

**The impact of the presence of a full-time live-in caregiver on the parents of a child diagnosed with Autism Spectrum Disorder**

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The impact of a full-time live-in caregiver on the parents of a child diagnosed with ASD

### **Declaration**

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work. I declare that I am the author thereof and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Karla Pretorius

March 2020

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Full name

Date

## The impact of a full-time live-in caregiver on the parents of a child diagnosed with ASD

### Summary

Autism Spectrum Disorder (ASD) is a developmental disorder that affects 1 out of 59 children as well as their families across the world. Parents of children diagnosed with ASD have reported various challenges in the search for appropriate support services. These challenges range from a lack of information about the availability of various support services to a paucity of respite from trained professionals. The lack of respite that parents report has a negative impact on the functioning of the family and might lead to demands on resources, such as difficulties in sustaining a successful marriage or partnership due to an increase in stress.

Having a full-time live-in caregiver is an example of support and respite that may address the challenges, and ultimately demands, on resources that parents with children diagnosed with ASD report, but there is a paucity of research about this. The aim of this study was therefore to explore the experiences of parents with a child diagnosed with ASD who have employed a full-time live-in caregiver. The focus was on the capabilities and demands that parents experienced related to having a full-time caregiver. The study was qualitative and exploratory in nature. The researcher conducted semi-structured interviews with individual parents (participants). The semi-structured interviews included specific questions related to the experience of having a child diagnosed with ASD. The interview questions also provided an opportunity for each participant to elaborate on their answers or experiences. A total of 11 participants were interviewed that were all clients of AG, which is a pseudonym for the organisation that formed part of this study. A total of 11 participants were interviewed for the current study. The responses were thematically analysed and the themes that were identified through the thematic analysis were conceptualised according to McCubbin and Patterson's (1983) Family Adjustment and Adaptation Response (FAAR) model.

Four main themes were identified through the process of thematic analysis, namely: (1) the experience of the parents (from diagnosis to finding a suitable live-in caregiver), (2) their family functioning, (3) social interaction and independence, as well as (4) support services currently available for their child, diagnosed with ASD. The findings of this study suggest that although participants experience various challenges during the period of needing more support, they were able to utilise the capabilities that a full-time live-in caregiver offered to decrease demands. An overarching theme that emerged throughout the process of data analysis was the value that the consistency of having a full-time live-in caregiver in various environments added to the experience of the participants. The value of this

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consistency was evident in particular through the generalisation of skills and strategies from one environment to another.

This study provides a point of departure for future studies to further investigate the effects of full-time caregiving services to the families of children diagnosed with ASD. It is possible that these findings might increase the awareness of the value related to employing a full-time live-in caregiver that might be required for parents and their children diagnosed with ASD.

Keywords: Autism Spectrum Disorder, full-time live-in caregiver, capabilities and demands

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### Opsomming

Autism Spectrum Disorder (ASD) is 'n ontwikkelingsversteuring wat 1 uit 59 kinders sowel as hul families regoor die wêreld aantast. Ouers van kinders wat met ASD gediagnoseer is, het verskeie uitdagings gerapporteer in die soeke na toepaslike ondersteuningsdienste. Hierdie uitdagings wissel van 'n gebrek aan inligting oor die beskikbaarheid van verskillende ondersteuningsdienste, tot 'n gebrek aan respirasie van opgeleide professionele persone. As gevolg van 'n gebrek aan verligting deur ouers, het dit 'n negatiewe impak op die gesin se funksionering en dit kan lei tot eise aan hulpbronne, soos probleme om 'n suksesvolle huwelik of 'n vennootskap te onderhou as gevolg van 'n toename in spanning.

Om 'n voltydse inwonende versorger te hê, is 'n voorbeeld van ondersteuning en verligting wat die uitdagings en uiteindelik eise kan aanpak oor hulpbronne wat ouers met kinders wat met ASD gediagnoseer is, maar daar is nog min navorsing hieroor. Die doel van hierdie studie was dus om die ervarings van ouers met 'n ASD-gediagnoseerde kind te ondersoek wat 'n voltydse inwonende versorger het. Die fokus was op die vermoëns en eise wat ouers ervaar met betrekking tot 'n voltydse versorger. Die studie was kwalitatief en verkennend van aard. Die navorser het semi-gestruktureerde onderhoude met individuele ouers (deelnemers) gevoer. Die semi-gestruktureerde onderhoude bevat spesifieke vrae wat verband hou met die ervaring van die diagnose van 'n kind met ASD. Die onderhoudsvrae het ook aan elke deelnemer die geleentheid gebied om hul antwoorde of ervarings uit te brei. Daar is onderhoude met 11 deelnemers gevoer wat almal kliënte van AG was, wat 'n skuilnaam is vir die organisasie wat deel vorm van hierdie studie. Die onderhoude is tematies ontleed en die temas wat deur die tematiese analise geïdentifiseer is, is gekonseptualiseer volgens McCubbin en Patterson (1983) se familieaanpassing en aanpassingsrespons (FAAR) model.

Vier hooftemas is geïdentifiseer deur middel van die tematiese ontleding, naamlik: (1) die ervaring van die ouers (van diagnose tot die vind van 'n geskikte inwonende versorger), (2) hul gesinsfunksionering, (3) sosiale interaksie en onafhanklikheid, sowel as (4) ondersteuningsdienste wat tans beskikbaar is vir hul kind, gediagnoseer met ASD. Die bevindinge van hierdie studie dui daarop dat alhoewel deelnemers verskillende uitdagings ervaar gedurende die periode waarin hulle meer ondersteuning nodig het, hulle die vaardighede kon benut wat 'n voltydse inwonende versorger aangebied het om eise te verlaag. 'n Oorkoepelende tema wat tydens die proses van data-ontleding na vore gekom het, was die waarde dat die konsekwentheid van 'n voltydse inwonende versorger in verskillende omgewings tot die ervaring van die deelnemers toegevoeg het. Die waarde van hierdie

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konsekwentheid blyk veral deur die veralgemening van vaardighede en strategieë van een omgewing na 'n ander.

Hierdie studie bied 'n vertrekpunt vir toekomstige studies om die gevolge van voltydse versorgingsdienste verder te ondersoek vir die gesinne van kinders wat met ASD gediagnoseer is. Dit is moontlik dat hierdie bevindinge die bewustheid van die waarde wat verband hou met die gebruik van 'n voltydse inwonende versorger kan verhoog wat nodig is vir ouers en hul kinders wat met ASD gediagnoseer is.

Sleutelwoorde: outisme spektrum versteuring, voltydse inwonende versorger, vermoëns en eise

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### Chapter 1: Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that affects people of all races, socio-economic sectors as well as genders throughout their lifespan (American Psychiatric Publishing, 2015; Park et al., 2016). According to the latest Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), an ASD diagnosis includes challenges with two areas of development: (1) social communication and social interaction as well as (2) restricted or repetitive behaviours. The Center for Disease Control and Prevention (2014) states that 1 out of every 59 children is diagnosed with ASD and confirms that the prevalence of ASD diagnoses are increasing (American Psychiatric Association, 2013).

