (Byford, et al., 2016). An American study by Dillenburger, McKerr and Jordan, (2014) found that raising a child with ASD was three times more expensive than raising a typically developing child. In the current study three caregivers receive disability grants for their children with ASD. Three of the participants were employed full-time and two worked part-time. The unemployment rate in KwaZulu-Natal is 26.1% (STATS SA, 2019). The high unemployment rate is indicated in the current study with 5 out of the 11 participants being unemployed and only one (CG11) being eligible for an old age pension. The employment status of the

caregiver forms part of the child with ASD's exosystem and has an indirect impact on them.

The caregivers in this study were already financially burdened, which is exacerbated by having to access various services for their child with ASD. Healthcare is not the only expense that caregivers of children with ASD face. CG10 found buying sensory toys expensive and CG6 and CG7 reported that CWA6's picky eating places them under financial strain as he often wastes food or prefers only specific textures and tastes and it is often trial and error with what he will eat. Children with ASD often take a longer time to become toilet-trained (Richardson, 2016). In the current study, caregivers needing to purchase diapers for a longer period than average created an extra financial burden. This relates to the hybrid theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) in which the over-arching component is time, children with developmental delays take longer to achieve certain milestones, therefore the cost of certain necessities is prolonged and may even increase over time

*CG6: UDokotela wasenzela incwadi yempesheni kwase kwaba ngcono. (The doctor applied for a grant for us so we are feeling better.)*

*CG7: Kubanzima ngoba akadli noma yini, angathanda ama-cornflakes izinsuku ezu-4 bese ngakusasa akasawafuni. Uthanda ama-burger izinsuku ezu-3 bese kuba ama-noodles izinsuku ezu-2. Akafuni ukudla amasi nepapa. Indlela adla ngayo ayiqondakali nje, manje kwezinye izikhathi kuba nzima ngasemalini ngoba kumele uthenge ukudla okuhlukahlukene. (It's difficult because he doesn't eat everything, he likes cornflakes for 4 days and tomorrow he doesn't like them. He likes burgers for 3 days and then noodles for 2 days. He wouldn't eat maas [sour milk] and pap [traditional porridge]. His diet isn't stable, so sometimes it gets difficult financially because we have to buy different foods.)*

CG8 described extreme financial challenges as she is currently unemployed, her husband is a taxi driver, and their financial challenges makes it difficult her to afford schooling for her children. CG1 was the only participant who accessed private healthcare for a period of time. She reported that when she was seeking private healthcare, it was extremely expensive and a single consultation from a specialist could cost R600 with a speech-language assessment costing R2500.

*CG1: It's a nightmare because with every consult you have to pay for, with just paed consults you are looking six to seven hundred rand, and you are also looking at specialising I think that when we consulted with him it was 950 just for a single consult. Then we started with speech therapy, the first two weeks were a consultation and third week an assessment and then following week a consult again. Now we are looking at 750 per consultation, and then 2500-3000 for an assessment because a consultation is 30 minutes and an assessment is 45 minutes and there is not much therapy on that day.*

CG3 works part-time as a waitress whilst her husband works in retail. It is difficult for them to budget as her money that was meant to be used for clothing and food is now used to take CWA3 to and from therapies. CG3 described her previous financial expectations and that she did not expect her son to cause them financial difficulties. CG9 reported that she is struggling financially as she works part-time as a domestic worker earning R1500 a month. She often cannot afford to take CWA9 to therapy and the constant referrals to different HCPs makes it difficult for her to cope financially, forcing her to request appointment dates further apart. CG2 was the only participant to mention future finances, she reported that she expects her financial situation to become more difficult in the future when her daughter begins attending school. Socio-economic status forms part of the child's macrosystem (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). The financial resources that are available to caregivers have a direct impact on the child with ASD and the services that they receive- this includes schooling, food and therapy. The strain on finances impacts other members of the child with ASD's microsystem as the financial strain on the family affects all its members.

Poverty in rural areas is another sad consequence of apartheid. The previous government's policies deliberately financially crippled a large portion of the population, which has effects now (Mariotti & Fourie, 2014). The further distances required to travel to and from appointments in rural areas further burdens caregivers financially. With regard to the hybrid theory in the current study, personal finance forms part of an individual's exosystem whilst government policies form part of their macrosystem

(Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). The financial difficulties faced by the families in the current study impact the children with ASD directly. For example, CG8 cannot afford to send CWA8 to school and CG9 has difficulties with obtaining timely intervention for her grandson as she cannot afford transportation.

*CG2: You see right now, I am okay because she is not in school. When she starts then I heard it is expensive.*

*CG3: Ngalemali ayitholayo, bengihlezi ngiya kodokotela. Angikwazi ukumusiza ngazo zonke izidingo zakhe. Bengingakulindele neze lokhu. (With the money he [CWA3] receives, I'd always go to the doctors, I can't assist him with all of his needs. I never expected this.)*

*CG8: It's hard because schools are expensive. Because people tell me about schools but I cannot afford those schools. I know that there are people who are thinking that I am keeping my child at home but I can't do anything, it's just my poor kids.*

*CG9: Ngihlezi nginganayo imali. Odokotela bahlezi bethi angehle ngenyuke. Ungathuka ukuthi mangingakutshela imali engiyiholayo u-R1500. Bajwayele ukungitshela ukuthi angaye kwenye indawo, ngithi mangifika kuleyo ndawo bathi angaye kwenye (gets emotional). Ngikengisho ukuthi ngicela banginikeze izinsuku ezigqagqene khona ngizokwazi ukuza kudokotela. Nomnyeni wami akasebenzi into esile, nengane iyayithumela imali kodwa ngisho kunjalo ngihlezi nginezikweletu. (I never have money. They [doctors/therapists] always make me travel up and down. You'd be surprised when I tell you that I only earn R1500. They often tell me to go to one place and when I get there, they tell me to go elsewhere (gets emotional) I often ask them to give me dates [appointments] that are far apart so that I can go to the doctors. My husband doesn't have a decent job and my child sends money, but I always have debt.)*

#### 4.6. 'She will act as if she is deaf'-Communication

Communication impairment is one of the two core characteristics of ASD according to the DSM-5 (APA, 2013). Language and communication difficulties are usually the first concern that caregivers have (Herlihy, Knoch, Vibert, & Fein, 2013). This was confirmed in the current study in which most caregivers accessed services when they became concerned about their child's ability to communicate.

In the current study, communication was viewed as the act of speech. Caregivers referred to all difficulties with communication as 'speech'.

*CG1: Every other milestone was hit before or on time but when it came to speech it was just not developing so we took her to the doctor and he assessed.*

*CG2: We noticed when she was two years, we noticed that when you speak to her. She [CWA2] will act as if she is deaf... she can't respond to you. Then we noticed that she can't even utter one word like 'mama'.*

*CG8: I thought that he was normal because he did everything in the right time, crawling, walking like my other children. I only started noticing [communication difficulties] when he was 3 years old because I noticed the neighbour's child she was like completely talking so on the day of the immunisation, I told the sisters that he is 3 years old and he doesn't say anything not even the word 'mummy'.*

##### 4.6.1. 'He understands a lot'-Current communication profile.

The communication profile of children with ASD forms part of their personal factors with regard to the hybrid theory that frames the study (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006).

##### 4.6.1.1. Receptive Language

Children with ASD present with delays in receptive language and expressive language (Paul & Norbury, 2012). Five caregivers (CG1, CG3, CG4, CG5 and CG10) reported that their children had good receptive language and "understand everything". This contradicts research which states that comprehension of language is always impaired

in children with severe ASD (Boucher, Mayes, & Bingham, 2008). A reason for this could be because the language that the children with ASD understand is often contextual language-meaning that it is embedded in their home and family context (i.e. specific to their microsystems). CG6 reported that her grandson understands common one-word commands. Four caregivers described their children with ASD's receptive language as being inconsistent, with three of these caregivers (CG8, CG9 and CG10) reporting that their children respond to instruction only when they want to. Whilst these caregivers felt that their children had a reduced desire to respond to auditory input on certain occasions, literature suggests that children with ASD ignoring voices around them and/or responding to auditory stimuli unreliably reflects difficulties with social engagement (Klin, 1991) and sustaining attention (Mody & Belliveau, 2013). The link between hearing and speech was raised by CG10 who felt that her child chooses not to respond as the only reason he wouldn't is if he couldn't hear. This links to the mesosystem and the communication between the health care professional and caregiver. The type of information that caregivers receive from health care professionals regarding having a non-verbal child with ASD impacts caregivers' understanding and therefore expectations.

*CG2: She is better now, she is growing up because we can talk to her, CWA8 go and take this and she will sometimes and she can't understand what you are saying but sometimes she will understand.*

*CG4: He understands a lot, he can make you a fool, he can make you a big fool if he wants to...He will come if he wants to, or he will walk away, he understands everything.*

*CG6: Mawumubiza ngegamelakhe uyaphendula. Uyalazi igama lakhe. Uma umuthuma njengokuthi uthi "thatha la" angeke akwenze. Angeke ayeke intambo yakhe anake wena, kodwa mawuthi "asihambe" uyakuzwisisa. (If you call him by his name, he responds. He knows his name. He can't follow instructions, if you say "take this" he won't be able to do it. He won't let go of his string to focus on you. But when you say, "let's go", he understands.)*

*CG10: I think he prefers not to follow instructions because he can hear clearly.*

#### 4.6.1.2. *Expressive Language*

Three caregivers (CG1, CG4 and CG10) reported that their children use verbal language.

CG1 reported that her daughter is able to communicate her needs and wants by pointing and attempts at verbal language. CG3, CG8 and CG9 also reported that their children point to communicate although this is inconsistent. Children with ASD use less pointing than typically developing children (Shumway & Wetherby, 2009).

Seven caregivers (CG2, CG4, CG5, CG6, CG8, CG9 and CG11) reported that their children will often fetch the items that they require themselves or grab their communication partner's hand and pull them towards the required object. This is characteristic of non-verbal ASD as children compensate for reduced use of conventional gestures such as eye-gaze and pointing by manipulation of the body or hands (Shumway & Wetherby, 2009).

One caregiver (CG10) reported that her grandson knows one word 'pee' (ichanga) in isiZulu and uses this word to communicate when he needs the toilet. Caregivers reported that their children are familiar with their routines and can be quite independent within these routines. One caregiver reported that her grandson is having difficulties as his routine is being disrupted by load-shedding<sup>2</sup> and he gets frustrated. Communication impairments can result in challenging behaviours, particularly in non-verbal children, as they have difficulties communicating and cannot query when things change, therefore becoming frustrated. With regard to the hybrid theory that frames the current study, one child with ASD'S (CWA6) personal factor (his diagnosis and related communication impairment) (Bronfenbrenner & Morris, 2006) prevents him from understanding the concept of load-shedding. Load-shedding is a government-level process that forms a part of CWA6's macrosystem and has a direct effect on him as it disrupts his routine and makes him frustrated, therefore in turn impacting his caregivers (microsystem).

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<sup>2</sup> Load-shedding is used when the demand for electricity is higher than the supply, therefore putting strain on the power-system, power is deliberately switched off to certain areas at allotted times to 'lessen the load' (Eskom, 2020)



*CG2: Every morning we are making hot chocolate and putting it there on the table and so every morning we are waking up and she goes to get the hot chocolate she knows.*

*CG6: Inkinga nje makuhambe ugesi kuyaliwa, akazwisisi ukuthi ugesi awukho okuyiwona okhanyisa izinto. (The only problem we encounter is when we have load shedding, he does not understand that electricity lights up things).*

#### **4.6.2. 'Not pushing too hard'-Expectations regarding communication.**

Caregivers in this study had varied expectations regarding their child's communication. Some expect their children to be competent verbal communicators whilst others expected varying levels of improvement from a small amount (CG1) to being a completely competent communicator (CG8). One caregiver (CG3) noted the difference between what she wanted for her son with regard to communication as compared to what she expects, Although she wants him to speak, she is unsure if this will happen. Three caregivers had more specific expectations: CG4 expects her grandson to be able to respond to her whilst CG5 would be happy if her child developed any form of communication, even if it is sign language. As mentioned above, CG10 provided a reason for her expecting her child to speak. She felt that if her child could hear, he should be able to speak. The varying responses from caregivers illustrate a need for a tool to identify caregiver expectations of areas such as communication which could assist health care professionals in providing counselling for caregivers of children with ASD who are non-verbal regarding managing their expectations in terms of communication.

One participant (CG1) expressed that she is aware of the impact that her expectations can have on her child, therefore she is careful to not place high expectations on her daughter with ASD. This is consistent with research which states that caregivers' expectations have an impact on their child (Ivey, 2004). In relation to the hybrid theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006), caregivers and their children with ASD form part of each other's microsystems, and enjoy a bi-directional relationship. The child with ASD's personal factors i.e. their communication difficulties influences what caregivers expect of them in the future which in turn, has an impact on them.

*CG1: I am not pushing too hard, all I am doing is that I am giving all of the support she needs and making sure that she gets it and trying by all means to make sure that she feels we are there for her.*

#### **4.6.3. How expectations for communication have changed since the diagnosis.**

Similar to above, caregivers had varying responses when asked how their expectations have changed since the diagnosis. Some caregivers' expectations have not changed upon hearing the diagnosis whilst others' have changed significantly. Most of their expectations were based on if and how their children had progressed. However, none were based on their child's intellectual functioning. This is possibly linked to how health care professionals, more specifically the speech-language therapists shared information regarding communication with caregivers. CG1, CG2 and CG7 reported that their expectations for their children's communication have increased significantly, CG7's expectations have now changed for the better as his nephew is now on medication.

*CG1: A lot, a lot a lot, when she was diagnosed it was very bad, barely any words, you could barely get your 'mama' and 'baba' out... now it's a lot more better; its things like that that I really love because it is progress and its better than nothing at all.*

*CG2: She is much better now. It was difficult when she was young, two years or three years sometimes she can't understand what you are saying.*

*CG7: Khona umehluko siyawubona siyafuna ukuthi yonke into ihambe ibengcono. Khona umehluko omkhulu manje futhi nemishanguzo iyasiza. (There is a difference, we want everything to go well. There's a big difference now, and the medications help.)*

*CG9: Usayingane yami ngakho ke nginethemba lokuhle kodwa. Ngicabanga ukuthi mhlampe maseya esikoleni engayifunda ngisho isign language (ukukhuluma ngezandla). mhlampe kube ngconywana. (He is my child, so I hope only for the best. I think that maybe when he goes to school he could learn sign language and maybe that will be better.)*

*CG8: He talks one word so each time he says that word I get happy so we are going somewhere, at home we speak. We don't use signs. I don't want anyone to use signs with my child because I feel like if they use signs he will not grow and develop that is what I feel.*

Three caregivers (CG3, CG4 and CG11) expectations have not changed. CG3 still expects her son's communication to improve despite him improving little with the help of therapy, whilst CG8 expects her son's communication to improve but does not want to introduce him to any form of sign language as she believes that this will hinder his verbal language development.

*CG4: They [expectations] haven't changed, I have accepted it. I am not expecting anything, as long as he will be normal as possible. That's good for me*

*CG10: It's [expectations] the same. I expect him to speak, or maybe follow at least simple instructions. If I say 'give me that' he should give me because his hearing is fine.*

*CG11: Akushintshanga lutho nje, ngoba nalento (ASD) angiyiqondi kahle. (Nothing has changed, I still don't understand this thing (ASD) well.)*

Caregivers' reasoning for their expectations was interesting. Many felt that the child would improve based on the fact that they have shown improvements since diagnosis, whilst others expected improvements despite seeing no changes. A few based their expectations on things that they thought were attainable e.g. sign language or following simple instructions. Only one caregiver had considered the implications of expecting too much for her daughter and how that may be unfair. The expectations that a parent has for their child has been shown to impact what the child achieves (Ivey, 2004). This illustrates how the hybrid theory particularly the child's caregivers (microsystem) and their expectations impacts the child directly (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). This links to the mesosystem and information that the health care professionals provide to the caregivers to help them manage their expectations and then to the exosystem (resources) which are limited for the health care professionals in South Africa making counselling caregivers appropriately challenging.