While the rise of ASD diagnoses affects the children receiving the diagnosis of ASD, it also impacts the family members of this child. Parents of children diagnosed with ASD have reported an increase in the level of stress they experience in several areas of their family life and reported needing support (Bluth, Robertson, Billen, & Sams, 2013; Fewster & Gurayah, 2015; Ooi et al., 2016; Padden & James, 2017). Various studies have examined the challenges parents experience when a child is diagnosed with ASD (Bluth et al., 2013; Fewster & Gurayah, 2015; Hodgetts, Zwaigenbaum, & Nicholas, 2015). These challenges include, but are not limited to, the initial diagnosis process, including the time it takes to receive a diagnosis, trusting the pediatrician to provide appropriate recommendations of support services as well as being able to afford the specific support services that are utilised (Bluth et al., 2013; Fewster & Gurayah, 2015; Hodgetts et al., 2015). Many other challenges have been reported by parents, including generalising skills learned in one therapeutic environment to another or to the home environment, the need for respite for parents and the need for more options of inclusive schools (Dionne & Martini, 2011).

The majority of studies that have examined parental stressors with a child diagnosed with ASD have focused on short-term therapy options that are mainly located outside of the family's home (DeFilippis & Wagner, 2016; Hoefman et al., 2014; Paul, 2009). These studies typically reported the effects of a variety of therapists that work with different children on an inconsistent basis (1–2 hours per day) (Hoefman et al., 2014). According to the latest diagnostic criteria listed in the DSM-5, children diagnosed with ASD often struggle with a change of routine or structure as part of their restrictive or repetitive behavioural patterns (American Psychiatric Publishing, 2015). This change of routine or structure might, for example, refer to a change in therapist in a child's daily schedule or the change from one type of support system to another. Parents usually include a variety of different support systems in their child's programme, such as Occupational therapy, Speech therapy and Applied Behavioural Analysis

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therapy, which will all be discussed in Chapter 2 (Baird, Cass, & Slonims, 2003; Park et al., 2016). Different therapists and therapeutic settings might suggest that changes in routine and structure occur on a daily basis in the lives of children that do not deal well with these kinds of changes.

Another well-documented unmet need of parents with children diagnosed with ASD is the need for more respite by qualified individuals (Baird et al., 2003). Parents have reported that the need for respite might motivate them to increase therapy sessions. This inclusion of various professionals into their child's programme might then lead the child to acquiring different skills, but these skills are not necessarily generalised to environments beyond the therapy room (Berkell, Cihak, & Stone-MacDonald, 2017). According to Berkell et al. (2017), the lack of generalisation from one environment to another leads to an increase in stress for families.

Research indicates that an increase in stress for parents with children diagnosed with ASD can lead to dissatisfaction in their marriage and ultimately increase the likelihood of divorcing their partners (Harper, Dyches, Harper, Olsen, & South, 2013). A study conducted by Harper et al. (2013) further illustrates that parents receiving more respite show an increase in the quality of their marriage. There is limited research available on the capabilities and demands related to a full-time caregiver for children diagnosed with ASD and their families that live with the family. According to Harper et al. (2013), an increase in respite alleviates some of the stress parents experience with a child diagnosed with ASD. This research indicates the necessity for parents to receive more support services that are equipped to generalise skills learned from one environment to another offering needed respite to parents in the process. The primary aim of this study was therefore to investigate the capabilities and demands parents experience employing a full-time live-in caregiver to support their child diagnosed with ASD.

### **1.1 Definition of key terminology**

#### **1.1.1 Autism Spectrum Disorder**

ASD is a lifelong neurodevelopmental disorder that affects the way in which an individual communicates and interacts with others (Park et al., 2016). The symptoms of ASD range across the spectrum, with some individuals exhibiting areas that might need less and others that need more support (Anagnostou et al., 2014). Characteristic features of individuals diagnosed with ASD include social communication and interaction as well as a behavioural component (American Psychiatric Publishing, 2015).

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### **1.1.2 Full-time live-in caregiver**

A full-time live-in caregiver can be defined as a person who looks after a child diagnosed with ASD on a full-time basis and lives with the family (Hodgetts et al., 2015). A caregiver in this study is defined as a paid individual that is employed by the family and lives with the family on a full-time basis. The full-time live-in caregiver works for the child diagnosed with ASD for seven to eight hours per day, five days a week.

### **1.1.3 Capabilities**

According to the FAAR model (McCubbin & Patterson, 1983), families possess the ability to utilise their resources (capabilities) to adjust and adapt to specific situations that might be experienced as stressful events or a crisis. In the current study, the capabilities are reported from parents' experience of utilising the support services of a full-time live-in caregiver.

### **1.1.4 Demands**

McCubbin and Patterson (1983) explain that families experience various stressors. During these stressful events, demands can be defined as a situation or person that places demands on the resources of the family. In the current study, the demands are reported by parents who have a child diagnosed with ASD.

## **1.2 Outline of the chapters**

Chapter 2 will provide a review of the current literature in relation to the experiences of parents with a child diagnosed with ASD. This literature will include an overview of the current challenges that parents experience as well as a general overview of ASD, its clinical picture, aetiology, prevalence and diagnosis and treatment. This will be followed by a discussion on the current literature on the need for respite and support for parents with a child diagnosed with ASD. The chapter will conclude with a description of the theoretical framework that was utilised to conceptualise the findings of the current study.

Chapter 3 will outline the research methodology that was utilised in the current study. This will include a discussion of the rationale, research question, the aims and objectives that were used and followed by the research design. The participants of the current study are described thereafter as well as the data collection and analysis. The chapter concludes with the ethical considerations that were incorporated in the current study.

In Chapter 4, the key findings of the current study will be presented. The main themes, as well as the sub-themes that were identified through thematic analysis, will be explained and

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presented here. These themes were identified through thematic analysis of the semi-structured interviews.

Chapter 5 will consist of a discussion of the key findings combined with appropriate literature. This chapter will also include the theoretical framework of the FAAR model (McCubbin & Patterson, 1983) to incorporate and explain the themes and sub-themes that were identified. The limitations of the current study, as well as recommendations for future studies, will conclude this chapter.

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## Chapter 2: Literature Review

This chapter provides background on Autism Spectrum Disorder (ASD), the diagnosis process, the increase of the diagnosis, current available services as well as parental stress related to the diagnosis. It serves as a point of departure for the current study by reviewing the current services offered to children diagnosed with ASD and highlighting the current challenges parents of children diagnosed with ASD experience.