#### 4.7. Education

Section 29 of the South African constitution (SAHRC, 2012) states that all children have the right to basic education, however, in South Africa, it is estimated that 70% of school-going aged children with disabilities are not in a school (Donohue & Bornman, 2014). Those that do attend usually attend a 'special school' or school for learners with special education needs (LSEN). In the current study, five of the ten children with ASD (CWA1, CWA4, CWA6, CWA9 and CWA10) currently attend school, with only one (CWA1) attending a special needs school. This theme highlights the difficulties finding schooling, special schooling as a hindrance and caregivers expectations of education for their child with ASD.

##### 4.7.1. 'A nightmare'-Difficulties finding a school.

Due to the children with ASD's personal factor of their age, education was a priority for many caregivers. Caregivers identified many barriers to obtaining an education for the children with ASD. Most caregivers expressed difficulties in finding appropriate education for their children. CG1 began the search for appropriate school placement three years ago in 2017. At first, she was told the child was too young. Two years later she was informed that CWA1 was too old to meet the age criteria. The threat of this being reported to Department of Education resulted in an assessment being conducted but the school did not accept CWA1 as she did not have proper documentation from the doctors regarding her ASD diagnosis. She then went via a local advocacy body to obtain these letters; the school thereafter informed her again that her daughter was too old. She finally managed to secure her daughter a school in 2020, after an occupational therapist at the hospital she accessed for her daughter put her into contact with someone who worked in the Department of Education.

CG1: It was a nightmare, so from 2017 I think I have been trying to find placement for CWA1, I have been emailing schools, I have been contacting schools, I have been losing my mind...

CG1 also mentioned that someone had suggested to her to try the local rural primary school which had an ASD unit. The South African education system has been trying, since the end of apartheid to increase inclusion in schools. The Education White Paper 6 (Department of Education, 2001) aimed to create an integrated education system

which would have no distinction between special needs and mainstream schools. However, two decades later, it is proving difficult to bring to fruition (Donohue & Bornman, 2014).

CG5 also reported that she did not hear back from the special needs school in her area about her daughter's school placement as she was on a waiting list. Most caregivers reported that waiting lists for special needs schools were incredibly long, and it could take years for their children to secure placement. Long waiting lists at special needs schools were also highlighted by the Department of Basic Education in 2015. Educational marginalisation of children in rural communities dates back to pre-1994 when the apartheid policies provided special need education institutions in predominately White and Indian communities. This leaves many residents of rural Black communities without access to education or being forced into mainstream schooling due to lack of services (Green, 1991).

*CG5: Ngabhalisa esikoleni ngezi-8 February. Ngike ngaya khona emasontweni awu-2 edlule ngaphambi kokuthi kuvalwe izikole [November], ngangiyobuza ukuthi usekude kangakanani kuhlu lwabalindile ukufakwa esikoleni. Bangitshela ukuthi ngeke bakwazi ukusho ngoba abanye abafundi bayahamba futhi abanye bayabhalisa. Bathi bazongifonela ngaphambi kokuthi kuvalwe izikole, angisazi ke manje. Kanti ukufuna isikole endaweni ekude kubanzima. (I applied at [school] on the 8<sup>th</sup> of February. I went there 2 weeks before schools closed [November] to ask about how far she was on the waiting list and they told me that they couldn't say because some students leave, and some enrol. They said they'll contact me before schools close, I don't know now. Finding a school in a distant area is difficult.)*

*CG9: Manje useya ku festiya, okuyikho bengimubhekela isikhala eskoleni. Ngikuhlu lokulinda esikoleni, bathi bazongifonela ngo-February. (Now he's going to grade one which is why I was looking for a space at [school]. I'm on the waiting list at school, they said they'll call me in February.)*

*CG10: It is very difficult because there is a long waiting list. Any school you take him to they tell you about the waiting list, all the schools basically. I have been trying but they all say that he is too young and I feel that he is not. They say that he is too young and that I must wait until he is six and then they will put him on the waiting list.*

CG11: Kunzima ukuthola isikole, ngoba phela bavele bakutshela ukuthi uzongena kuhlu lokulinda, uyoze aye esikoleni emva kweminyaka ewu-4 noma-5 elindile. *(Finding a school is difficult because they just tell us that he'll be on their waiting list, he'll only go to school after 4 or 5 years [of waiting].)*

CG2 and CG6 reported that they are having difficulties finding a school for their children as they are not toilet-trained, which is a pre-requisite for many special needs schools. One school was willing to take CWA2 in even though she is not toilet trained, however they have a long waiting list.

CG2: *I heard that the schools are very expensive. The government schools I have tried- but they said no, she is wearing a nappy, they cannot take her that what's my experience, and the only school, after doing my research I found that there is only one school that will take her and that is \_\_\_\_ school that can accommodate her with a nappy but now next year I must try to apply even though I heard that the queue is long, it's very hard, maybe 2 years to get in.*

CG7: *I was talking to those ladies about special school. I need to go to the special school and find out, if they are going to change his diaper. I have to phone and find out if they will change him.*

Four caregivers sent their children to mainstream pre-schools or crèches. CG2 reported that her daughter attended a crèche until she was too old to, whilst CG4 paid extra for her grandson to be in a "good pre-school" where the teacher has assured her that she will get him to speak so that he can get placed in a mainstream school. This links to CG4's expectations, that her grandson will begin speaking due to attending this school. CG4, CG6, CG9 and CG10 reported that their children enjoy the routine that attending pre-school brings and are well-liked by the teachers. Involuntary mainstreaming of children with disabilities as seen in this study may be attributed to the lack of inclusive education options for children with ASD in South Africa (Donahue, 2014). With regard to the hybrid theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) governmental policy regarding inclusive education forms part of the macrosystem. Whilst there is policy in place, the resources available e.g. trained teachers and appropriate information may be lacking (macrosystem).

*CG4: The teacher, she asked if she could hold him back next year. I can see the progress. So by the time he is ready to go to a mainstream school, she knows that he won't be mocked at or you know. So that's why next year he is going to this class again. All the teachers understand. She had three children like him who weren't talking and by the time she left there they were talking and in a mainstream school. Her own son is [now] in a mainstream school because other than that he understands everything, it's just the talking.*

Some participants expressed that they were worried about the cost of special schooling as there are limited places available at government schools, leaving private schools as their only option. A report by Hodgson and Khumalo (2016) which focused on one rural community in KZN discussed the problems that the district faces in implementing inclusive education. The lack of government funding and lack of trained teachers were discussed as a hindrance to appropriate public special schooling. There is a distinct link between poverty and education. In many areas poverty chronically impedes education (Palardy, 2013). CG8 reported that she could not send her son to school as she could not afford it.

Due to the limited special needs schools available, CG2 considered sending her daughter to a boarding school until her doctor advised against it as he mentioned that girls with disabilities are often sexually assaulted at school and become pregnant, unable to tell authorities who raped them. The poor treatment of children at boarding schools for children with disabilities has been highlighted by Hodgson and Khumalo (2016). Due to the aforementioned factors, caregivers are tasked with finding schools that are close-by to ensure their child's safety, as reported by CG5. They also have to deal with the expensive cost of transportation and often have to pay double the amount for transportation as their children are unable to travel to school alone like typically developing children. Available schooling forms part of the child's exosystem (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). This limited resource could result in financial repercussions and more serious emotional and physical repercussions such as sexual assault.

#### 4.7.2. 'She'll get better'-Expectations regarding education.

Most caregivers in this study felt that education would be a 'way out' for their children. Many felt that it would 'cure' the characteristics of ASD and help their children become functioning members of society. They placed much of their hopes for their child on the education system and felt that if their children were surrounded by other children it would benefit their development, particularly communication. They also felt that the teachers at the special needs schools would help improve their children's behaviour. Two caregivers see special education as a path to mainstream schooling. Most caregivers want their children with disabilities to go to mainstream school (Rogers, 2007). Despite considering her daughter as being 'high functioning', only one participant (CG1) acknowledged the implications of expecting her daughter to attend mainstream schooling may be asking too much of her. However none of the caregivers mentioned their child's intellectual functioning as a possible hindrance to their educational progress. Children in the current study would be categorised as level 3 severity according to the DSM-5 (APA, 2013) and therefore may present with co-occurring conditions such as intellectual disability. With regard to the hybrid theory (Bronfenbrenner 1979; Bronfenbrenner & Morris, 2006), caregivers' expectations of education impacts the child with ASD directly. If a caregiver has high expectations of education then they may try harder to find a school for their child. Caregivers in the current study had varying expectations regarding their child's future in education. Some expected a slight improvement (CG2, CG3, CG6, CG8, CG9, CG10 and CG11) whilst others expected it to lead to tertiary education and careers (CG1, CG4 and CG5). Some caregivers hoped that their children would develop literacy though many did not expect it.

*CG2: [I expect] If she can learn and then she can be independent in the future because one day I will die... at least she can learn something that can help her when I am gone. I will be dead, I don't know if that will happen.*

*CG1: I want her to be in mainstream, yes. But I also feel that I am being too hard on myself and her.*



CG5: *Ngilindele ukuthi mayeya esikoleni, akhulume kangcono mayenezinye izingane. Into engiyaziyo ukuthi uma eya esikoleni uzobangcono ngoba uzoba nabantwana isikhathi esiningi kanye nothisha abamuzwisisayo. Ekhaya abekho abanye abantwana. Uwaphimisa kangconywana amagama umangabe enezinye izingane kunoma enabantu abadala. Ngiyabona ukuthi kunomthelela futhi uzobangcono esikoleni kunasekhaya nabantu abadala. (I am expecting better communication if she is around kids. What I do know is that if she goes to school, she'll get better because she'll be around other children for most of the time along with teachers that understand her. There aren't any children at home. She pronounces words better around kids than she does with adults, I can see the influence and she'd be better at school than at home with adults.)*

CG6: *Ngilindele ukuthi afunde ukukhuluma ngezandla. I-psychologist yasitshela ukuthi konke okwakhe angeke kwenzeka ngendlela ejwayelekile, engingakwazike ukuthi koze kobe nini noma mhlampe obe eseniminyaka ewu-10. Noma basitshela ukuthi akuyona into engaphela manje. ([I expect him] to learn how to communicate via sign language. The psychologist told us that everything will not happen as expected, what I don't know is how long this will take...maybe at 10 years old. Although they did tell us that it is not something that will go away now*

CG10: *[I expect him] to improve his social skills and then know the basics like know the colours yeah. Some days are better than others, that's what the teachers say. I expect him to have a career.*

#### **4.7.3. 'That will exhaust his mind'- Special education as a hindrance.**

Some caregivers were concerned that their children would get 'worse' by attending a special needs school as they would be surrounded by other children with disabilities. Two caregivers were worried that their children would be taught sign language at school and therefore would not develop verbal language. Negative expectations of education for parents of children with ASD are less common than positive expectations (Bush, 2017). Similarly, three out of eleven caregivers in this study had negative expectations.

CG3: Sengibonile ukuthi ngoba kugcwele izingane ezikhubazekile uzogcina naye egqilazeka emqondweni. *(I've noticed that there are a lot of children with disabilities so that will exhaust his mind.)*

CG8: *I don't want anyone to use signs with my child because I feel that if they use signs he will not grow and develop, that's what I feel.*

CG11: Ngeke ngisho ngoba akakafundi, kodwa ngikhathazekile ukuthi bayovele bafunde ukukhuluma ngezandla kanti isifiso sami ukuthi akwazi ukufunda nokubhala, agcine ekhuluma. *(I can't say because he's not in school, although I am worried that he'll learn sign language even if my wish is for him to learn how to read and write and eventually talk.)*

The educational resources available in a particular area (the exosystem) is a deciding factor if the child with ASD attends school. The limited availability of special needs education options in KwaZulu-Natal often means that many children with ASD are unable to access schooling.

#### 4.8. 'Prefers to play with the goats'-Social Participation

Persistent deficits in social participation and social development form part of the core characteristics of ASD (APA, 2013). Children with ASD experience difficulties in initiating and maintaining friendships (Kasari, Rotheram-Fuller, Locke, & Gulsrud, 2011). This may be because individuals with ASD have social and cognitive characteristics that may impact their understanding and expectations of friendships (Bauminger, Solomon & Rogers, 2010). Most caregivers in the current study reported that their children do not have any friends. This supports the literature which states that non-verbal children with ASD have poorer social outcomes than verbal individuals with ASD (Stazmari et al., 2003). They attributed this to their children not attending school yet (and therefore not being around children) or being too young for friends. This again links to the high expectations that caregivers have of education. CG4 reported that whilst her grandson does not have friends, teachers at his school mentioned that he does interact with other children.

*CG8: (laughs) CWA8 doesn't have friends, Haibo, CWA8 doesn't have any friends, CWA8 doesn't play with other children. At my mother's place there are children, my brother's children, young children but he prefers to play with the goats (laughs).*

*CG11: Akanabo abangani, uhlala nami nje. (He doesn't have any friends, he is always with me).*

Violent behaviour towards other children was expressed by CG2, CG9 and CG10. CG9 reported that the children from their community enjoy playing with her grandson and that he hugs them when they cry, however, he does not like to share and becomes violent when they play with his toys. CG2 and CG10 reported that their children would become violent with children at home and at school. Children with ASD and their behaviours have an impact on individuals in their microsystem. Teachers and classmates are therefore directly impacted by their behaviours and it may determine how they interact with them and each other. This could impact the child directly. Communications within the mesosystem e.g. the relationship between teachers and caregivers may be of importance when dealing with challenging behaviours.

Challenging behaviours are common in individuals with developmental delays including ASD (Dixon, Kurtz, & Chin, 2008). Challenging behaviours are defined as persistent and intense behaviours which are 'culturally abnormal' and destructive and disruptive (Emerson, Robertson, Gregory, Hatton, & Kessissoglou, 2000). These behaviours form part of a child with ASD's personal factors (a characteristic of their diagnosis). This may have an impact on their microsystem as others could have difficulties being around them. CG9 often invites the local children to her house as she feels that she cannot send CWA9 to their houses due to his behaviour. Therefore CG9 takes on more responsibility to ensure that her child has social interaction. Caregivers often play a central role in supporting and facilitating friendships for their children with ASD (Laugeson, Frankel, Mogil & Dillon, 2009). Challenging behaviours in children with ASD has significant social implications for caregivers and impacts their stress levels (McStay et al., 2014).

*CG2: No friends because she is always at home; and at the crèche, no, she used to play with anyone but she was rough sometimes, the parents were complaining, the teachers were complaining; she is fine now, no more rough.*

*CG9: Zikhona izingane ezimthandayo ngasekhaya kodwa zikezimsabe. Ziyafika zizidlala naye. Kodwa ke kuyake kufuneke ngibatshela ukuthi zingazithinti izinto zakhe ngoba uzobakinya. Akafuni nje ukuthi intoyakhe ithintwe. Ikho ngize ngizitshela izingane ukuthi mazidinga into yokubhala zicele mina, kunokuthi bathinte into yakhe, ukuze bonke badlale kahle. (There are children that like him in our neighbourhood but sometimes they're scared of him. They do come over to play with him. Although I do have to warn them not to touch his belongings as he would strangle them. He does not want anyone to touch his belongings. That's why I tell the children to ask me for something to write on rather than to touch his stuff – in order for everyone to play in peace).*

CWA5 has a friend who is three years old (four years younger than CWA5). Research has suggested that children with ASD are more likely to form and maintain friendships in their earlier years, but have difficulties with these relationships as they become older (Rotheram-Fuller, Kasari & Locke, 2010). Two caregivers (CG1 and CG4) reported that their children with ASD had good relationships with their siblings and that they were looked after by them, which could be due to these sibling being older than the child with ASD. Siblings of children with ASD often take on a nurturing role (Diener, Anderson, Wright & Dunn, 2015). CG10 reported that previously her son was a loner but now he accepts the other children. This may be because they live with CWA10 and he now accepts them as part of his household.

CG5: Ukhona umntwana owumakhelwane wakithi, sihlukaniswe ucingo nje. Ukuthi yena una-3, banokudlala ndawonye. Uma emubona uyambiza noma eze yena bafike badlala ndawonye. (*There is a child next door, we're separated by a fence. He's 3, they often play together, he calls her over and or he comes over and they play together*).

Despite children in the study not having friends, it was not reported that they experienced social exclusion or bullying, which is contrary to literature (Rowley et al., 2018). This may be due to most children not attending school or the caregivers being unaware of any specific exclusion. It appeared that most children with ASD excluded themselves from other children rather than the other way around. Most children appeared to be included when other children were together and would even visit their houses (CWA6). This could be attributed to the close-knit communities that the children with ASD resided in, perhaps an advantage to rural living.

#### 4.8.1. 'If she can go to school'- Future Expectations of Social Participation.

Caregivers had varying expectations regarding their child's social participation in the future.

CG1 reported that she noted a significant improvement as her daughter was previously reserved however, she now interacts with other children. Three participants placed their expectations for their children's social participation on schooling. They believed that once their children began attending school, they would be able to integrate

socially. It has been suggested that children with ASD who are placed in inclusive classrooms have been shown to improve socially (Harrower & Dunlap, 2001). This links back to a previous sub-theme, education as a way out, in which caregivers felt that schooling would improve functioning in many areas of ASD.

*CG2: If she can go to school, I am sure that she can have friends, but the problem is that she is at home, she is at home and plays by herself but if she goes to school, I am sure that she will come around.*

*CG4: I expect him to be able to interact with other people that will help him I suppose.*

*CG5: Uzoba nabo abangani kodwa ngiyazi ukuthi uzobenza kalula esikoleni, ngoba uzobe ephakathi kwabantu abamuqondayo. Esikoleni uzobe enabantu azokhuluma nabo. (She'll make friends, but I know that school will make it easier because she'll be around people that understand her. At school she'll have people she will communicate with.)*

*CG11: Angazi kahle kodwa ngifuna ukumuyisa enkulisa (creche) ngibone uzokwazi yini ukuphilisana nokudlala nezinye izingane. (I'm not quite sure, that's why I want to take him to crèche to gauge if he can get along with and play with other children.*

Two caregivers felt that their children would never improve socially due to their current behaviours. This may be due to caregivers having realistic expectations of their children (Poon et al., 2013).

*CG3: Mayeqhubeka kanje [indlela aziphatha ngayo] angiboni ukuthi kuzokwenzeka. (If he continues like this [his behaviour], I don't see it happening.)*

*CG8: Ay, I don't see CWA8 with a friend, I don't.*

CG6 reported that whilst she hopes that her grandson has friends and gets married in the future, she is not sure that it will happen. This is consistent with studies by Poon et al., (2013) as well as Girli (2018), which reported that whilst caregivers found marriage and relationships to be important and hoped that their children would experience it, they did not find it likely to happen. One caregiver (CG1) expressed that

she does not place any emphasis on marriage as her daughter should be free make her own choices and she is confident that her daughter will thrive socially. This may be because CG1 feels that her daughter has a 'milder' form of ASD which will not impact her greatly long term.

*CG1: I am sorry, I am not the type of female, especially black female that believes that marriage is everything, as long as she is happy, I am happy... I feel she wouldn't really struggle, she is very friendly and out there... so for me I am not really worried.*

*CG4: Lot of people say: 'you are gonna be a womaniser, such a handsome little boy' lots of people say. So I do see a future for him.*

*CG6: Ngiyaye ngifise ukuthi ashade, ngibone isizukulwane sami... Ithemba alibulali, makwenzeka kuyenzeka uma kungenzeki akwenzeki. (I sometimes wish that he will get married and I'll see my great-grandchildren... hope doesn't kill, if it does happen it does, if it doesn't, it doesn't.)*

*CG10: I expect him to have almost normal life, have friends, have relationships.*

CG9 expects her grandson to have friends the future who will take on a nurturing role and assist him because he is different. CG4 currently lives in an apartment, she expects her grandson to have friends when she moves to a house with neighbours as she does not let CWA4 go downstairs to play with other children often. CG10 expects her son to become less violent around other children and have an 'almost' normal life.

*CG9: Ngilindelele ukuthi ngoba ehluke ebenabangani abarighti abamnakekelayo. (As he is different, I expect him to have good friends who will take care of him).*

*CG10: I expect him to be able to play with other kids without being aggressive. He was aggressive, he used to push other children, then they gave him Risperdal and he is better now.*

The relationships that children with ASD have with other individuals form part of their microsystem. Their diagnosis (personal factor) can impact this significantly. Caregivers often did not understand the impact that the characteristics of ASD can

have on their children's lives. Caregivers' understanding the implications of diagnosis forms part of the microsystem, their understanding impacts their help-seeking behaviours and what they prioritise. This then highlights the mesosystem as there is a need for education by health care professionals to assist caregivers in managing and understanding ASD.

Whilst caregivers did consider social participation as important, it was not prioritised. This is contrary to literature which implies that caregivers of children with severe intellectual disabilities rated friendships as more important than academics (Pituch et al., 2011). The reason for social participation not being a significant concern for caregivers may be due to them considering the lack of exposure to other children as a significant reason for their child's social deficits. The expectation of education is highlighted in this theme as caregivers expected their children to become socially adept once they attended school. CG9 was the only caregiver who brought up the possibility of her grandson needing support socially in the future. This may be because other caregivers expect their children to improve enough to not require support in the future. This emphasises the link between expectations and future planning as CG9 is aware that her grandson will require assistance in the future and therefore may consider this as he grows.

#### **4.8.2. 'If she goes to school'-Employment.**

Employment requires integration into a social structure, making decisions and being part of society (Roux et al., 2013). Social and communication deficits impede successful employment for individuals with ASD as it impacts participation in the workplace (Hendriks, 2010; McKnight-Lizotte, 2018). Internationally, employment outcome studies for individuals with ASD report low employment rates (Chen, Leader, Sung & Leahy, 2015). These employment rates are lower than for any other disability (Howlin, Moss, Savage & Rutter, 2013). Individuals diagnosed with both ASD and ID (severe ASD) are less likely to be employed in comparison to individuals who are diagnosed with only ASD (Chiang, Cheung, Li & Tsai, 2013). Children in the current study could be classified as level three under the DSM 5 (APA, 2013). Individuals who are considered 'severe' have reduced job opportunities due to an increase in co-morbid conditions and challenging behaviours (Swaminathan, 2015). Most caregivers reported that their children's future employment was dependent on their level of



education. The level of education is a factor that may impede employment as individuals with ASD who are not high school educated are less likely to find employment (Lawer et al., 2009). Education was noted to be a recurring theme in the current study, which caregivers felt was an indicator for future success in their children with ASD's lives.

*CG2: I am sure she can be employed but the first step is to go to school; but I have seen autistic children being employed, I see a lot of them, I think the school is the first thing, if she can go to school*

*CG4: It will depend on his education, how far he goes and what he achieves, uhm, I won't force him to be a doctor when I know that he can't be a doctor, we will cross the bridge when we get there and see which direction he will be able to cope in.*

*CG5: Uthanda kakhulu ukusebenzisa izandla, ngyazi ukuthi uma eya esikoleni uzokwazi ukukhula abemdala athole umsebenzi ngoba uyakuthanda ukusebenzisa izandla kakhulu. (She loves using her hands, I know that if she goes to school she'll be able to grow and find a job because she loves using her hands a lot.)*

*CG11: Ayi, uma eyokwazi nje ukufunda, asabenze angabi umthwalo kwezinye izingane. (Oh, if he will be able to learn and get a job and not be a burden to the other children.)*

#### *4.8.2.1. 'Something with his hands'-Expectations regarding employment*

Some caregivers hoped that their children would be employed but were unsure that this would happen. CG11 hoped that her grandson would be able to find employment so that he would not be a burden on his siblings when she passes on. Adults with ASD often live with their caregivers and rarely gain residential independence (Levy & Perry, 2011; Henninger & Taylor, 2013) and have been shown to have less independence than individuals with Down syndrome (Esbenson, Bishop, Seltzer, Greenberg, & Taylor, 2010). Individuals with disabilities in rural South Africa have limited options for skills development and employment (Cramm, Lorenzo & Nieboer, 2013). With regard to the hybrid theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) the child with ASD and their caregiver form part of each other's microsystems. Due to the bi-

directional nature of the microsystem, they have significant influence over the other's lives. The future employment of the child with ASD has a direct and large impact on their immediate family. If they are unable to find a job and be independent they will be a responsibility for their caregivers well into adulthood which could create further financial burden on caregivers and eventually siblings.

*CG9: Angazi, ingqondo yami ingitshela ukuthi lento izodlula kodwa angazi noma ngiyazikhohlisa yini, kodwa ngiyazi ukuthi uma eya esikoleni kunethuba lokuthi mhlampe athole umsebenzi. Uhlakaniphile inkinga ukukhuluma. (I don't know, my mind is telling me that this will pass, and I don't know if I'm lying to myself, but I do know that if he goes to school there is a chance that he could maybe get a job. He is clever, the problem is talking.)*

With regard to possible careers that participants expected their children with ASD to follow, most caregivers felt that their children would pursue careers in activities that they enjoy. Many individuals with ASD have intense interests in certain areas (Parsons, Bayliss & Remington, 2017). Caregivers expected their children to not only find employment but go into these specific fields of interest. This may be attributed to caregiver background (education). Kirby (2016) reported that caregiver background (caregiver education, socio-economic status and race) and the individual with ASD's functioning (social skills, self-care skills and academic performance) impact on what caregivers expect of their children with ASD. This in turn impacts child outcomes as caregivers and the child with ASD form part of each other's microsystem (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). These current expectations could be due to the children still being young and caregivers hoping that they will outgrow some of their difficulties and the hope that these special interests would enable them to find employment. Two caregivers expected their children to possibly become doctors when they were older. CG1 reported that her daughter enjoys the tools at the doctor's surgery and enjoys imitating doctors and CG10 reported that she expects her son to become a neurologist due to his diagnosis of ASD.

*CG1: Every time she walks in like if you take her to the doctor or to a clinic, her first interest is equipment they use more than the main purpose she is there. So maybe, you never know!*

*CG10: I'd love him to be a neurologist because of his diagnosis.*

Many caregivers expected their children to pursue careers that involve them working with their hands as they displayed an interest in it. CG6 said that she jokes that her grandson will be an electrician as he enjoys playing with phone charging cables. CG5 reported that maybe her daughter would become a sculptor as she enjoys playing with mud. Technology was another career path that caregivers expected their children to pursue as their children enjoyed playing with their phones and laptops.

*CG3: Uthanda ifoni. Mhlampe into ephathelene nefoni. (He likes cell-phones. So maybe something involving cell-phones.)*

*CG5: Uthanda kakhulu ubumba. Uma ephuza amanzi umthola esewaphimisela phansi emhlabathini bese eyawubumba. Isikhathi sakhe usichitha lapho. (She particularly likes clay. When she's drinking water, she spits it on sand and moulds it – that's how she spends most of her time.)*

*CG9: Ngicabanga ukuthi engawuthola umsebenzi ophathelene ngokusebenzisa izandla noma ilaptop ngoba uyayithanda. Umangabe eyisebenzisa uziphatha kahle ahlale phansi isikhathi eside. (I think he could get a job that involves working with his hands or maybe a laptop because he likes it. Because when he's on it, he is fine and can sit for a long time.)*

CG11 felt that she should not be the one to decide what career her grandson would pursue as it is his choice. CG4 was the only caregiver who explicitly identified her grandson's intellectual functioning as a possible hindrance to him seeking a high-paying job. Individuals with ASD generally have deficits in areas that employers consider a skill e.g. communication and social interaction (Chen et al., 2015). None of the caregivers mentioned that their children with ASD may encounter difficulties in seeking employment due to their deficits or needing support services in the future. This could be due to participants assuming that ASD would not persist, feeling optimistic regarding their child with ASD's future or due to caregivers not identifying the barriers that ASD may cause with regard to their future and simply not giving it much thought due to their child's age.

Caregivers expecting their child with ASD to easily find future employment impacts the child directly (microsystem) as they place a larger emphasis on education in the hopes of bringing this to fruition. This may make caregivers work harder to find schooling for their children. None of the caregivers mentioned their child's communication or social deficits as a possible hindrance to employment. This could be due to them expecting their child to become functional communicators in the future.

CG11 reported that she did not have any expectations as she does not understand her grandson's diagnosis or the purpose of therapy. This highlights the importance of providing relevant health information to caregivers. CG11's expectations are a direct consequence of her understanding of the disorder and therapy in general.

*CG11: As I am old and don't fully understand, I don't know much, and I don't expect anything specific.*

## 4.9. Therapy

### 4.9.1. 'I don't know'-Caregivers' understanding of therapy.

All caregivers reported that their children currently receive speech-language therapy and occupational therapy from their local public hospitals. Most participants understood therapy as a means to assist their children with ASD in their development. Three caregivers were unclear regarding the purpose of therapy and had difficulties differentiating between speech-language therapy and occupational therapy. One caregiver (CG3) explained that she does not understand the therapies, as they are having no effect on her child.

*CG3: Bayazama, ayikho into engingayisho. Bayazama ukumusiza kodwa kushuthi sekukuyena [CWA6] manje. (They try, what can I say...they try but it is up to him [CWA6] now.)*

*CG4: Therapy is to assist him, direct him. Calm him you know to assist him to be able to handle any challenges if he gets any challenges.*

*CG5: Ngiyazi ukuthi bazama ukuthi alingise igama lakhe, ukumubonisa ama-shape nemibala, nokudlala kanye nokudlala yonke imidlalo ndawonye. (I know that they try getting her imitating her name, to show her shapes and colours and playing all the games together.)*

*CG8: I don't know, it's just to help the child you know to understand things; it helps the child's brain to develop through play, you know, it helps them to talk, they talk during these things you know it is about development.*

*CG9: Angazi, ngazi ukuthi mayeza kwispeech uzokhuluma. (I don't know, I know that when he goes to speech [therapy], he will talk.)*

*CG11: Zonke lezinto ngiyazihamba ngoba besho kodwa angiziqondi kahle. (I attend all these things (therapy) but I don't understand them well.)*

CG5 described therapy by the activities that were done during the therapy sessions e.g. playing with toys or learning shapes and colours. CG1 reported that she had interesting experiences with therapy as she had accessed both private and public

therapy for her daughter. She expressed that she found no difference in the quality of therapy, just that she paid money for one. CG1 mentioned that her daughter excels in occupational therapy and has some difficulties in speech-language therapy. CG2 felt that therapy would help CWA2 however she had difficulties keeping to her appointments as she works in Durban during the week and therefore cannot take CWA2 to therapy herself.

A similar finding was reported by Sitimin, Fikry, Ismail, and Hussein (2017) in which parents of children with ASD had difficulties balancing their work lives and caring for their children, particularly when it came to attending appointments for their children with ASD. Caregiver attendance, participation and engagement are important aspects of therapy for children (Phoenix, Jack, Rosenbaum & Missiuna, 2019).