### 2.1 Autism Spectrum Disorder (ASD) defined

Autism Spectrum Disorder (ASD) can be defined as a “set of neurodevelopmental disorders characterised by a lack of social interaction, verbal and nonverbal communication in the first 3 years of life. The distinctive social behaviours include an avoidance of eye contact, problems with emotional control or understanding the emotions of others, and a markedly restricted range of activities and interests” (Park et al., 2016, p. 1226). According to the latest Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), the term ASD is adopted with a dyadic description of core symptoms: early-onset of difficulties in communication and social interaction, and repetitive, restricted behaviours, activities, or interests (American Psychiatric Publishing, 2015).

The latest DSM states that for a person to be diagnosed with ASD, individuals must have deficits in two groups of characteristics: (1) social communication and social interaction as well as (2) restricted, repetitive patterns of behaviour. Individuals must have a social communication deficit, past or present in multiple contexts, in each of the following areas defined:

1. Deficits in social-emotional reciprocity, which can be defined as irregular social approaches and a failure or lack of normal reciprocal conversation or a reduced sharing of interests, affect or emotion with others.
2. Deficits in non-verbal communicative behaviours, such as irregular or absent of consistent eye-contact, body language or deficits in using and understanding gestures. This indicates a poorly integrated verbal and non-verbal communicative intent.
3. Deficits in developing, understanding and maintaining relationships. This includes adjusting their behaviour to suit various social contexts. It also includes difficulty in making friends and sharing imaginative play ideas.

Individuals must also present with at least two of the following four restricted and repetitive behavioural patterns:

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1. Stereotypical or repetitive motor movements, speech or use of objects, such as simple motor stereotypies, lining up of items or flipping objects.
2. An insistence on sameness and fixed routines or ritualised patterns of verbal and non-verbal behaviour. This includes extreme distress at small changes, difficulties with transitions or rigid thinking patterns.
3. Highly restricted and fixated interests that are abnormal in focus or intensity, which might include unusual objects.
4. Hyperactivity or hypoactivity to sensory input or an unusual interest in sensory aspects of the environment, such as an apparent indifference to pain or temperature or an adverse response to specific sounds, textures or visual input.

“Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life). Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum and intellectual disability, social communication should be below that expected for general developmental level.” (American Psychiatric Publishing, 2015, p. 788).

It should also be noted that all diagnoses of autism fall under the umbrella term “Autism Spectrum Disorder”, which includes Pervasive Developmental Disorders not otherwise specified (PDD-NOS), autistic disorder, Asperger’s syndrome and childhood disintegrative disorder. According to Anagnostou et al. (2014, p. 514), the classifications of all these disorders into an omnibus category shows the “continuum from mild to severe rather than qualitatively distinct disorders”.

The clinical features of ASD have been studied and explained as a deficit in social interaction, social communication and restricted or repetitive behavioural patterns (Masi, DeMayo, Glozier & Guastella (2017). The necessary levels of support determine the specific severity of the classification of ASD in children diagnosed with this disorder (APA, 2013). According to Masi, et al. (2017), determining an ASD diagnosis according to the level of support needed can lead to inconsistencies in prevalence rates, prognosis and support offered. ASDs are “complex, pervasive and multifactorial neurodevelopmental conditions” that are still



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being researched to determine more precise descriptions of aetiology and clinical features (Masi et al., 2017, p. 138).

## **2.2 Etiology**

ASD is now “broadly considered to be a multi-factorial disorder resulting from genetic and non-genetic risk factors and their interaction”, rather than a single disorder (Park et al., 2016, p. 1227). There has been a considerable increase in research studies conducted on the aetiology, treatment options and prognosis of an individual diagnosed with ASD in the last two decades (Murphy et al., 2016). The general consensus is that there have been considerable gains made in terms of our understanding of ASD, the genetic factors through twin-studies as well as environmental factors, but that more focused research is needed to establish an accurate understanding of the treatment protocol and health service delivery for children and adults diagnosed with ASD (Murphy et al., 2016).

## **2.3 Prevalence**

It is widely accepted that the prevalence of ASD has increased in the last twenty years, since it was first diagnosed in 1980 (Park et al., 2016). The increase of diagnoses can be due to a variety of reasons, such as changes to the diagnostic description, an increase of autism services and thus a general awareness of ASD, as well as a common belief of an actual increase in individuals that receive an ASD diagnosis (Baird et al., 2003; DeFilippis & Wagner, 2016; Nassar et al., 2009). According to Baird et al. (2003), changes to the diagnostic description by identifying ASD as a spectrum rather than a primary categorical condition is one of the main reasons for the increase in diagnoses. It is argued that this change to the diagnostic description has increased the diagnosis of ASD to a wider variety population of children, who might not have been diagnosed with ASD in the earlier years (DeFilippis & Wagner, 2016). King and Bearman (2009) highlight that the increase in ASD diagnoses correlated directly to the decrease of diagnoses of Intellectual Disability (ID), which eludes that with more awareness of ASD, more individuals are diagnosed with ASD instead of other disorders or disabilities.

According to Neggers (2014), clinicians diagnose children with ASD following a brief observation, but not clinical testing conducted. Neggers (2014) added that inaccurate diagnosis combined with the lack of appropriate ASD support services in some regions would lead to an increase in the diagnosis of ASD. An increase in autism services has led to children being diagnosed at a younger age, which also leads to an increase in the diagnosis of ASD (Nassar et al., 2009). Although Neggers (2014) warns clinicians that developmental regression in children

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diagnosed with ASD (after the age of three years old) is not taken into consideration in some studies and thus reveals inaccurate prevalence statistics. Developmental regression occurs in about one third of children diagnosed with ASD, according to Al Backer (2015), when children start losing developmental skills, previously acquired, during the preschool years. According to Al Backer (2015), these skills usually include expressive speech, but can also include play skills, nonverbal communication and social skills.

Neggers (2014) adds environmental contributions as well as cultural factors as reasons for the increase in the diagnosis. An actual increase in the disorder cannot be excluded (Nassar et al., 2009). The general consensus of the definite rise of ASD diagnoses cannot, however, be attributed to any single factor and thus is still, for the most part, unexplained (Hertz-Picciotto & Delwiche, 2009).

Although the rise of ASD diagnoses is still a controversial issue, it is agreed upon by professionals that the increase stresses the need for more support services for families on a global scale (Baird et al., 2003). Although it is mentioned that more support services for children diagnosed with ASD can be one of the reasons for the increase in ASD diagnoses (Nassar et al., 2009), the need for more affordable, child-specific and flexible programmes still exists (Baird et al., 2003). Parents of children diagnosed with ASD need more detailed support service information, faster response rate of professionals involved for queries relating to their children and guidance through the process of an autism diagnosis, prognosis, treatment plan and management of their child's programme (Baird et al., 2003).