Caregivers' employment forms part of the child's exosystem. The caregiver's job has an impact on the child with autism not only financially but in other areas of their lives as illustrated by CG2 who works away from home and therefore does not spend much time with CWA2. As the microsystem is bi-directional, the child with ASD needing to attend appointments impacts caregivers' careers as they may have to take leave or work less hours in order to care for their child with ASD which may make it difficult for them to find understanding employers (Sitimin et al., 2017). This impacts the family not only financially but has implications for caregiver mental health as employed caregivers of individuals with ASD describe their jobs as a form of escapism and independence and have reported higher health related quality of life (Hill, Jones, Lanes, Yarker & Patterson, 2015; Bourke-Taylor et al., 2010). This was highlighted by CG2 who claimed that she was not bothered by the day-to-day stressors of raising CWA2 as she works away from home during the week.

*CG1: I was even shocked. When I come back and talk about this is what happened for our session, people will constantly ask 'are you taking her for private sessions ?' and I say no its not private sessions, it is a government place where I am taking her, but the way that they received and the welcomingness of the environment or the state that we are in is amazing and they would be shocked because it is something that is hardly seen or said about government centres because everyone has very negative feedback about those places.*

#### 4.9.2. 'Sometimes I feel as if it is nothing'- Perceptions of therapy.

Caregivers expressed varied feelings towards therapy. Two caregivers reported that they did not feel that therapy would help. They explained that this was due to them not understanding the purpose of therapy. This is consistent with a study done by Wetherston et al., (2017) in KZN which reported that 78.2% of its participants were not informed about different types of treatment before beginning therapy. CG8 sometimes feels as if continuing with therapy is pointless as she sees minimal improvement. CG6 reported that whilst she doesn't understand the therapy that her grandson receives, the therapists have helped her understand his diagnosis better. This may be linked to the lack of government support and long waiting times which could influence caregivers' views of therapy negatively (Dymond et al., 2007). The poor perception of therapy may be why caregivers had higher expectations for education, perhaps because it was the only thing that they had yet to try.

*CG8: Sometimes I feel like it is nothing, sometimes I go home and I am like why am I keep on doing these things you know because it doesn't go anywhere; but they keep on telling me that whatever small things he is growing. They are saying that comparing to when he started he is growing. Like before he wasn't doing this now he is doing things. For me I am always expecting to see big things because he is a big boy.*

*CG3: Ayikho into engingayisho kahle kahle kodwa bona bayazama. Bayazama ukumUsiza kodwa kushuthi sekukuyena [CWA6] manje. (I can't say much but they do try. They do try to help him but I suppose it's all up to him now.)*

*CG6: Ngingasho nje ukuthi kuyasiza ngoba ngesinye isikhathi uyakwazi ukukwenza. (I can say that it helps, sometimes he is able to do it.)*

A few caregivers expressed positive feelings towards therapy. They felt that it helped their children with ASD or made them happy. CG11 felt indifferent towards therapy, and takes her grandchild to therapy as she could afford it and had the time to.

CG9: Kuyangijabulisa ngoba masiye \_\_\_\_\_ uyafika lowo dokotela amuthathe amugibeze ebholeni, amujikelezise. Udokotela [OT] umuyisa enkundleni yokudlala bese eyamukhulumisa ngenkathi emdlalisa amathoyizi. Ngiyambona ukuthi ujabulile. *(It makes me happy because when we arrive at \_\_\_\_\_, a doctor [OT] comes and places him on a ball then spins him around it. The doctor also takes him to the ground and talks to him while playing with toys. I can see that he's happy.)*

CG11: *I don't have a problem and I'm not worried about taxi fare.*

Caregivers form part of the child with ASD's microsystem (Bronfenbrenner, 1979. Bronfenbrenner & Morris, 2006). Their feelings and perceptions towards therapy have a direct impact on the child with as if they do not believe that the therapy is helping their child, it may affect adherence to treatment as they may choose to remove their child from therapy should they see minimal improvement (Bowker et al., 2010; Brookman-Frazee, Drahota & Stadnick, 2012; Lanners & Mombaerts, 2000). In public healthcare, therapy is often offered on a monthly basis, due to inadequate human resources and an unequal distribution of healthcare professionals between public and private healthcare (Barron & Padarath, 2017). This may influence their feelings and expectations which could hinder progress immensely as caregivers may not facilitate carry-over in the home context.

#### **4.9.3. Help loosen the tongue'- Expectations regarding Therapy.**

Participants had varying expectations of therapy. Some caregivers did not expect therapy to assist their children, whilst others expected it to help their children to become more typically-developing. Despite all children with ASD in the current study being non-verbal, only one caregiver (CG3) reported having expectations for communication. She expected speech-language therapy to help 'loosen the tongue' and therefore make CWA3 like other children whilst CG9 placed hope on therapy and views it as a 'cure'. This highlights how caregivers' (microsystem) perception of their child's diagnosis and of specific therapies impacts their expectations of that therapy and of their child.



*CG2: Just to assist her to communicate better, assist me with potty training, the neuro told me that without the help of the OT it is very hard to train these kids [with ASD].*

*CG3: Ngokuhamba kwesikhathi, ngilindele ukuthi bakwazi ukumusiza aqaqueke ulimi, ukuze akwazi ukufana nezinye izingane. (As time goes on, I expect that they can help him to loosen his tongue, so he can be the same as other children.)*

*CG9: I have a feeling that he will get better. When I have an appointment and can't make it, I feel bad because I have hope that he will get better when he goes to the doctor [therapist].*

CG9 reported that although she struggles financially and is unsure what the therapies are for, she still pays for transport to attend therapy in the hopes that it would help her grandson. Some caregivers acknowledged that they cannot solely rely on the health care professionals as therapy is usually once a month. Therefore, they have to put in the work at home to gain favourable results. Therapy offered by public health forms part of the child with ASD's exosystem (Bronfenbrenner, 1979, Bronfenbrenner & Morris, 2006). Time between therapy sessions forms part of the chronosystem – the more time that passes between sessions often means that caregivers have to take on more responsibility in the home context.

Reduced expectations of therapy as illustrated may lead caregivers to become apathetic towards therapy which could result in poor attendance, and hinder progress. Due to caregivers finding it difficult to pay for transport, they may not prioritise therapy as they have low expectations of it. As previously mentioned (p. 89), education would often take precedence over other areas in terms of what caregivers expected would help the most and perhaps they viewed therapy at the hospital as a way to bide their time until their child could attend a special needs school.

#### 4.9.4. 'They write it down and I leave' - Information received by Health Care Professionals.

Many caregivers described home programmes given to them by the occupational therapist and speech-language therapist when discussing information that they received. CG9 and CG10 reported receiving inadequate information from health care providers. Caregivers are often not provided with treatment that they require (Bowker, et al., 2010).

CG9: Akekho owangitshela ngokwelashwa. Njengoba ngishilo, ngafika babuza ngoLuzuko ukuthi unjani, babhala phansi sase sahamba. *(No-one told me about therapy. Like I said, I arrived, and they asked about CWA9, how he is, and they write it down then we leave.)*

CG10 learnt of her son's diagnosis by reading it on his hospital card. When probed regarding her feelings towards this, she expressed that she understood that doctors were busy in public hospitals. Health care professionals need to be there for caregivers emotionally during the time of diagnosis (Fernandez- Alcantara et al., 2016). The scarce availability of rehabilitation services in rural South Africa and the high turn-over of doctors and therapists in rural facilities impede good care for individuals accessing these services (Bateman, 2012). This was also reported by a Malaysian study by Nik Adib et al., (2019) which found that post-diagnosis support for caregivers of children with ASD was lacking. Caregiver education and support is extremely important for non-verbal children with ASD; this along with parent expectations have been shown to correlate with child outcomes (Kirby, 2016).

CG10: *Honestly the doctor didn't really communicate anything with me, he writes it down. I read it on the card. I read the diagnosis down on the card. He just told me that his milestones are delayed and when I read the card thoroughly, I see that there is ASD.*

*Researcher: How did you feel about that?*

*How do I feel? I didn't feel anything, Yeah I think in a public hospital there are plenty people, I think that they are busy, maybe.*

CG1, CG5 and CG6 reported that they were counselled regarding ASD and how to cope. With regard to the microsystem (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). Caregivers who understand their child's diagnosis as well as receive information regarding their treatment have improved skills and knowledge needed for raising a child with ASD (Schultz, Smith & Stitche, 2013). This in turn reduces caregiver stress and improves their feelings of capability (Schultz et al., 2013). Caregivers who are counselled regarding their child's condition may adjust their expectations accordingly.

*CG6: Ngangithi mangingazi kwenzakalani ngangibatshela odokotela bese bayangisiza. (When I was confused and didn't understand, I would inform the doctors and they would help me.)*

*CG1: A lot of information, a lot of help, a lot of paper work. For me I was even shocked because people like when I come back and talk about this is what happened for our session, people will constantly ask are you taking her for private sessions and I say no its not private sessions, it is a government place where I am taking her*

CG3 reported that she was counselled regarding the characteristics that her son will exhibit, but she still does not understand what ASD is. Four caregivers (CG3, CG6, CG9 and CG11) are monolingual isiZulu speakers. There is a need for healthcare information to be provided in the caregiver's first language. There is no isiZulu word for ASD, therefore it is often explained by its characteristics. Resources available form part of the child's with ASD's exosystem (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). Limited resources available in the caregivers' first language has a direct impact on how they receive information and therefore affects their perceptions and understanding of ASD. Research suggests that there is a lack of information on recommended practice for individuals with ASD who are non-verbal. There has been less attention in research paid to pre-linguistic children beyond infancy and the toddler years (Tager-Flusberg & Kasari, 2013). Caregivers of non-verbal children with ASD have been underrepresented in literature regarding caregiver training and intervention as a whole. This suggests that there is limited resources for therapists to consult regarding how to treat non-verbal individuals with ASD and how to counsel their

parents Koegel et al., 2020. Resources available form part of the child's with ASD's exosystem (Bronfenbrenner, 1979, Bronfenbrenner & Morris, 2006).

Limited resources available regarding how to manage individuals with non-verbal ASD in general and limited information in caregivers' first language has a direct impact on how they receive information and therefore affects their perceptions and understanding of ASD. It also impacts the mesosystem due to lacking information on caregiver education, therapists may face difficulties on caregiver counselling and managing their expectations. As caregivers form part of the child with ASD's microsystem their perceptions and understanding of ASD have a direct impact on the child with ASD.

#### **4.9.5. 'Better life and future'-Expectations of Healthcare Professionals.**

With regard to the hybrid theory framing this study (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) healthcare professionals and caregivers form part of the child with ASD's microsystem as they both have a direct impact on the child with ASD. The relationship that they share forms part of the mesosystem. Communication between caregivers and healthcare professionals is extremely important as it helps them to make informed decisions regarding the child with ASD's treatment (Goin-Kochel, 2007). The interaction between caregivers and service providers is important as caregivers are less likely to bring their children for therapy if they feel ignored or judged. None of the caregivers in the current study reported feeling that their health care professionals were not qualified, or did not have enough information, to treat their children with ASD as highlighted in literature (Wetherston et al., 2017). This may be due to caregivers accessing public health services which they are aware are overburdened as CG10 mentioned.

In the current study, most caregivers reported expecting support and assistance from healthcare professionals. A few had more specific expectations such as assistance with picky eating (CG3) or medication (CG7). CG11 reported that she just expects health care professionals to keep her grandson alive. This expectation can be linked to the above discussion regarding caregiver education and how it impacts their understanding and expectations of raising a child with ASD. Caregivers need to feel confident about asking questions regarding their child's healthcare as this enables

them to make informed decisions (Odom, Brown, Frey, Karasu, Smith-Canter, & Strain, 2003).

As previously mentioned (p. 108), a few caregivers reported receiving counselling and support regarding their child's diagnosis however, there was not a vast difference between their expectations and the expectations of those that reported not receiving the same support. This may indicate that expectations may not be necessarily linked to *if* the caregivers receive information from health care professionals but rather *how* the information is shared. Language barriers (macrosystem) and lack of educational resources (exosystem) all played a significant role in this. This alludes to a larger issue and a link to the macrosystem, where the cultural and linguistic factors need to be considered when providing health care information.

*CG1: Uhm, Everyone else I think, my expectation would be the very same, support, support support support.*

*CG2: Just to assist her to have a better life and future and I wish her to have a better life and future, just to be independent that is my wish for her.*

*CG3: Ngilindele ukuthi... hhayi angazi ukuthi ngingayichaza kanjani lento. Njengoba engakuthandi ukudla ngilindele ukuthi bamusize ngokumunikeza into engamuvula inhliziyo bese bemunikeza amaphilisi okwehlise ukukhathazeka ngokweqile. (I'm expecting...I don't know how to describe this. Since he doesn't like food, I expect them to help him with something that will help him with his appetite and also give him pills to reduce the hyperactivity.)*

*CG10: I expect them to help him get better, help him to be a better person in life, to be able to live with Autism*

*CG11: Angilindele okutheni mayephila nje umntwana. (I don't expect much, as long as the child is alive.)*

#### 4.9.6. 'Not a quick fix'-How have expectations for therapy changed.

Three caregivers in the current study reported that their expectations changed significantly since beginning therapy as they initially believed that therapy would be an immediate solution and not a process. It appeared that previously caregivers initially placed similar hopes on therapy as they do for education currently. This may be because they place their hopes on the treatment that they have not yet attempted. CG8 felt that the title 'speech therapy' was misleading as she expected her son to begin using verbal language upon starting therapy. A South African study by Mthombeni and Nyowe (2018) reported that caregivers can often become frustrated when treatments do not seem to work.

*CG1: When I heard we had to go for therapy my initial expectation was maybe it was something of a quick fix, I initially thought that maybe in the space of 3 months we will see a massive, massive improvement, which was not the case. Took way longer than that.*

*CG3: Kusafana njengasekuqaleni. Ngingathini, ngilindele ngoba bayazama kodwa awubonakali umehluko. Ekuqaleni ngangilindele ukuthi uzoshintsha (It's still the same as before. What can I say I'm expecting because they're trying but there doesn't seem to be a difference. In the beginning I expected that he would change.)*

*CG8: I was even thinking you know the name is 'speech therapy' so I was thinking you know it's when CWA8 is going to speak. But now I was hoping since we are attending the sessions that the child will start to speak soon. He will be able to do things he can't do.*

CG2 reported a change in her expectations or rather a new formation of expectations. Previously, she did not know what ASD was or the purpose of therapy; she now understands her daughter's diagnosis and treatment therefore has developed expectations. With regard to the hybrid theory (Bronfenbrenner 1979, Bronfenbrenner & Morris, 2006) caregivers form part of the microsystem. CG2 gaining a better understanding of her daughter's diagnosis and treatment available to her impacts CWA2 directly as it affects her choices regarding treatment. This highlights the

importance of caregiver education regarding ASD and the impact it can have on the child with ASD.

*CG2: First of all I didn't even know that there was a speech therapist that was the first thing; everything was new to me, I didn't know what was autism [and] that there was a speech therapist. That was the first time for everything, everything was new to me I was so stressed she told me that she will try to help her to communicate. I was like a new person in a new world. I had to Google this autism. Most of the time talking to parents with children with ASD.*

CG4 and CG6 reported that they now expect more from therapy after witnessing positive outcomes for their children. This indicates how the view of effectiveness is impacted by their view of therapy (Mahlali & Dlamini, 2015).

*CG4: Definitely [It helps] because I can see the difference.*

CG10 and CG11 reported no change in their expectations. CG10 expects her son to be given the tools to manage his diagnosis whilst CG11 does not expect much as she has accepted her grandson's diagnosis. CG10 was aware that her son may have life-long limitations due to ASD and has based her expectations on this. These expectations could be formed from her doing her own research as previously reported. It may also be because she is currently a university student and fluent in English so information may be more readily available to her.

*CG10: I expect them to help him get better, help him to be a better person in life, to be able to live with Autism.*

*CG11: Mina nje sengamukele ukuthi unalento abayishoyo, kodwa nje angilindele olukhulu. (I've accepted that he has what they say he has but I'm not expecting much.)*

As seen above, some caregivers (who form part of the microsystem) have changed their initial expectations to either expect more or less from therapy. This change in expectations appears to be dependent on information received regarding the diagnosis, therapy and progress (or lack thereof) made during treatment. These new

expectations often stem from their perception of therapy changing. Caregivers' perceptions have an impact on expectations and consequently have a direct impact on the child with ASD in terms of how caregivers approach their therapy.



#### 4.10. Societal responses

The community that the child with ASD and their caregivers reside in forms part of their exosystem (Bronfenbrenner, 1979, Bronfenbrenner & Morris, 2006). In the current study, many children with ASD and their caregivers enjoyed close relationships and daily interactions with members of their communities therefore these individuals form part of their microsystem. Caregivers in the current study lived in various communities from a newly developed settlement in a rural area with no electricity or running water (CG5) to a more developed area with amenities (CG1).

*CG1: We not in a very open community, everyone is to themselves.*

*CG4: I don't interact with them much, I am not an outgoing person.*

*CG5: Ngihlala nje endaweni elungile esemakhaya... Imizi ihlukaniswe ucingo, kodwa ke indawo entsha engakabinawo amanzi kanye nogesi. (I live in a good rural area... Houses are separated by a fence, it's a new area that doesn't have running water and electricity.)*

##### 4.10.1. 'He is not naughty, he is dealing with autism'-Community and Family Responses to ASD.

Most caregivers in the current study reported that their children were the first to present with ASD in their communities, therefore individuals in their communities did not know what ASD was prior to the children with ASD presenting with it. This speaks to the lack of public awareness surrounding ASD (Harandi & Fischbach, 2016) and the need to improve the awareness among both health care providers and the public to expedite the path to care for these children (Ruparelia et al., 2016). Members of caregivers' communities had varying reactions to the children with ASD. Some members of the community had negative reactions to the children (CG1, CG2 and CG10) with ASD whilst others were more supportive (CG5 and CG6). CG2 reported that her community thinks that her child is 'mad' and often assumes that her son's disability is a result of her bad parenting. Individuals with ASD are often considered as mentally unstable, which could be attributed to limited knowledge on ASD (John, Knott & Harvey, 2018). Caregivers of children with ASD in low to middle income countries are often tasked with explaining to others that their children do not fit into the typical understanding of

'madness' (Tilahun, Hanlon, Fekadu, Tekola & Beheretibeb, 2016). CG10 reported that individuals in her community often perceive her son as 'naughty'. This was echoed in a South African study by Guler, Devries, Seris, Shabalala and Franz (2018) where caregivers described strangers labelling their children as 'naughty' when they displayed challenging behaviours. The behaviours that children with ASD present with may lead to parents being stigmatised for 'poor parenting' (Neely-Barnes et al., 2011). There is a need to improve recognition and acceptance of ASD in communities across Africa (Ruparelia et al., 2016).

CG1 reported that her family believes her daughter will 'outgrow' her difficulties whilst others believed that she does not use verbal language by choice. As ASD is an 'invisible' disability due to a lack of physical characteristics, the public are often judgemental of children with ASD and their parents. There is a general stereotype that disability is physical, whereas ASD is generally invisible until the child displays challenging behaviours (Gorlin, 2019). This adds to caregiver stress as they often feel like they have to explain their child's diagnosis to strangers. There is a need to improve public awareness of ASD which will aid in reducing stigma (Alsehem, Abousaadah & Jan, 2017).

*CG1: I don't think that they can understand what she is going through and what autism is and what we are looking at with autistics. A lot of them will say no man, she is fine, it is just that she chooses not to speak, and I'm like okay if that's how you feel, okay because it's pointless.*

*Some people will be like no you just like wasting money, you just like doing this and doing that. And I'm just like okay. I've literally had to go through that so many times when they say you are just looking for the problem she is fine, my sister's child is this and my cousin's child is that and I am like this is not your sister's child, this is not your cousin's child, this is my child. So I am just like let me deal with it my way, and I am good.*

*CG10: You know raising a child with autism sometimes appears to be naughty but he is not naughty, he is just dealing with autism.*

CG2 reported that her community often suggests traditional healing to 'cure' CWA2 but she does not believe that it would work. This is consistent with a study by Mthombeni and Nwoye, (2018) which found that family members often believe that ASD is caused by supernatural factors. Cultural values and beliefs often influence individuals' understanding of a disorder (Freeth, Foulsham & Kingstone, 2013). Including traditional healers in the treatment team for children with ASD should be considered as they may be able to assist in destigmatising the disorder within their community (Sorsdhal, Stein, & Myer, 2009). These cultural beliefs form part of the child with ASD's macrosystem as individuals' beliefs regarding ASD can indirectly affect the child with ASD and their caregivers by them being stigmatised based on cultural beliefs.

*CG2: Don't even go there. Some they will say, she needs 'emasiko' or the rituals. They say this child needs rituals maybe I must take her home to the father's parents to do the ritual, maybe she can be better; all those things they make me very angry because I know that they won't work. The child is autistic I understand that, but people they don't understand that there is the autism, they don't understand so if you have a child like that they will think so many things. You must slaughter a goat and speak to the ancestors then the child will be okay, they say a lot of things but I don't believe it because I know it won't work. Even my physician told me that If you have a child like that she will always be autistic, she told me don't waste your money, don't listen to other people, if you have a child like that you must accept she will always be there. My mum is a Christian she doesn't believe in these things, she doesn't do these things, me too I don't believe in those things.*

CG3 reported that her mother-in-law, who lives with them and looks after CWA3 during the day, hits CWA3 a lot as she does not understand ASD and gets frustrated by his behaviours. She expressed that the abuse happens when she is at work and the neighbours often report it to her. CG3 has reported the abuse to social work, who have told her mother-in-law to stop hitting CWA3 but she denies hitting him. CG3 then had a friend call her mother-in-law and pretend to be a social worker to scare her but this did not work and she still hits him. This highlights how an individual's perceptions and understanding of ASD can impact their actions. CWA's grandmother forms part of his microsystem, her perceptions and her expectations of him as being the 'good' grand

child is not met. These feelings impact him directly as her frustration towards his behaviours lead to physical abuse. This may also link to what was mentioned above regarding ASD being an invisible disability, leaving many to believe that children with ASD are 'naughty'. Children with disabilities are often at a higher risk for abuse and neglect as compared to typically developing children (O'Donnell, Nassar & Leonard, 2010). Individuals with ASD have been shown to be more sensitive to traumatic events as compared to typically developing individuals (Hoover, 2015), therefore incidents of abuse would have lasting psychological trauma.

*CG3: Ngingathini...ugogo wakhe uyamushaya kodwa osozonhlalakahle bathi singamushayi ngoba siyamukhubaza kakhulu. Isikhathi esiningi angimshiyi naye ngoba uyamushaya amuthethise kakhulu mase eyacikeka. Mina ngatshelwa umakhelwane ukuthi mangingekho umamezala uyamuthethisa amushaye kakhulu baze bezwe bonke abantu. Kubi ngoba ingane enjena ayishawa kangaka. (What can I say...his granny hits him, but the social workers said we mustn't hit him because that disables him more. Most of the time I don't leave him with her because she hits him and shouts at him a lot and he gets frustrated. I was informed that when I'm not around my mother-in-law shouts and hits him a lot, people can even hear. It is bad that a child like this should be hit this much.)*

*Ngolunye usuku ngabuya enepopo wathi ugogo washaywa itafula. Ngabuya ngolunye usuku wamshaya ngesitsha sensipho ekhanda. Ngabona ke ukuthi ngisho ekuqaleni wayeshaywe uyena. (One day I came back to him with a lump and his gran reported that he bumped his head on the table. I came back another day and she hit him with a soap dish on his head. I then realized that she was the one that hit him before.)*

CG4 and CG9 both described positive reactions from their families and communities. CG5 reported that her family often 'babies' CWA5 and that she had to tell them to let her learn to be independent. Individuals with ASD are often infantilized well into adulthood (Stevenson, Harp & Gernsbacher, 2011). This indicates how individuals in the child with ASD's microsystem (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2008) can influence her future functioning. The carers in CWA5's life infantilising her may result in less independence in the future.

*CG5: Ngike ngaphawula ngokuthi akumele bamuyekelele kanje, kumele athunywe bangamenzeli izinto. (I told them that they shouldn't spoil her, she has to do chores and people used to baby her.)*

*CG4: They love him hey, he is a very lovable child and my family adores him.*

CG6 reported that members of their community check on her grandson and often tell her if he wanders off. He frequently visits their neighbours' houses and behaves appropriately there. CG8 reported that her family is used to her son as she had a brother with a disability. CG11 mentioned that her community treats her grandson similarly to how they treat other children in the community. Caregivers who receive support from their family regarding their child with ASD are less stressed than caregivers who do not receive familial support (Goedeke, Shepard, Landon & Taylor, 2019).

*CG6: Kuyaye kube ilaba abanozwelo nje sebeyamuqonda, noma sebebona ukuthi akasekho eduze kwasekhaya bayakwazi ukuthi bamukhuze bamtshele aye ekhaya. Enyinto ngaye ukuthi angeke afike emzini yabantu enze njengoba enza ekhaya avule ama-fridge, izicabha namakhabethe. Ufike azihlalele nje. (Those who are sensitive to our situation understand him now, they see him and are able to reprimand him and tell him to go home when they see that he is far from home. One thing about him is that in other people's houses he doesn't behave like he does at home [opening fridge doors and cupboards]. He sits still in other people's homes.)*

*CG8: My mother understands and my family understands. Even by my in-laws they understand you know, I told them that this child has this condition.*

#### 4.10.2. 'Why is he not in school?'- Communities' Expectations.

Many caregivers felt that their communities did not expect much, or care about their children. CG6 reported that she as unsure what her community expected whilst CG9 expressed that some individuals are supportive and expect the best, whilst others are negative. CG10's community does not understand ASD and often expects him to behave, whilst her family understands the diagnosis but expects him to outgrow it.

Education was an expectation of members of the community reported by two caregivers. CG5 expressed that her community constantly asks her if she has found a school for her daughter, whilst CG8 reported that her community would often question why her son isn't at school, but now have a better understanding of his diagnosis. CG11 reported that her community does not expect anything yet as her son is not in school. As caregivers in the current study placed emphasis on education and often considered it a measure of success, the same appeared to be true for the communities they resided in. CG8 noted feeling hurt by questions surrounding CWA8'S education. Affiliate stigma is often reported by caregivers of children with ASD (Werner & Schulman, 2013). In reference to the hybrid theory which frames the current study (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). The communities in which the individuals reside form part of their exosystem and individuals within these communities could form part of their microsystem and mesosystem, their feelings and expectations of the child with ASD could influence or impact their caregivers and in turn impact the child with ASD.

*CG8: You know the condition like this um for me I was feeling that. Sometimes they were asking haibo where is CWA8, why does he not go to school and I was saying how can you expect a child with Autism to go to school? You know? The mother got a child the same age as CWA8 was asking me why is CWA8 not going to school, why is he at home and for me it was very you know painful. But now I think that they understand that CWA8 is CWA8 and he will do things In his own time and you know I keep on telling them that CWA8 is CWA8 and he is not like your child, he will never be, he can be like my family but he won't be like your family, you cannot expect him to do things that your children can do.*

*CG5: Abasho, abahlezi bengibuza khona ukuthi isikole sengisitholile yini. Bese ngiyachaza ke ukuthi angikasitholi. Balindele nabo ukuthi ngelinye ilanga ngisithole ngoba kuzomsiza kakhulu. (They don't say, all they ever ask me is if I've found a school. I then explain that I haven't found one. They're also expecting that I'll find it one day as it would help tremendously.)*

*CG11: Ngoba akakafundi akekho umuntu osebonile ukuthi alindele ini. (Because he is not in school, no one knows what to expect.)*

#### **4.10.3. 'They can't see that he is autistic'- Response in public.**

Caregivers face a complex and emotional situation each time they take their children out in public; they have many variables to manage including anticipating their child's distress, their behaviour and the public responses (Ryan, 2010). The general public form part of the child with ASD's exosystem (Bronfenbrenner, 1979, Bronfenbrenner & Morris, 2006) with feelings and attitudes of the public at large forming part of their macrosystem. Their reactions to children with ASD may indirectly impact them. As most caregivers in the study reported that as ASD does not manifest physically, many people in public do not notice that there is a problem unless they try to speak to the children with ASD. The lack of physical characteristics of ASD may cause strangers to make judgements about their children and their parenting (Ryan, 2010).

*CG2: In the mall they can't see that she is autistic, they can't see unless you can spend maybe few minutes with her then they can see something is not right but if we are walking in the mall they can't notice.*

*CG3: Bayambingelela. Abasho lutho nje, bambona eyingane. (They greet him. They don't say anything, they just see him as a child.)*

Some caregivers reported negative reactions to their children in public. Most caregivers expressed that they do not pay the negative reactions any attention. CG1 reported that she had been shouted at by a man in a shop for speaking to CWA1 in English as she doesn't understand isiZulu. Children's behaviours in public is often viewed as a reflection of their caregiver's competence (Ryan, 2010).

*CG1: I think because of communication, she is more of an English communicator, so sometimes you get looks from people, for me its things like that that don't concern me, I have had a time when a guy literally attacked me for it... Its things like that that I block out, I say you deal with your nonsense and I will deal with mine and that is it.*

CG9 reported that people look at them in public, particularly when her grandson exhibits characteristic behaviours such as shouting. Non-verbal children with ASD provide additional challenges in communicating with their caregivers, which may draw attention in public spaces and lead to frustration for both communication partners (McStay et al., 2014). CG4 reported a similar reaction as her grandson enjoys playing with women's shoes in public. Socially inappropriate behaviours exhibited by children with ASD can lead to negative perceptions by others (Al nazly & Abojedi, 2019). Caregivers had varying ways of dealing with individuals in public settings, some chose to educate others on ASD whilst others did not feel the need to explain themselves. CG4 was the only caregiver who reported feeling embarrassed in public by CWA4's behaviour, whilst others (such as CG11) chose to ignore those who stared.

*CG4: They say hi, not only to family, to people at the mall. Loves ladies' shoes. He has a fetish; ladies at the mall used to run away. He will actually go on his knees and play with them, pretty shiny ones with flowers. They used to wonder why. I say he just has a fetish for ladies shoes. I see now he doesn't do it as much now. I used to be embarrassed. Just ladies' shoes.*

*CG9: Bayambuka, mhlampe enyinto emenza bembuke kakhulu ukuthi mayezama ukukhuluma uke athi 'aaaah'. Futhi mayefuna okuthile nginganayo imali, uyakhala, bamubuke kodwa angibanaki. (They look at him, maybe another thing that makes them look at him more is that when he attempts to talk, he says, "aaah". And also, when he wants something and I don't have money, he cries, and people look at us but I don't pay attention to them.)*



CG11: Anginaki, uma ngihamba naye anginandaba ukuthi abantu bathini. Kodwa ke uma silana esibhedlela sisalindile uye ubone ukuthi abanye abantu abathandi uma uSanele eya kubo. *(I don't pay attention to it and I don't care what people say when I go out with him. But when we're here at the hospital waiting, you can see that some people don't like it when CWA11 goes to them.)*

#### 4.10.4. 'I see him as he is'-How do caregivers' view their children with ASD?

Caregivers had varying views of their children with ASD. Some were upset when comparing them to other children as they had not met their developmental milestones or presented with behavioural challenges.