Due to changing classifications of ASD diagnoses and the rapid increase in the number of children being diagnosed with ASD, it is crucial that therapeutic modalities evolve with the increase in understanding of the complexity of this disorder (Constantino & Charman, 2016). Statistical data regarding autism prevalence, according to the Center for Disease Control and Prevention (CDC) (2012), states that one out of every 68 children is diagnosed with ASD. This considerable increase from the year 2000 of one out of every 150 children is another reason for an emphasis of successful therapeutic modalities and support currently offered and the need for continuous evolving care (CDC, 2012).

### **2.4 Diagnosis and treatment**

A pediatrician typically assesses a child once parents notice there are some milestones that their child has missed or reached later than their neurologically typical or "neurotypical" peers (individuals who do not have a diagnosis of ASD) (Jordan & Caldwell-Harris, 2012). The diagnostic process of receiving a diagnosis of autism for a child can take time according

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to Richards, Mossey, and Robins (2016). Parents are generally concerned years before they receive a diagnosis for their child. Access to resources, such as financial means, accessibility, and cultural beliefs of each family plays a role in receiving the appropriate care for the child, once diagnosed (Anagnostou et al., 2014).

Bluth et al. (2013) mention that the diagnostic process can be particularly stressful for parents. The diagnosis of a child with ASD is generally a much lengthier process than receiving a diagnosis of other delays, such as Down syndrome for example (Bluth et al., 2013). According to Crane et al. (2018), the length of receiving a diagnosis is extremely stressful for parents as it is a time of uncertainty and of losing previous aspirations for their child.

Once the pediatrician has diagnosed a child with an ASD, parents are referred to a variety of services, including speech-, occupational-, and/or behavioural therapy as well as suggestions for a specific schooling system (Baird et al., 2003; Park et al., 2016). According to Hodgetts et al. (2015), parents' needs were unmet in terms of receiving sufficient information on services available. Crane et al. (2018) agree that the postdiagnosis period of receiving a diagnosis of ASD increases parents' frustration exponentially. Parental expectations of obtaining a diagnosis are believed to lead to readily available support services, yet not receiving these services can be one reason for this increase in frustration (Crane et al., 2018). Pediatricians might only give selected options of different therapeutic services to parents and this lack of information might instill feelings of distrust towards professionals (Hodgetts et al., 2015). Parents experience intense emotions, such as confusion, frustration and isolation during the path to a diagnosis of ASD for their child (Fewster & Gurayah, 2015).

Paul (2009) mentions that once a diagnosis of ASD is finalised, the next step for parents is to make sure their child starts with appropriate therapeutic interventions. Paul (2009) states further that various organisations will suggest a number of hours of one-on-one therapy per week, ranging from one hour (for e.g., Speech therapy and Occupational therapy) up to 40 hours (Applied Behavioural Analysis, ABA). Paul (2009, p. 835) mentions, "it is clear that children with ASD benefit from intensive, early intervention that focuses on increasing the frequency, form, and function of communicative acts". Hoefman et al. (2014) state that parents often feel unsupported after therapy sessions, when the child returns to his or her home environment. Reasons for this include the difficulty of continuing behaviour management strategies at home, encouraging the use of appropriate coping skills and trying to remember what professionals have implemented in the therapy sessions (Hoefman et al., 2014). According to Myers, Mackintosh, and Goin-Kochel (2009, p. 671), children diagnosed with ASD often "exhibit behaviors that are disruptive and hard to manage", which leads to parents

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feeling inadequate regarding taking children out of their home environment and into public spaces. Subsequently, Myers et al. (2009) found these challenging behaviours to be a major stressor to parents of children diagnosed with ASD.

According to Brentani et al. (2013), treatment of ASD should focus on the following areas: functional spontaneous communication, play skills (including peer interaction), social skills acquisition, maintenance and generalisation of new skills across natural environments as well as functional assessment and positive behaviour support. Brentani et al. (2013) state further that these areas should be evaluated every 3 to 6 months and focusing on social, communication, adaptive and organisational skills. Pediatricians typically refer to ABA, Speech and Occupational therapists to assist with these areas of development that need support.

The next part of the literature review will focus mainly on details of ABA and school placement and not as comprehensively on details of Occupational therapy and Speech therapy. The reason for this selective focus is the increased number of hours dedicated to behavioural sessions and school participation, compared to 1-2 hours per week of Speech and/or Occupational therapy.

Speech therapists use different methods to encourage communication with children diagnosed with ASD (Paul, 2009). A strategy for increased communication is to focus on pre-verbal skills and then concentrating the treatment programme on an effective way to communicate. These methods, according to Miguel, Carr, and Michael (2001), include increasing expressive speech by offering highly preferred items whenever a child engages in babble-like behaviours or pairs certain sounds with specific activities. Another way is to offer an alternative way of communicating, whether this is through pictures (Picture Exchange Communication System) or an Augmentative or Alternative Communication mode (such as a speech-output programme loaded on an iPad or smartphone) (Ganz, Simpson, & Lund, 2012).

As with Speech therapy, Occupational therapy too helps with the development of certain concepts that are important for any child. Unlike Speech therapists, Occupational therapists focus more on the improvement of a variety of motor skills than on speech output (Case-Smith, Frolek-Clark, & Schlabach, 2013). Fine motor, gross motor and oral motor skills are areas that are targeted within an occupational therapy session through the implementation of a variety of interactive games (Case-Smith, et al., 2013). Occupational therapists also concentrate on supporting children diagnosed with ASD in understanding their sensory system better to be able to become more self-aware of their sensory needs and self-

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regulate when they feel over-stimulated or under-stimulated (Bumin, Huri, Salar, & Kayihan, 2015).

ABA refers to the application of empirically derived learning principles to produce meaningful changes in behaviour (Anagnostou, et al., 2014). According to Brentani et al. (2013), ABA therapists follow a developed treatment plan (created by the supervisor of the programme) that outlines what causes certain excessive behaviours and potential consequences that can decrease these undesired behaviours or increase desired ones. Brentani et al. (2013) explain that ABA therapists gather data on the implementation of different strategies to increase or decrease specific behaviours and consequently reassess treatment goals. A few of the strategies that ABA therapists use during their sessions with children diagnosed with ASD include: positive reinforcement (praise, snacks, food or toys), shaping (rewarding approximations of the desired or “appropriate” behaviour displayed), fading prompts and extinction of attention to challenging behaviours exhibited (Brentani et al., 2013).