CG2: *Obviously you can see that there is something that is not right in her head. I am telling you very bad, very stressful but I am coping, I have to, I have no choice.*

CG3: *Mangimuqhathanisa nezinye izingane, ngimubona ehlukile nje kakhulu. Wenza izinto ezingafani. Ngisho izingane zizomvakashela nje wenza izinto ezingajwayelekile. Uzwa ngengane nje isikhala eyikinya. Akakwazi ukudlala nezinye izingane ngoba uyazilimaza. Akakwenzi ngamabomu kodwa ukuthi nje yena udlala kabi. (Compared to other children I see him as very different... He does different things. Even when other children come to visit him, he doesn't do normal things. You just hear one of the children crying as he strangles them. He can't play with other children as he hurts them. He doesn't do it on purpose though, he just plays rough.*

CG8: *Woah, There is a big gap, he doesn't go with his peers, CWA8 is a bit behind. It is hard, I love him too much but it's hard.*

Other caregivers did not view their children as 'different' and noted that they needed more assistance. Caregivers and children with ASD form part of each other's microsystem, therefore the child's diagnosis which is a personal factor (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) impacts the caregiver directly and the way in which the caregiver views their child with ASD impacts the child with ASD directly. Many caregivers have internalised stigma regarding having a child with ASD. This stigma could impact both the child with ASD and their caregivers negatively.

CG9 described how her daughter (CWA9's mother) does not visit or contact her son; she suspects that this is due to his diagnosis. This is an example of how parents can feel stigma towards their own children. How caregivers view their children could shape their expectations, caregivers who view their children as different from other children would have dissimilar expectations when compared to a caregiver who does not view their child as being different. Acknowledging that their children are different could spur caregivers into action (CG4) or cause them to feel ashamed and affect their relationship with their child (CWA9's mother). Caregivers who do not feel like their children are different may have similar expectations for their children as caregivers of typically developing children do.

*CG4: I don't view him as different, I just view him as a child that has a challenge that other children don't have. Because he is normal. He has two eyes like them he has a mouth and everything.*

*CG10: I see him as he is, I mean, he is my kid. Honestly it is overwhelming and so stressful at times.*

*CG11: Lokhu kuyaqala ukwenzeka, manje kuyathusa kodwa sengamukelile. (This is the first time this has happened so it's shocking, but I have accepted it.)*

#### **4.11. Summary of chapter four**

The above chapter highlights the results of the study illustrated by the ten themes and their subthemes discovered during data analysis. The themes are discussed using the hybrid theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) that frames the study. Grandparents as primary caregivers (the microsystem) and educational expectations (the microsystem and exosystem) were noted to be dominant themes. It appeared that expectations were based on the understanding of information received from healthcare professionals (the mesosystem), whilst resources available in these rural areas were also a consideration in expectations.

## **Chapter Five: Conclusion, Limitations and Implications**

### **5.1. Conclusion**

This study aimed to explore the expectations of caregivers of non-verbal children with ASD, particularly in rural KwaZulu-Natal. A hybrid between the ecological theory (Bronfenbrenner, 1979) and bioecological theory (Bronfenbrenner & Morris, 2008) was used to guide the researcher when reviewing the literature, conducting the study and interpreting results. The results of this study were categorised into ten main themes and related sub-themes within each. The results revealed varied expectations of caregivers which were influenced by many factors. The hybrid theory was used to explore and interpret these expectations and their impact on the child. Figure 6 (p. 52) illustrates the data in relation to the hybrid theory that frames the study. The use of the hybrid model strengthened the interpretation of the results as it allowed for the consideration of contributing factors and their influence on the expectations of the caregivers of non-verbal children with ASD.

As previously mentioned (Background information, P. 1), during my community service year I noticed that health care professionals often did not ask the caregivers of non-verbal children with ASD in rural KZN what they expected of their children. I observed that caregivers often did not receive adequate information regarding their child's diagnosis. These factors were explored in the current study using the hybrid theory which is illustrated in Figure 6.

The personal and processing factors of the hybrid theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) are used to illustrate the findings of the study. The personal factors including age, diagnosis and intellectual abilities and the processing

factors including the microsystem, mesosystem, exosystem, macrosystem and chronosystem.

It was noted that the child with ASD's personal factors had implications for caregivers' expectations. The children with ASD in the current study were school-aged and as a result education was a major concern and expectation for caregivers. Challenging behaviours that the children with ASD displayed due to their diagnosis often shaped caregivers' experiences raising them and impacted their expectations for areas of their lives such as social participation. The children with ASD in the current study were non-verbal, their communication abilities were as a result of their diagnosis and was often the antecedent for caregivers seeking help and eventually obtaining a diagnosis. Most caregivers expected their child to speak at some time in the future and had other current priorities such as education and toilet training.

The processing factors played an important role in understanding caregiver's expectations in relation to various aspects of their child's lives. The bi-directional relationship of the microsystem meant that caregiver's expectations had a direct impact on the child with ASD, with the child's personal factors, as mentioned above, had a direct impact on the caregivers and therefore their expectations. The microsystem was fluid, with caregivers changing due to factors such as employment often leaving grandparents to care for the children with ASD.

The fluidity of the microsystem had an effect on the mesosystem. Health care professionals may have to explain things to different caregivers which could lead to miscommunication. Another important factor in the mesosystem was the language that health care information was shared in as in South Africa, most health information is not provided in the caregiver's first language (Levin, 2014). These factors impacted how caregivers understood information about their child's diagnosis and therefore their expectations regarding different areas of their lives. The guidance and information that health care professionals shared with caregivers as well as progress made thus far also impacted caregivers' expectations of therapy. A few caregivers reported receiving little to no information regarding ASD and therapy, this may be due to aforementioned factors such as the language barrier and limited informational resources available to health care professionals.

Factors within the exosystem such as resources available to health care professionals links to how caregivers receive information and therefore their understanding and expectations. Resources within the exosystem were also considered when it came to education. There is limited availability of special needs schools making it difficult for caregivers to find satisfactory educational options for their children. Caregivers placed a lot of their expectations on education and often thought that it would alleviate many of the ASD characteristics such as communication and social deficits. Education was noted to have taken precedence over therapy in terms of what caregivers expected to assist their child the most. Caregivers often did not consider their child's intellectual functioning (personal factors) when creating expectations for education, social participation and employment. This links back to the discussion about the mesosystem and how caregivers are counselled regarding ASD.

The community and their response to children with ASD formed part of the child's macrosystem. Caregivers reported stigma as well as advice to consider traditional healing from their communities. Education was also noted to be an expectation of the community that the individuals with ASD resided in. The general public were often unaware that their children presented with a disability due to the 'invisible' nature of ASD. Due to the study taking place in rural KZN, the previous governmental policy of apartheid played a role in how the children were cared for. Due to apartheid, rural areas were left underdeveloped forcing individuals to move to urban areas to find employment thus often creating a fluid microsystem.

The previous policy of apartheid is also linked to the chronosystem as it is a historic event. The chronosystem could also impact caregivers' expectations of therapy as in public healthcare therapy sessions are often monthly, which may hinder progress and therefore influence caregivers' expectations. The specific time in a child's life has a significant impact on what caregivers expect at that time as the children in the current study were of school age, education was considered to be an important expectation to caregivers.

*Hope springs eternal in the human breast*

*-Alexander Pope*

Hope was a common thread that weaved throughout the study. Despite their familial, physical, geographical and financial challenges, caregivers faced their difficulties with

optimism. By trying to be realistic caregivers did not expect certain things from their children with ASD, but they hoped that it would happen. Their primary expectation for their children, like most caregivers of any child, was a life of happiness and love, buoyed by the hope that they would get the support they need to better their lives. This study revealed that there is a need for health care professionals to understand the expectations of caregivers, particularly in rural South Africa, in order to better provide support for them and consequentially, the children with ASD.

## **5.2. Limitations**

The following were the limitations of the study

1. There were no participants who had children with ASD in the 8-18 year age-range. This could be due to caregivers not accessing therapy for their children once they have passed a certain age due to being discharged from therapy or obtaining appropriate schooling. The lack of participants with children within this age range meant that caregivers' expectations of their older children could not be researched.

## **5.3. Implications**

### **5.3.1. Implications for practice.**

1. There is a need for in-depth counselling by health care professionals to caregivers of children with ASD in rural KZN focused on short term and long term expectations.
2. Resources in different languages need to be developed by and thereafter made available to health care professionals to utilise when counselling.
3. Health care professionals such as nurses need to be provided with counselling regarding the characteristics of ASD or a short checklist to fill in as well as the appropriate channels of referrals to eradicate the long process that caregivers currently experience.
4. There is need to provide counselling for teachers in mainstream schools in rural areas that who have students with ASD by providing information on identifying characteristics of ASD and referral pathways to expedite the diagnostic process.

5. Speech-language therapists and other health care professionals should facilitate support groups with caregivers of children with ASD as speaking to other caregivers of children with ASD assisted their understanding of the diagnosis and provided ongoing support.

#### **2.10.2. Implications for research.**

Further research into the expectations of caregivers of children with ASD should include:

1. Exploring the expectations of caregivers of non-verbal children with ASD in rural areas in other provinces
2. Exploring the expectations of caregivers of non-verbal children between the ages of 8 and 18 with ASD in rural KZN
3. Exploring the expectations of caregivers of verbal children with ASD in rural KZN as a comparison
4. Exploring the expectations of caregivers with non-verbal children with ASD in urban KZN
5. Exploring the expectations of Health Care Professionals for non-verbal children with ASD
6. Exploring health care professionals understanding of ASD in rural KZN
7. Exploring community members' understanding of ASD
8. Exploring the understanding of ASD by teachers in mainstream schools in rural KZN.
9. The role of support groups for caregivers of children with ASD in rural KZN.

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**Appendix A: Letter to the department of health requesting assistance to recruit participants**

**DISCIPLINE OF SPEECH- LANGUAGE THERAPY  
SCHOOL OF HEALTH SCIENCES**

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[KWAZULU-NATAL DEPARTMENT OF HEALTH](#)

**Natalia**

**330 Langalibalele (Longmarket) Street**

**Pietermaritzburg**

**3201**

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Dear Sir/ Madam

**June 2019**

**REQUEST: ASSISTANCE WITH PARTICIPANTS FOR SPEECH-LANGUAGE  
THERAPY RESEARCH PROJECT**

**Research Study Title:** Caregivers' expectations for their non-verbal child who present with Autism Spectrum Disorder (ASD) in rural KwaZulu-Natal (KZN).

My name is Fatima Haffejee and I am a Speech-Language Therapy Master's student at the University of KwaZulu-Natal, Westville Campus conducting a research study in the field of Autism Spectrum Disorder. My research study focuses on caregivers' expectations for their non-verbal child who presents with ASD in rural KwaZulu-Natal. I am conducting this research to gain an understanding about the expectations that caregivers have for their children with ASD. There is a paucity of information regarding the expectations of caregivers of non-verbal children with ASD. Parental expectations

have a direct impact on their child's life and therefore the study could benefit the caregivers of non-verbal children with ASD, the non-verbal children with ASD and professionals who work with this population by providing information that could improve intervention. Provisional ethical clearance for this research study was obtained from the University of KwaZulu-Natal's Biomedical Research Ethics Committee (BREC) (Ref No: 00000096/2019).

This research study involves one on one audio recorded interviews with the caregivers. The interviews will last approximately an hour and a half, at the hospital that they receive treatment at, following an appointment. The contents of the interview will relate to the participants' expectations of their non-verbal child with ASD. Participation in this study is voluntary and participants have the right to withdraw at any time. Withdrawing from the research study will have no impact on the participants or their children in any way. Should the participant experience psychological distress, a list of public sector psychologists will be provided, and appropriate referrals made if requested by the participant. There will be no compensation provided for any psychological distress that may be caused by discussing their expectations. The identity of the hospitals accessed, all personal information and responses obtained during this study will remain confidential. Each participant needs to read an information letter and sign the informed consent form.

I humbly request your assistance in helping me with this study by giving me permission to access the following public health care facilities in rural KZN that provide services to children with ASD and which have a speech-language therapist: \_\_\_\_\_ . I look forward to your correspondence and greatly appreciate any assistance that you can offer me. Should you have further queries pertaining to my study, kindly contact me or my research supervisors (details below).

Thank you for your assistance.

Yours faithfully,



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Fatima Haffejee (Researcher)

Phone: 073 442 8460



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**Appendix B: Letter to public hospitals requesting permission to recruit participants****DISCIPLINE OF SPEECH- LANGUAGE THERAPY****SCHOOL OF HEALTH SCIENCES****TEL: 031 260 8983****FAX: 031 260 8984****EMAIL: [Khumalot8@ukzn.ac.za](mailto:Khumalot8@ukzn.ac.za)**

Dear Hospital manager

**June 2019****REQUEST: ASSISTANCE WITH PARTICIPANTS FOR SPEECH-LANGUAGE  
THERAPY RESEARCH PROJECT**

**Research Study Title:** Caregivers' expectations of their non-verbal children who present with Autism Spectrum Disorder (ASD) in rural KwaZulu-Natal (KZN).

My name is Fatima Haffejee and I am a Master's student at the University of KwaZulu-Natal, Westville Campus conducting a research study in the field of Autism Spectrum Disorders. My research study focuses on caregivers' expectations for the non-verbal child who presents with ASD in rural KwaZulu- Natal. I am conducting this research to gain understanding on the various expectations that caregivers of non-verbal children with ASD in rural KZN as there is limited research regarding ASD in South Africa. The study will produce results that could benefit the caregivers of non-verbal children with ASD, the non-verbal children with ASD and professionals who work with this population. Ethical clearance for this research study was obtained from the University

of KwaZulu-Natal's Biomedical Research Ethics Committee (BREC). (BREC Ref No: 00000096/2019).

This research study involves one on one audio recorded interviews with the caregivers. The interviews will last approximately an hour and a half, preferably at your hospital as this will be the easiest for the participants. The contents of the interview will relate to the participants' expectations of their non-verbal child with ASD. Participation in this study is voluntary and participants have the right to withdraw at any time. Withdrawing from the research study will have no impact on the participants or their children in any way.

Should the participant experience psychological distress, a list of psychologists (public and private) will be provided and appropriate referrals made if requested by the participant. There will be no compensation provided for any psychological distress that may be caused by discussing their expectations. All personal information and responses obtained during this study will remain confidential. Each participant needs to read the information letter and sign the informed consent form provided by the researcher.

In order to participate in the study participants must be:

- The primary caregiver. [A primary caregiver refers to a 'person who cares for, nurtures, loves and looks after one or more children, role is like that of a parent (Department of Social Development & UNICEF, 2008)]
- The caregiver of a non-verbal child with ASD (Non-verbal referring to the child using less than 10 words)
- The caregiver of a child between the ages of 5-18.
- Currently accessing or have accessed therapy for their child with ASD (speech therapy, occupational therapy, physical therapy etc.).
- A Caregiver of non-verbal children with ASD who does not have any co-occurring syndromes (e.g. Down syndrome, Rett syndrome, Fragile X syndrome)

I humbly request your assistance in helping me with this study by giving me permission to access to the caregivers of your patients with ASD and a quiet space at your hospital as a venue to conduct the interviews should the participant find it convenient. I would appreciate it if your resident speech-language therapist will help me to identify

participants for my study. If you are able to assist with recruitment of participants from your patients, please complete the permission slip below.

I look forward to your correspondence and greatly appreciate any assistance that you can offer me. Should you have further enquiries pertaining to my study, please contact me or my research supervisors listed below.