Currently, ABA is considered best practice for children diagnosed with ASD, as it has been shown to improve language, cognitive and adaptive skills (Anagnostou et al., 2014; DeFilippis & Wagner, 2016; Paul, 2009). According to DeFilippis and Wagner (2016), ABA includes detailed and specific targets with Independent Educational Plans (IEP’s) paired with a positive reinforcement programme. Anagnostou et al. (2014, p. 517), however, state, “although the overall quality of evidence is low, it is the best evidence available”. A well-documented limitation of ABA is the generalisation of skills learned in therapy sessions to the home environment (DeFilippis & Wagner, 2016). As mentioned earlier, parents find it difficult to generalise behavioural management techniques from therapy to their home environment and other social gatherings, when they are without a trained professional (Fewster & Gurayah, 2015).

According to Baird et al. (2003), parents are in dire need of a more holistic support structure, taking into consideration each child’s varying level of impairment due to an autism spectrum diagnosis, the specific family dynamic as well as siblings of the child diagnosed with ASD and their individual needs. Due to ASDs presenting differently in most children diagnosed, it is imperative to tailor programmes to each child’s interests, specific needs and their family (Hebert, 2014). Some children with an ASD diagnosis might present with limited to no expressive speech abilities, whereas others might present with above average language abilities, which contributes to the need for specialised services (Kujala, Lepistö, & Näättänen, 2013). Another limitation of administering conventional ABA therapy, without combining it with other therapeutic modalities, is the lack of true individual programming for each child and

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thus, a multidisciplinary approach should be investigated by families (Dillenburger et al., 2014). According to Dillenburger et al. (2014), a true multidisciplinary approach should include a variety of professionals with varying backgrounds working towards the same goal – creating a holistic programme for each child that improves deficits, by utilising each child’s strengths through their interests and motivation.

Just like each child diagnosed with ASD presents differently, so too does the family and their way of interacting with each other, the child diagnosed with ASD and the sibling of the child, if applicable (Hebert, 2014). Some families might not present as a nuclear family and consecutively might have different needs to a family that has a conventional or nuclear support structure in place (Gorlin, McAlpine, Garwick, & Wieling, 2016). Dionne and Martini (2011) state that families found some ABA therapy to be beneficial during therapy hours, but struggle to find support after therapy hours, in terms of generalising to the home environment and behaviour management. Myers et al. (2009) found that parents expressed an intense fear of taking their child out in public at times, due to aggressive and violent behaviours. Parents often felt unsupported after therapy hours and did not feel confident in managing challenging behaviours by themselves (Myers et al., 2009).

Sibling interaction has been another area of concern for parents who have a child diagnosed with ASD who attends ABA therapy (Myers et al., 2009). Parents feel that not enough attention is placed on the well-being of the siblings involved and too much attention is placed on the child diagnosed with ASD (Nealy, O’Hare, Powers, & Swick, 2012). Mothers of children diagnosed with ASD confirmed this experience of unequal distribution of attention and time. According to Nealy et al. (2012), mothers felt guilty for spending more time with their child diagnosed with ASD and less so with the other child or children. They also stated that they felt there was a focus on the sibling of the child diagnosed with ASD to mature faster than other neurotypical children to be able to help advocate for their brother or sister with an ASD diagnosis (Nealy et al., 2012).

To summarise the benefits and challenges of implementing ABA therapy, parents stated that they are satisfied with the developmental gains their children are making during sessions in terms of improved communication abilities, eye contact and listening skills (Walsh, 2011). Parents stated, however, that they still feel unsupported after therapy hours, during holiday periods with their entire family and in terms of social interaction with siblings or friends (Nealy et al., 2012). Dionne and Martini (2011) also found that parents struggle with generalising skills their child learned in a structured setting to a more natural setting and state that “intervention with these children should include a therapeutic approach based on the child’s uniqueness,

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rather than follow a standard program designed for all children with the same diagnosis” (Dionne & Martini, 2011, p 196).

School placement for children diagnosed with ASD differs according to the child’s specific needs and support needed to attend the classroom setting (Lauderdale-Littin, Howell & Blacher, 2013). As mentioned before, children diagnosed with ASD range in terms of functioning level and thus the level of support needed. School placements range from inclusive mainstream environments “to highly specialized 52-week boarding facilities” (Baird et al., 2003, p. 493). Dukpa (2015) takes on a critical review of inclusion with sufficient teacher staff support and training versus forced inclusion. The same study cautions parents and professionals regarding including children diagnosed with ASD in mainstream schools with inadequate support structures or experienced teachers (Dukpa, 2015). Due to the number of hours that a child attends school, it is important to find the best suited school setting for each child diagnosed with ASD (Lauderdale-Littin et al., 2013). Parents often feel unsupported in the important decision of choosing an appropriate school for their child and best describes the process as a “trial-and-error” experience, where their child often attends a number of schools before they find a “good fit” (Mann, Cuskelly, & Moni, 2015).

## **2.5 Main concerns of parents with children diagnosed with ASD**

Several factors increase the likelihood of parental stress and concerns for parents with a child diagnosed with ASD (Bluth et al., 2013). There are multiple studies that have explained some of the concerns parents face on their journey with their child diagnosed with ASD (Bluth et al., 2013; Fewster & Gurayah, 2015; Ooi et al., 2016; Padden & James, 2017). During the diagnosis process, parents typically report feelings of denial, isolation and anger (Fewster & Gurayah, 2015). According to Ooi et al. (2016, p. 746), “parents are faced with the loss of expectations for a typically developing child and are faced with uncertainties regarding not only the child’s but also the family’s future”. As mentioned before, parents have unmet feelings of expectations during the diagnostic process of not receiving adequate information regarding service providers available and feel obligated to proceed with the limited options provided by pediatricians (Hodgetts et al., 2015). Baird et al. (2003) summarises parental needs by showing unmet requirements from parents before the diagnosis period throughout their journey with their child diagnosed with ASD.

According to Padden and James (2017), parents of children diagnosed with ASD have been reported as experiencing poorer physical and mental health (due to an increase in stress levels) compared to parents of neurotypical children. This increased level of stress of parents

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with a child diagnosed with ASD, compared to other parents, is shared in more studies. Bluth et al. (2013) found parents with children diagnosed with other developmental disabilities (e.g., Down syndrome, intellectual disabilities, developmental delays) and those with neurotypical children to have significantly lower parental stress when compared to parents of children with ASD.

According to Baird, et al. (2003), parents require capable professionals to make a tactful as well as a fairness of the distribution and access of services. Another concern of parents during the diagnosis process is not having access to a variety of educational and therapeutic interventions which provide progress of their child's developmental areas in need and some respite during weekends and after-hours (Baird et al., 2003).

Once therapy commences, there are more concerns for parents that arise. Ooi et al. (2016) interviewed mothers who had to quit their jobs due to taking their child diagnosed with ASD to a variety of specialised therapy during or after school hours. Another factor for mothers having to postpone their career goals is the time it takes to care for a child diagnosed with ASD in terms of understanding their behavioural needs, managing these sometimes aggressive behaviours and generalising behavioural techniques to a variety of environments and social gatherings (Ooi et al., 2016).

The cost of therapy from a financial point of view also affects families in a negative way (Hoefman et al., 2014). Due to the lack of a variety of service providers received during the diagnosis process, parents often feel obliged to try out multiple forms of therapies (Hebert, 2014). These therapies are at times covered by their medical aid (such as ABA in certain countries), but most of the time therapies are paid for privately and out-of-pocket (Wang, Mandell, Lawer, Cidav, & Leslie, 2013). According to Horlin, Falkmer, Parsons, Albrecht, and Falkmer (2014), the yearly amount of supporting a child diagnosed with ASD in receiving early intervention therapy and specialised schooling amounts to AUD \$34 900 (approximately R35 400 or \$24 400). Horlin et al. (2014) also state that 90% of the sum of this amount is due to the loss of income of one parent. Some parents (especially mothers) of children diagnosed with ASD report that they were forced to quit their jobs to support their child and help them to generalise skills taught from therapy to the home environment (Nealy et al., 2012), which contributes to the financial stress parents face. Horlin et al. (2014) found that the annual amount discussed increases by AUD \$1 400 (approximately R14 300 or \$990) for each additional ASD symptom of the child diagnosed, reported by his or her parents.

From a family perspective, parents have expressed their concerns about the marital strain they experience due to having a child with ASD. Bluth et al. (2013) discussed couples'



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stress in-depth with higher rates of divorce and separation of families with a child diagnosed with ASD. The themes identified by Bluth et al. (2013) included the impact a child with ASD has on the parents, the entire family, the social interaction as well as health and educational services. A direct link of children diagnosed with ASD who engaged in more challenging behaviours to higher levels of parental stress was found (Ooi et al., 2016). Challenging behaviours were explained as tantrum behaviour, sensory meltdowns, aggression, intolerance to changes in the environment and highly routinised behaviours (Ooi et al., 2016). A major concern for parents that Bluth et al. (2013) found was the prognosis of the child with ASD and a concern for the future and independence of their child. Bluth et al. (2013) also found that parental stress increases when parents blame each other for the diagnosis of their child instead of advocating for their child as a team.

Another concern of families included the lack of understanding of autism in the extended family and social relations with friends. According to Ooi et al. (2016) family and friends could not provide needed support to the parents or understanding of a child diagnosed with ASD. Bluth et al. (2013) add that social stigma still exists in the general public and can be explained by the normal appearance of children diagnosed with ASD compared to other special needs children. Due to individuals diagnosed with ASD's not having a distinctive external "look" as in the case of other disorders, like Down Syndrome, many parents feel they are being judged by the community at times (Bluth et al., 2013). In a study conducted by Kinnear, Link, Ballan, and Fischbach (2015), social stigma increases the difficulty in raising a child diagnosed with ASD. From the interviews conducted with 502 parents, it was revealed that social stigma included stereotyping, rejection and exclusion for the child as well as the family, mainly due to the child's behaviour (Kinnear et al., 2015).

When siblings of children diagnosed with ASD were asked what they struggled most with having a brother or sister with ASD, the most frequent response was also the challenging behaviour and lack of understanding of the specifically aggressive behaviours of their sibling (Mascha & Boucher, 2006). The general consensus though is that growing up with a sibling diagnosed with ASD can have both positive and negative effects. According to Green (2013), emotional and behavioural adjustment for a sibling of a child diagnosed with ASD remains a challenge, whereas they show more of an appreciation of life and an understanding of differences in people. Welch et al. (2012) found that siblings desire more time spent with their parents.

According to Hodgetts et al. (2015), parents need more options related to qualified full-time respite-care providers to give them respite from caring for their child with ASD. Fewster

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and Gurayah (2015) also found that parents need more readily available childminders and continuous options of respite care for their child. It is emotionally, financially and physically draining to care for a child diagnosed with ASD (Becerra et al., 2017). With the increase in ASD diagnoses, combined with parental strain discussed, it seems that an increase in support services should be evident. However, parents report a lack of options for support services as well as significant challenges in caregiving for a child diagnosed with ASD (Lai & Oei, 2014). A full-time live-in caregiver might alleviate some of the challenges experienced by parents during these demanding situations. According to a study done with 101 parents of a child diagnosed with ASD, by Harper et al. (2013, p. 2604), “more respite care was associated with increased uplifts and reduced stress...” According to findings of the same study, an increase in uplifts and reduced stress led to improved marital quality (Harper et al., 2013).

### **2.6 Live-in caregiving**

At the time of conducting this study, I could not locate any published studies that investigated the impact of live-in caregivers specialising in services for children diagnosed with ASD and their families on a full-time basis. Live-in caregiving support for a child diagnosed with ASD can be compared to full-time live-in caregiving support for other disorders or diseases. For example, in a study done by Basnyat and Chang (2016), elderly people diagnosed with dementia are cared for by live-in caregivers on a full-time basis. According to Basnyat and Chang (2016), a full-time live-in caregiver lives with the family and cares for the individual on a full-time basis, by providing practical life skills as well as emotional support to not only the patient suffering from dementia, but also his or her family members. When referring to a live-in caregiver in this study, the definition of Basnyat and Chang (2016) will be applied.

A broader investigation of in-home services offered to families with neurotypical children and/or a child diagnosed with a developmental disability receiving respite care provided a substantial amount of studies conducted (e.g., Bromley, Hare, Davison, & Emerson, 2004; Chan & Sigafos, 2001; Harper et al., 2013; Mullins, Aniol, Boyd, Page, & Chaney, 2002). In-home respite care can be defined as regularly scheduled or intermittent caregiving support to parents through outside professionals, family or friends (Vandepitte et al., 2016). Informal respite services include care from partners, siblings of the child diagnosed with ASD and other family members, for example, Bromley et al. (2004). Informal respite care is typically unpaid and this can lead to inconsistent support offered by individuals. The reason for this might be a lack of training and a feeling of inadequacy to care for a child diagnosed with a

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disability (Harding et al., 2012). Formal care is typically explained as a trained professional offering paid services on a consistent basis to families (Madden et al., 2016). In general, formal respite care is preferred by parents and seems to decrease parental stress, according to a number of studies (Harding et al., 2012; Madden et al., 2016; Norton, Dyches, Harper, Roper, & Caldarella, 2016). Chen and Chiou (2015), however, found that the time-benefit that respite care offers provides more benefit to parents than the overall quality of life or marital satisfaction.

According to Harper et al. (2013), the number of hours of respite service received for children with ASD was positively related to the quality of the parents' marriage. According to Chan and Sigafos (2001), respite services improved parents' quality of life by increasing their participation in social and leisure activities. Other areas of improvement included their sleep patterns, grooming and improved personal care (Chan & Sigafos, 2001). Welch et al. (2012) examined the effects of respite care for siblings of children with developmental disabilities and found siblings felt more positive about spending more time with their parents. Although these studies differ in terms of type of benefit that respite care offers, it seems that participants of the studies mentioned above agree that there is a benefit for parents of children diagnosed with ASD in alleviating stress (in a variety of forms) by utilising respite care services, thus increasing their capabilities.