Thank you for your assistance.

Yours faithfully,



---

Fatima Haffejee (researcher)

Phone: 073 442 8460



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Ms. Saira Banu Karrim (research supervisor)

Email: [Karimsb@ukzn.ac.za](mailto:Karimsb@ukzn.ac.za)

Phone: 031 260 7550/8983



Ms Jenny Pahl (research supervisor)

Email: [Pahlj@ukzn.ac.za](mailto:Pahlj@ukzn.ac.za)

Phone: 031 2607642

Biomedical Research Ethics Administration

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000 KwaZulu-Natal, South Africa

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: BREC@ukzn.ac.za

### **Declaration of informed consent: Public Hospital**

I \_\_\_\_\_ (full name and title)

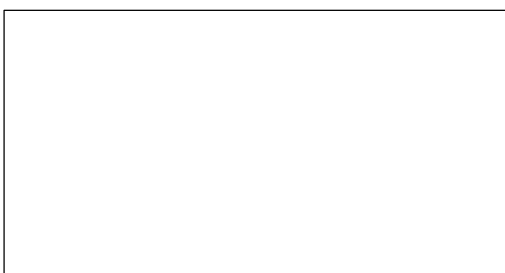
from \_\_\_\_\_ (full name of hospital) hereby confirm that I have read the above letter and understood the nature of the research study.

I consent to assisting the researcher from the University of KwaZulu-Natal, Discipline of Speech-Language Pathology by allowing her to recruit participants

from \_\_\_\_\_ (name of hospital).

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date



Hospital stamp

**Appendix C: Letter to potential participants (English)****DISCIPLINE OF SPEECH- LANGUAGE THERAPY****SCHOOL OF HEALTH SCIENCES****TEL: 031 260 8983****FAX: 031 260 8984****EMAIL: Khumalot8@ukzn.ac.za****Dear Sir/ Madam****December 2019****REQUEST FOR PARTICIPATION IN A SPEECH-LANGUAGE PATHOLOGY RESEARCH STUDY**

My name is Fatima Haffejee and I am a Master's student at the University of KwaZulu-Natal, Westville Campus carrying out a research study in the field of Autism Spectrum Disorder. My research study focuses on caregivers' expectations for the non-verbal child who presents with ASD in rural KwaZulu- Natal. The study will help therapists to understand what caregivers expect of their child with ASD, therefore helping therapists to provide better counselling and care to children with ASD and their caregivers.

This research study involves one on one audio recorded interviews which will last about an hour and a half, at a time and place that is easiest for you. Audio recordings will help the researcher to remember the information given when writing up the results of this study. The interview will be about expectations that you have for your child with ASD.

If you feel uncomfortable or upset during the interview, we can stop the interview at any time, and you can be referred to or given the details of a psychologist to speak to. The cost of the psychologist will not be covered by the researcher.

The study will gather information that could help children with ASD and their caregivers by providing information that will improve therapy.

Taking part in this study is your choice, you have the right to leave at any time. Deciding to not take part on the study will not affect you in any way. All personal information and responses that is given for this study will remain private.

For you to participate in this study you must be:

- The primary caregiver. This is someone who cares for, nurtures, loves and looks after a child with Autism Spectrum Disorder.
- The caregiver of a child with Autism Spectrum Disorder who uses less than 10 words
- The caregiver of a child between the ages of 5-18.
- Taking or took your child for therapy (speech therapy, occupational therapy, physical therapy, etc.).
- A Caregiver of non-verbal children with ASD who does not have any other syndromes (e.g. Down syndrome, Rett syndrome, Fragile X syndrome)

Attached is an informed consent document for you to sign in order to take part in this study. Should you choose to take part, please sign the consent form attached. The document may be left with the speech therapist at the hospital that you visit. You may keep the original copies of all documents as a reference. Alternatively, the document can be sent back via email to fhaffs@gmail.com or fax (031) 260 8984. Please return no later than \_\_\_\_\_ 2019

If you need additional information, do not hesitate to contact me (Fatima Haffejee) on: 0734428460.

Thank you for your assistance,

Yours faithfully,



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Fatima Haffejee (Researcher)



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Ms. Saira Banu Karrim (Research supervisor)

Phone: 0734428460



Jenny Pahl (Research supervisor)

Email: [Pahlj@ukzn.ac.za](mailto:Pahlj@ukzn.ac.za)

Phone: 031 2607642

**Appendix D: Letter to potential participants (isiZulu)****DISCIPLINE OF SPEECH- LANGUAGE THERAPY****SCHOOL OF HEALTH SCIENCES****TEL: 031 260 8983****FAX: 031 260 8984****EMAIL: [Khumalot8@ukzn.ac.za](mailto:Khumalot8@ukzn.ac.za)**

Mnumzane/Nkosokazi/Nkosazane

**Lwezi 2019****ISICELO SOKUTHI UBE INGXENYE YESISTADI EYISICWANINGO  
KWEZOBUDOKOTELA BEZINKULUMO**

Igama lami ngu Fatima Haffejee. Ngingumfundi owenza IMasters eyunivesi yase Kwa-Zulu Natal e Westville Campus. Isistadi sami singucwaningo sesifo se Autism Spectrum Disorder. Ucwaningo lami lugcula ngokulindelwe ngabanakekeli bezingane ezine ASD emakhaya ase Kwa-Zulu Natal.

Lolu cwaningo lami lizosiza amatherapist ukuthi ekwazi ukuqonda ukuthi abanakekeli bezingane ezine ASD balindeleni kibona. Lokhu kuzosiza amatherapists ekwazi ukunikeza abazali ukwelulekwa okungcono nokunakekela ezingane ezine ASD nabanakekeli babo.

Lesistadi socwaningo sizoba nama-inthavyu ayi hora nemizuzu engamashumi amathathu (30) aqoshiwe, ngesikhathi nendawo ekufanele wena. Ukuqoshwa kwama inthavyu kuzosiza ucwaningayo ukuthi ekukhumbule ebekukhulunywe ngakho maseloba imipumela yalesistadi. I-inthavyu izobe ingokulindele kwingane yakho eneASD.

Mawuzizwa ungakhululekile noma uphatheke kabi sisenza i-inthavyu, singayiyeka i-inthavyu noma ngasiphi isikhathi bese sikudlulisele kudokotela wezingqondo ukuthi uthole usizo kuyena. Umcwaningi uyena ozokunikeza usizo ngekwezimali makukwenzeka lokhu.



Lesistadi sizo butha lonke ulwazi elingasiza izingane ezineASD nabanakakeli babo ngokunika ulwazi elizo thuthukisa ukwelapha.

Ukuba ingxenye yalesistadi kukuwena futhi ungakwazi ukuphuma kusona noma ngasiphi isikhathi. Ukungabi ingxenye yalesistadi ngeke kukuthinte noma ngayiphi indlela. Yonke imininigwane yakho izohlala iyimfihlo.

Khona ukwazi ukuba ingxenye yalesistadi kufanele ube:

- Umnakekeli wengane. Lona ngumuntu oyinakekelayo, oyithandayo futhi oyigadayo ingane ene Autism Spectrum Disorder.
- Ube umnakekeli wengane ene Autism Spectrum Disorder esebenzisa amagama ambalwa kunayishumi.
- Umnakekeli wengane eneminyaka ewu 5- 18.
- Uhambisa inagane yakho kwitheraphi (speech theraphi, occupational theraphi, physical theraphi njl.)
- Umnakekeli yengane engakhulumi eneASD enganawo amanye amasyndromi (isb. I-Down syndromi, i-Rett syndromi ne Fragile X syndromi)

Kukhona iphepha lemvumo lana ongalisayina khona ube ingxenye yalestadi. Mawuzoba ingxenye yalesistadi uyacelwa ukuthi usayine leliphepha elinika imvumo. Leliphepha ungalishiya nodokotela wezinkulumo wakho kulesibhedlela osivakashelayo. Ungawagcina amakhophi angamaoriginali ahlale kwena. Noma ungayihambisa ifomu nge email ku [fhaffs@gmail.com](mailto:fhaffs@gmail.com) noma ufaxe u (031) 260 8984. Uyacelwa ukuthi ungalibuyise ngemva kwa \_\_\_\_\_ 2019

Uma udinga ulwazi kwabanzi, ungangabazi ukungithinta mina (u Fatima Haffejee) ku : 0734428460.

Uyabongwa ngosizo lwakho,

Yimina ozithobayo,



---

Fatima Haffejee (Umcwaningi)

Ucingo: 073 442 8460



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Nkk. Saira Banu Karrim (Usuphaviza wocwaningo)

Email: [Karimsb@ukzn.ac.za](mailto:Karimsb@ukzn.ac.za)

Ucingo: 031 260 7550



Nkk. Jenny Pahl (Usuphaviza wocwaningo)

Email: [Pahlj@ukzn.ac.za](mailto:Pahlj@ukzn.ac.za)

Ucingo: 031 2607642

Biomedical Research Ethics Administration

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000 KwaZulu-Natal, South Africa

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

**Appendix E: Informed consent form (English)****DISCIPLINE OF SPEECH- LANGUAGE THERAPY****SCHOOL OF HEALTH SCIENCES****TEL: 031 260 8983****FAX: 031 260 8984****EMAIL: Khumalot8@ukzn.ac.za****CONSENT****December 2019**

I \_\_\_\_\_ (your name) have received information about the study '*Caregivers' expectations of their non-verbal child with ASD in rural KZN*' by the researcher (Fatima Haffejee).

I understand the purpose and procedures of the study.

I have been given a chance to ask questions about the study and have had answers to my satisfaction.

I have read the above letter about the research study being done and understand what it says.

I wish to take part in the study and will agree upon a scheduled time to meet for the interview.

I understand that should I change my mind I can withdraw from participating in this study at any time. I fully understand and acknowledge that should I wish to withdraw; no harm shall come to me and that this study will aid the researchers in gathering information that will benefit the non-verbal children with ASD and their caregivers.

I give consent to the researchers to audio record the interview.

If I have any further questions/concerns or queries regarding this study, I understand that I may contact the researcher at: Fatima Haffejee- 0734428460

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of this study or the researcher, then I may contact:

Biomedical Research Ethics Administration Research Office

Westville Campus

Govan Mbeki Building Private Bag X 54001

Durban 4000

KwaZulu-Natal, South Africa

Tel: 27 31 2604769

Fax: 27 31 2604609

Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

A summary of the results (once this study has been completed) will be sent to you. Please supply an email address or postal address to which the summary may be sent to.

E-mail Address: \_\_\_\_\_

Postal Address: \_\_\_\_\_

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of witness

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of translator (where applicable)

\_\_\_\_\_  
Date

**Appendix F: Informed consent form (isiZulu)****DISCIPLINE OF SPEECH- LANGUAGE THERAPY****SCHOOL OF HEALTH SCIENCES****TEL: 031 260 8983****FAX: 031 260 8984****EMAIL: [Khumalot8@ukzn.ac.za](mailto:Khumalot8@ukzn.ac.za)****IMVUMO****Lwezi 2019**

Mina u \_\_\_\_\_ (igama lakho) ngithole ulwazi ngesistadi esithi '*Caregivers' expectations of their non-verbal child with ASD in rural KZN*' esicwaningwa ngu (Fatima Haffejee).

Ngiyasiqondo isizathu nezinhlelo zalesistadi.

Nginikezilwe ithuba lokubuza imibuzo ngalesistadi ngazithola izimpendulo ezingigculisile.

Ngiyifundile lencwadi engaphezulu echaza lesistadi socwaningo futhi ngiyayiqonda ukuthi ithini.

Ngiyafisa ukuba ingxenye yalesistadi futhi ngiyavumelana ngesikhathi esihleliwe ukuthi kuhlanguwanelwe i-inthavyu.

Ngiyakuqonda ukuthi ngingakwazi ukushintsha umqondo wami noma ngasiphi isikhathi ngingabi yingxenye yalesistadi.

Ngiyakuqonda konke ubungozi okukhona ngokuba yingxenye yalesistadi nokuthi akukho okwezimali okuziyimibuyiselo makukhona usizi kokwezingqondo okukwenzeka ngokukhuluma ngokungakuzwa.

Ngiyakuqonda futhi ngiyavuma ukuthi makukwenzeka ukuthi ngifune ukuphuma kulesistadi ; akukho ububi okuzokwenzeka kimi nokuthi lesistadi sizob'usizo kuba

cwaningayo mabebutha ulwazi elizosiza izingane ezingakhulumi ezineASD nabanakakeli balo.

Ngiyayinikeza imvumo yami kubacwaningayo ukuthi beyiqophe i-inthavyu.

Manginayo enye imibuzo noma izikhalazo ezimayelene nalesistadi, Ngियाqonda ukuthi ngingamuthinta umcwaningi ku: Fatima Haffejee - 0734428460

Manginayo imibuzo noma izikhalazo nagamlungelo ami njengexhenye yalesistadi, noma mangikhathazekile ngento ethintene nalesistadi noma umcwaningi, ngingathinta:

Biomedical Research Ethics Administration Research Office

Westville Campus

Govan Mbeki Building Private Bag X 54001

Durban 4000

KwaZulu-Natal, South Africa

Tel: 27 31 2604769

Fax: 27 31 2604609

Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

Isifinyezo semimpumelo (maselesistadi sesiphelile) sizothunyelwa kuwe. Uyacelwa ukuthi usinikeze i-email address noma ikheli lakho oposelwa kulo lapho isifinyezo sizothunyelwa ku

E-mail Address: \_\_\_\_\_

Postal Address: \_\_\_\_\_

\_\_\_\_\_  
Isignesha se participant

\_\_\_\_\_  
Usuku

\_\_\_\_\_  
Isignesha se fakazayo (i-witness)

\_\_\_\_\_  
Usuku

\_\_\_\_\_  
Isignesha sotolikayo (lapho ekufanele)

\_\_\_\_\_  
Usuku

<b>Appendix G: Interview schedule (English)</b>
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## CAREGIVERS' EXPECTATIONS FOR THEIR NON-VERBAL CHILDREN WITH ASD IN RURAL KZN

### INTERVIEW SCHEDULE

<b>Participant:</b>	<b>Date:</b>
<b>Hospital:</b>	<b>Participant code:</b>
<b>Age:</b>	<b>Interviewer:</b>
<b>Age of child:</b>	<b>Time and length of interview:</b>
<b>Employment status:</b>	<b>Date of diagnosis:</b>
<b>Non-verbal status:</b>	<b>Interpreter:</b>

### Introduction

Hello, my name is Fatima Haffejee. I will be asking you some questions today. This is \_\_\_\_\_ and she will be translating into isiZulu. I am not the therapist at this hospital so I will not be able to help with therapy. Should you have any questions about \_\_\_\_\_'s therapy you may ask the therapist/ social worker, I will be happy to give you the details.

### General

1. Tell me what you understand about ASD, OR what you understand by \_\_\_\_\_'s behaviours and limited speech (depends on client response)

Probe: What is Autism?

2. Can you tell me about how you found out that your child has ASD

Probe: Did you get a diagnosis for \_\_\_\_\_

3. Tell me about where you live and about your house.
4. Tell me about your life at home.
5. Tell me about schooling/if \_\_\_\_\_ attends school.
6. Tell me about your other children.
7. Tell me about yourself (age, what your day is like, etc)

### **Experiences raising a child with ASD**

8. Tell me about your experience raising \_\_\_\_\_.
9. Tell me how you felt when \_\_\_\_\_ was diagnosed with ASD.

Probe: What did the doctor tell you about \_\_\_\_\_

Probe: How did you feel about what the doctor told you regarding \_\_\_\_\_

10. Tell me about your expectations of \_\_\_\_\_ at the time of his/her diagnosis.
11. Tell me about your experiences regarding finance and raising a child with ASD.