### **2.7 Theoretical framework**

The perspectives of parents related to capabilities and demands offered by live-in caregivers for children diagnosed with ASD were examined and interpreted within McCubbin and Patterson's (1983) Family Adjustment and Adaptation Response (FAAR). This model of adjustment and adaptation of families exposed to significant risk can be explained in two parts, firstly the adjustment phase, where families undergo stressful events (demands) and utilise their capabilities (resources and coping behaviours) to adjust to these events. Adjustment, according to the FAAR model (McCubbin & Patterson, 1983), can be defined as the family unit's ability to balance its capabilities and demands as well as adding meaning during a stressful event. The second phase, the adaptation phase, occurs after a crisis presents itself (McCubbin & Patterson, 1983). Similarly to the adjustment phase, the adaptation phase can also be defined as the family unit's ability to balance their capabilities and demands, while adding meaning to this event, but where this event is now seen as a crisis (McCubbin & Patterson, 1983). In each of these phases, Patterson (2002) explains that families exposed to increased risk will need to balance out the

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number of demands placed on them compared to the number of capabilities (McCubbin & Patterson, 1983).

According to the FAAR model (McCubbin & Patterson, 1983), individuals go through continuous cycles of, firstly, adjusting to the demands and the meaning placed on these demands by utilising capabilities. Secondly, families experience crises and again, the meaning the family unit places on these demands during a crisis leads into the family's way of adapting (McCubbin & Patterson, 1983). This process is seen as a cyclical event, where once adjustment has been attained, another stressor or challenge presents itself and it is then up to the family to adjust and ultimately, through a crisis, to adapt. Please see Figure 1 below for a visual representation of the FAAR model (Patterson, 1988):

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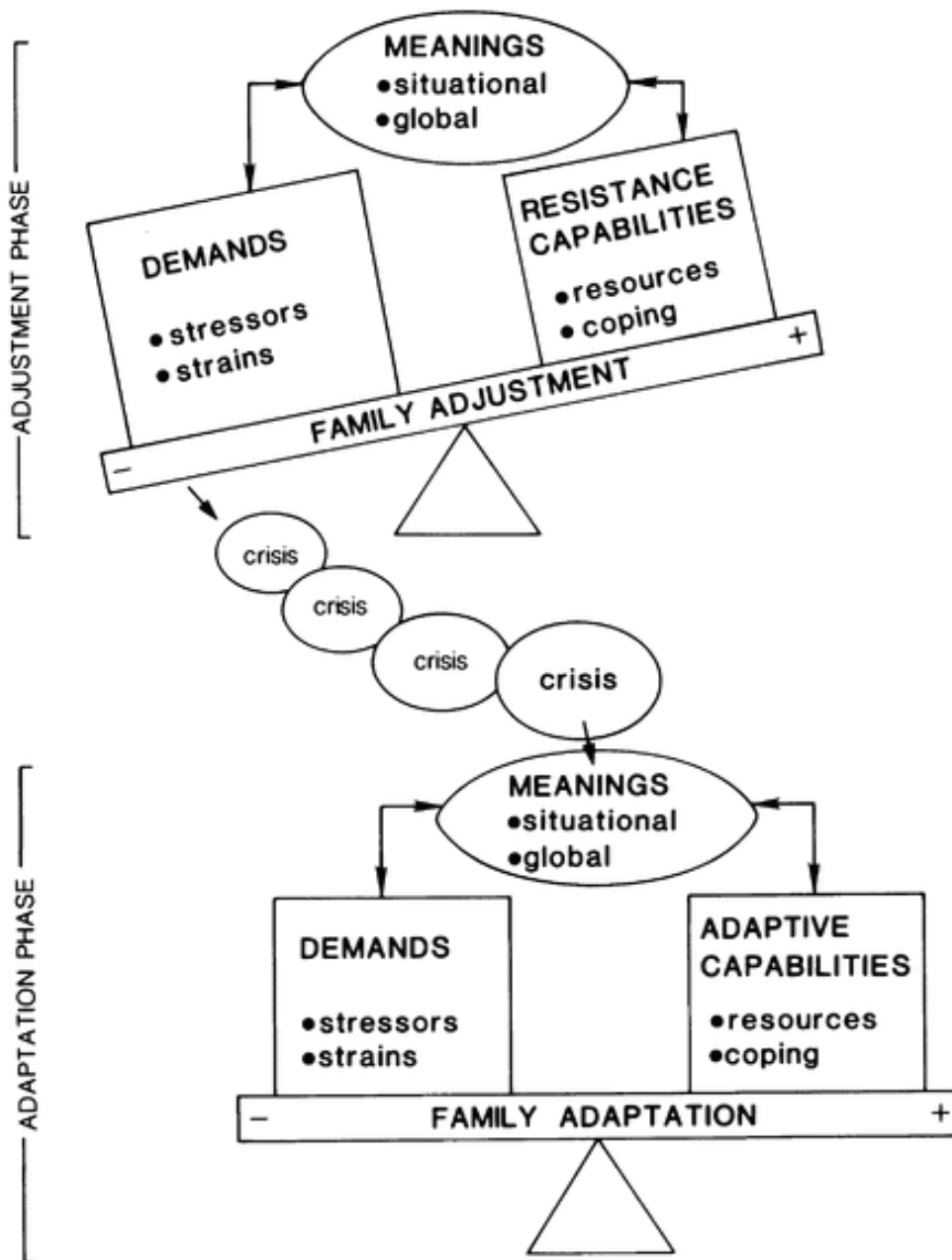


Figure 1. A visual representation of the FAAR model (McCubbin & Patterson, 1983),

When looking at a family with a child diagnosed with ASD, it is clear from the literature review above that there is a significant increase in stress in a variety of domains of family life. At the time of diagnosis received for their child, the family can be seen as moving into the adjustment phase, according to Patterson (2002). During this adjustment phase, Patterson (2002) explains that a family is then able to increase their capabilities to cope or be more resilient with the increase of demands (finding, being able to afford and sustaining appropriate support systems). The crisis period for each participant in this study can be seen as having a child with a diagnosis of ASD and the need for continuous respite and support. It is clear from

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the literature that parents with children diagnosed with ASD may have many demands as well as potential capabilities during the crisis period. Some of the demands parents experience during this phase may include: poorer physical and mental health (due to an increase in stress levels), cost of therapy, lack of therapy options, marital strain and blaming each other for the diagnosis as well as the need for respite care (Bluth et al., 2013; Fewster & Gurayah, 2015; Hodgetts et al., 2015; Ooi et al., 2016; Padden & James, 2017). Some of the capabilities that parents have reported that have alleviated stress include realistic expectations for their child, collaboration with therapists or professionals to generalise skills and strategies learned in therapy to the home environment, and successful behaviour management strategies to utilise at home (Berkell et al., 2017; Thomas et al., 2018).