If the has any queries pertaining to a grant, the interviewer will state the following:  
I am not a therapist at the hospital and therefore will not be able to help you regarding a grant, I am more than happy to provide you with the details of the therapist/social worker who can answer any questions you may have regarding this.

12. Tell me about how you manage your time with other aspects of your life and a child with ASD.

Probe: Tell me about a day in your life

### **Communication**

13. Tell me about how \_\_\_\_\_ communicates.

Probe: Tell me about how much does \_\_\_\_\_ understand when you speak to him/her?

Probe: Does \_\_\_\_\_ use gestures, words or sounds to communicate?

14. Tell me about what you expect for \_\_\_\_\_ in terms of communication.
15. Tell me about how your expectations for \_\_\_\_\_'s communication has changed since their diagnosis.



Probe: Has your expectations changed since the doctor told you that \_\_\_\_\_ has ASD? (how)

### **Expectations regarding Education**

16. Tell me about schooling for \_\_\_\_\_.

Probe: How easy/ difficult is it to find a school.

17. Tell me about the type of schooling you access for \_\_\_\_\_.

Probe: Do you access a creche, a special school or a mainstream school

18. Tell me what you expect \_\_\_\_\_ to achieve from schooling currently.

Probe: Tell me about what you expect from \_\_\_\_\_ regarding reading and writing.

19. Tell me about your future expectations regarding schooling for \_\_\_\_\_.

### **Social Participation**

20. Tell me about \_\_\_\_\_ 's friends.

21. Tell me about what you expect from \_\_\_\_\_ socially.

Probe: What do you expect regarding making friends, having relationships etc.

### **Employment**

22. Tell me about what you expect for \_\_\_\_\_ regarding employment.

Probe: Tell me about what you expect for \_\_\_\_\_ regarding work in the future.

Probe: Can you tell me about what kind of job you expect \_\_\_\_\_ to have

### **Expectations regarding therapy**

23. Tell me about the therapy that \_\_\_\_\_ receives.

Probe: i.e. speech therapy, occupational therapy and physical therapy

Probe: What do you understand by therapy?

24. Tell me about how you feel about the therapy that \_\_\_\_\_ receives.

25. Tell me about what you expect from therapy.

26. Tell me about the information received regarding therapy.

27. Tell me about the expectations that you have of healthcare professionals involved in your child's care
28. Tell me about your expectations of therapy now as compared to when you began.

### **Expectations regarding ASD and Societal responses**

29. Tell me about your community.
30. Tell me about how your family/ community responds to \_\_\_\_\_.
31. Tell me about what your community expects of \_\_\_\_\_.
32. Tell me about how people respond to you and \_\_\_\_\_ in public.
33. In comparison to other children in the family and in your community, how do you view \_\_\_\_\_

Probe: Tell me about how you feel about your child having ASD.

### **General Expectations**

34. Tell me about how your expectations changed over time.
- Probe: from pre-diagnosis, to just after the diagnosis to now.
35. Tell me about the hopes you have for your child.

Thank you again for participating in this study. I will be paying for your transportation today to say thank you as you came in to see me for the research.

<b>Appendix H: Interview schedule (isiZulu)</b>
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**CAREGIVER'S EXPECTATIONS FOR THEIR NON-VERBAL CHILDREN WITH  
ASD IN RURAL KZN**

**INTERVIEW SCHEDULE**

<b>Participant:</b>	<b>Date:</b>
<b>Hospital:</b>	<b>Participant code:</b>
<b>Age:</b>	<b>Interviewer:</b>
<b>Age of child:</b>	<b>Time and length of interview:</b>
<b>Employment status:</b>	<b>Date of diagnosis:</b>
<b>Non-verbal status:</b>	<b>Interpreter:</b>

Sanibonani, igama lami nguFatima Haffejee. Ngizobe nginibuza imibuzo namhlanje. Lona ngu\_\_\_\_\_nguyena ozobe esitolikela ngolimi lwesiZulu. Angisiye umelaphi kulesi sibhedlela ngakho angeke ngikwazi ukusiza ngokwelapha. Uma kwenzeka niba nemibuzo mayelana nokwelapha kuka \_\_\_\_\_ ningabuza umelaphi noma usonhlala kahle, kuzongithokozisa ukuninika yonke imininingwane.

**Jikelele**

1. Ngichazele kabanzi ngokukwaziyo mayelana ne-ASD, okanye yini oyiqondayo ngokuziphatha kuka\_\_\_\_\_ Limited Speech (kuzoya ngempendulo yeklayenti)  
Tholisisa: Yini i-Autism?
2. Ungangazisa kabanzi ukuthi wathola kanjani ukuthi ingane yakho ine-ASD  
Tholisisa: Wakuthola yini ukuxilongwa u\_\_\_\_\_
3. Ngazise kabanzi ngendawo enihlala kuyona nangomuzi wakho.
4. Ngazise ngempilo eniyiphilayo ekhaya.
5. Ngazise ngesikole u\_\_\_\_\_ afunda kuso.
6. Ngixoxele ngezinye izingane onazo.
7. Ngixoxele ngawe (Iminyaka yakho, suku lwakho luhamba kanjani, njalo njalo)

**Ukubhekana nokukhulisa ingane ene-ASD**

8. Ngazise ngosuke wabhekana nakho ekukhuliseni u\_\_\_\_\_.
9. Ngazise ngokuthi wazizwa kanjani ngenkathi u\_\_\_\_\_ esexilongwe watholwa ukuthi une-ASD.  
Tholisisa: Udokotela wathini kuwe mayelana no\_\_\_\_\_.  
Tholisisa: Waphatheka kanjani ngalokhu udokotela akutshela khona mayelana no\_\_\_\_\_.
10. Ngazise ngowawukulindele ku\_\_\_\_\_ ngesikhathi athola ngaso ukuxilongwa.
11. Ngazise kabanzi nesimo owabhekana naso mayelana nezezimali nokukhulisa ingane ene-ASD.

Uma iklayenti lineminye imibuzo mayela nesinxephezelo, umuntu obexoxisana naye uzosho okulandelayo: Angisiye umelaphi wakulesi sibhedlela ngakho angeke ngikwazi ukukusiza mayelana nesinxephezelo. Ngingakuthokozela ukukunika

imininingwane yomelaphi noma usonhlala kahle ongaphendula noma yimiphi imibuzo onayo mayelana nalokhu.

12. Ngazise ngendlela ophatha ngayo isikhathi sakho kwezinye izingxenye zempilo yakho kanye nengane ene-ASD.

Tholisisa: Ngazise ngosuku olujwayelekile empilweni yakho

### **Ukuxhumana**

13. Ngazise ngendlela yokuxhumana esebenziswa u\_\_\_\_\_.

Tholisisa: Ngazise ngokuthi u\_\_\_\_\_ uqondisisa kangakanani uma ukhuluma naye?

Tholisisa: U\_\_\_\_\_ uyawasebenzisa izandla, amagama kanye nemisindo njengendlela yokuxhumana?

14. Ngazise ngosuke ukulindele ku\_\_\_\_\_ mayelana nendlela yakhe yokuxhumana.

15. Ngazise ngendlela okushintshe ngayo obukulindele mayelana nendlela yokuxhumana kuka\_\_\_\_\_ emva kokuxilongwa kwakhe.

Tholisisa: Ngabe obukulindele sekwashintsha emva kokwaziswa ngudokotela ukuthi u\_\_\_\_\_ une-ASD? (kanjani)

### **Okulindelekile mayelana nemfundo**

16. Ngazise ngokufunda kuka\_\_\_\_\_.

Tholisisa: Kulula noma kunzima kangakanani ukuthola isikole.

17. Ngazise ngohlobo lwemfundo ulutholayo luka\_\_\_\_\_.

Tholisisa: Uyakwazi ukuthola i-creche, isikole sabakhethekile okanye isikole esijwayelekile.

18. Ngazise ngolindele ukuthi kuzuzwe u\_\_\_\_\_ ekufundeni okwamanje.

Tholisisa: Ngazise ngokulinde ku\_\_\_\_\_ mayelana nokufunda kanye nokubhala.

19. Ngazise ngokulindele mayelane nekusasa lemfundo ka\_\_\_\_\_.

### **Ukubamba iqhaza kwezenhlalo**

20. Ngazise ngabangani baka\_\_\_\_\_.

21. Ngazise ngokulindele ku\_\_\_\_\_ ngakwezenhlalo.

Tholisisa: Ulindeleni mayelana nokwenza kwakhe abangani, ukwakha ubudlelwano, njalo njalo.

### **Umsebenzi**

22. Ngazise ngokulindele ku\_\_\_\_\_ mayelana nomsebenzi.

Tholisisa: Ngazise ngokulindele ku\_\_\_\_\_ mayelana nekusasa lakhe ekusebenzeni.

Tholisisa: Ngazise ngomsebenzi olindele ukuthi u\_\_\_\_\_ abenawo.

### **Okulindelwe mayelana nokwelashwa**

23. Ngazise ngokwelashwa okwatholwa u\_\_\_\_\_.

Tholisisa: Speech therapy, occupational therapy and physical therapy.

Tholisisa: Yikuphi okwaziyo ngokwelashwa phecelezi therapy?

24. Ngazise ngendlela ozizwa ngayo mayelana nokwelashwa okutholwa u\_\_\_\_\_.

25. Ngazise ngokulindele ekwelashweni.

26. Ngazise ngolwazi owaluthola mayelana nokwelashwa phecelezi therapy.

27. Ngazise ngokulindele kubasebenzi bezempilo ababhekene nempilo yengane yakho.

28. Ngazise ngokulindele ekwelashweni phecelezi therapy, manje uma uqhathanisa nasekuqaleni.

### **Okulindelwe mayelana ne-ASD kanye ne Societal responses**

29. Ngazise ngomphakathi ohlala kuwo.

30. Ngazise ngendlela umphakathi kanye nomndeni omphatha ngayo u\_\_\_\_\_.

31. Ngazise ukuthi umphakathi ulindele ini ku\_\_\_\_\_.

32. Ngazise ngendlela abantu abaniphatha ngayo ngaphandle wena kanye no\_\_\_\_\_.

33. Uma uqhathanisa nezinye izingane emndenini kanye nasemphakathini, umbuka kanjani u\_\_\_\_\_.

Tholisisa: Ngazise ukuthi uzizwa kanjani ngokuthi ingane yakho ine-ASD.

### **Okulindelwe jikelele**

34. Ngazise ngokuthi obukulindele kushintshe kanjani ngokuhamba kwesikhathi.

Tholisisa: Ngaphambi koxilongo, nasemva koxilongo kuze kube manje.

35. Ngazise ngezifiso onazo ngengane yakho.

Ngiyabonga futhi ngokubamba iqhaza kulolucwaningo. Ngizozikhokhela izindleko zokugibela kwenu kwanamuhla njengendlela yokudlulisa ukubonga njengoba nizile nazoba ingxenye yalolucwaningo.

## Appendix I: Biomedical Research Ethics Committee (BREC) approval letter



07 October 2019

Miss Fatima Haffjee (214541910)  
School Of Health Sciences  
Westville Campus

Dear Miss Fatima Haffjee,

Protocol reference number: BREC/00000096/2019

Project title: Caregivers expectations of their non-verbal child with Autism Spectrum Disorder in rural KwaZulu-Natal

Degree: Masters

### EXPEDITED APPLICATION: APPROVAL LETTER

A sub-committee of the Biomedical Research Ethics Committee has considered and noted your application.

The conditions have been met and the study is given full ethics approval and may begin as from 07 October 2019. Please ensure that outstanding site permissions are obtained and forwarded to BREC for approval before commencing research at a site.

This approval is valid for one year from 07 October 2019. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The sub-committee's decision will be noted by a full Committee at its next meeting taking place on 12 November 2019.

Yours sincerely

Prof V Rambiritch (Chair)

Biomedical Research Ethics Committee  
Prof V Rambiritch (Chair)  
UKZN Research Ethics Office Westville Campus, Govan Mbeki Building  
Postal Address: Private Bag X54001, Durban 4000  
Website: <http://research.ukzn.ac.za/Research-Ethics/>

Founding Campuses: Edgewood Howard College Medical School Pietermaritzburg Westville

INSPIRING GREATNESS



**Appendix J: KZN Health Research Department approval****health**Department:  
Health  
PROVINCE OF KWAZULU-NATAL

DIRECTORATE: NCD- DISABILITY &amp; REHABILITATION

330 Langalibalele Street  
Pietermaritzburg, 3201  
Tel: 033 395 2927 Fax: 033 395 2795 Email: daniel.simbe@kznhealth.gov.za  
www.kznhealth.gov.za

Date: 30 September 2019

Ms. Fatima Haffeejee  
University of KwaZulu-Natal  
Westville Campus  
Durban

Dear Ms. Fatima Haffeejee,

**RE: PERMISSION TO CONDUCT RESEARCH IN UMGUNGUNDLOVU, ILEMBE, UTHUKELA, ZULULAND, UGU, UTHUNGULU AND AMAJUBA DISTRICTS –KZN DOH**

I have pleasure in informing you that permission has been granted to you by the Disability and Rehabilitation Programme to conduct research on "Caregiver's expectations for their non-verbal children who present with Autism Spectrum Disorder (ASD) in rural KwaZulu-Natal" in the Health Districts of KwaZulu-Natal.


Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received approval of your study from the Provincial Health Research and Ethics Committee (PHREC) in the KZN Department of Health.
3. Please ensure this office is informed before you commence your research.
4. The Disability and Rehabilitation Programme will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to the Disability and Rehabilitation Programme in the Department of Health KwaZulu-Natal
6. You are required to contact this office regarding dates for providing feedback when the research has been completed.

Thank you:

  
MR. D. SIMBEYE  
ACTING DEPUTY DIRECTOR:  
DISABILITY AND REHABILITATION

## Appendix K: Approval Letter from KZN Department of Health



**health**

Department:  
Health  
PROVINCE OF KWAZULU-NATAL

Physical Address: 339 Langenhedde Street, Pietermaritzburg  
Postal Address: Private Bag X9051  
Tel: 033 395 3189/ 3189/ 3123 Fax: 033 394 3782  
Email: [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za)  
[www.kznhealth.gov.za](http://www.kznhealth.gov.za)

**DIRECTORATE:**  
Health Research & Knowledge  
Management

**Ref: KZ\_201910\_004**

Dear Ms F Haffejee  
(UKZN)

**Subject: Approval of a Research Proposal:**

- The research proposal titled 'Caregivers' Expectations of their Non-Verbal Child who presents with Autism Spectrum Disorder in Rural KwaZulu-Natal' was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).  
  
The proposal is hereby **approved** for research to be undertaken at the selected facilities at KZN-DoH.
- You are requested to take note of the following:
  - Kindly liaise with the facility manager **BEFORE** your research begins in order to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.
  - Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.
  - Provide an interim progress report and final report (electronic and hard copies) when your research is complete.
- Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za)

For any additional information please contact Ms G Khumalo on 033-395 3189.

Yours Sincerely

**Dr E Lutge**  
Chairperson, Health Research Committee

Date: 21/10/19

**Appendix L: List of social workers and psychologists in public health per district**

<b><u>District</u></b>	<b><u>Social worker</u></b>	<b><u>Psychology</u></b>
<u>Ilembe</u>	<u>032 437 6000</u>	<u>032 437 6000</u>
<u>Amajuba</u>	<u>034 328 2500</u>	<u>034 328 2488</u>
<u>Ugu</u>	<u>039 687 1195</u>	-
<u>uMgungundlovu</u>	<u>033 395 4188</u>	<u>033 395 4788</u>

### Appendix M: Ethics certificates