When looking at Figure 2 (please refer to the next page) it is illustrated, based on the literature, how the FAAR model could potentially be applied to the adaptation phase, which occurs once a crisis (in this case, the need for continuous support for parents of a child who has been diagnosed with ASD) is experienced. I will elaborate on how this model was applied to the current study in Chapter 4 when I report the key findings of the study.

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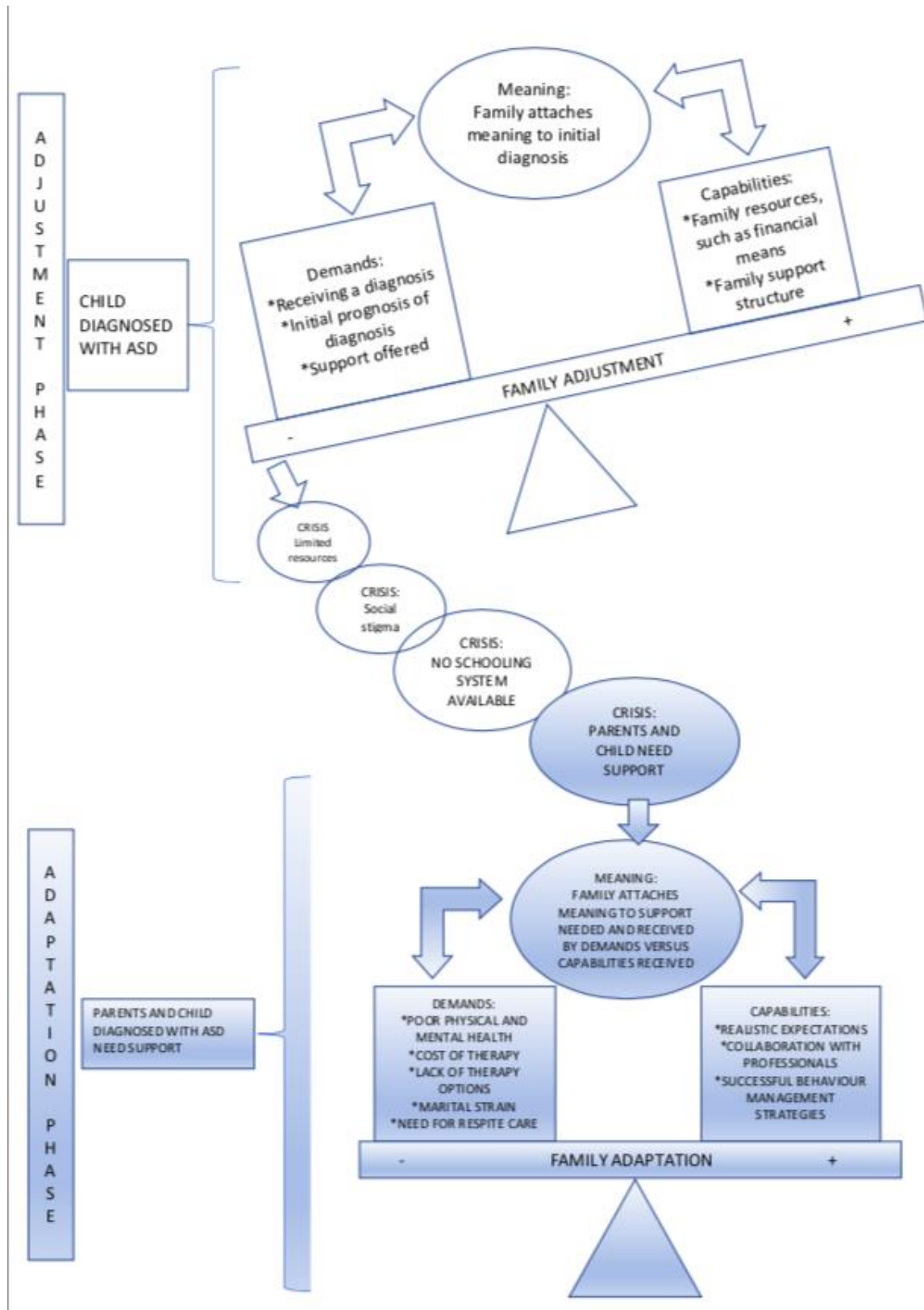


Figure 2. A visual representation of the FAAR model applied to the current study (adapted from McCubbin & Patterson, 1983).

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## **2.8 Criticism of the FAAR model**

Although the FAAR model opens the possibility of including a variety of risks and capabilities in the framework as it does not specifically state the nature of what each should contain, this too can be seen as a potential challenge of utilising this model for the study. The reason for this is the vagueness of the model and the subjectivity that the researcher can link to each potential risk versus capability. According to Afshar et al. (2015), people's own personal experiences in life determine the way they prioritise a potential challenging behaviour versus a coping mechanism. This should be kept in mind when analysing data, that there might be potential biases from previous experiences that the researcher has dealt with in their own life.

## **2.9 Conclusion**

This chapter provided an overview of the literature in relation to children diagnosed with ASD and the current needs of their parents. A background of ASD was provided by discussing its aetiology, clinical features, prevalence as well as the factors related to caring for a child diagnosed with ASD. It is evident from the current available research on parents with a child diagnosed with ASD, that they experience stress in a variety of domains of their family life. To highlight the experiences of parents that care for a child diagnosed with ASD, the challenges were discussed. The discussion included ways of potentially alleviating some of the stressful situations for parents in terms of employing a full-time, live-in caregiver.

To conclude, the FAAR model was described as the theoretical framework that was used to interpret the findings of this study (McCubbin & Patterson, 1983). The methodology that was used in the current study will be discussed in Chapter 3.



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### Chapter 3: Methodology

This chapter serves as an overview of the methodology that was utilised in the present study. Firstly, the rationale of the study is presented, followed by the research question, the aims and objectives. This is followed by a discussion of data collection and analysis. The process involved in maintaining trustworthiness is explained and followed by the ethical considerations applicable to the study.

#### 3.1 Rationale

There is a significant body of research that has been conducted regarding autism and current treatment options and support offered (Anagnostou et al., 2014; Bishop-Fitzpatrick, Minshew, & Eack, 2013; DeFilippis & Wagner, 2016; Park et al., 2016). However, from the literature review, it is clear that parents with children diagnosed with ASD have ongoing demands that need to be addressed.

Parents with children diagnosed with ASD have expressed a lack of support during the diagnosis process, obtaining adequate information about treatment programmes available as well as parental stress increasing when therapy for their children commences (Bluth et al., 2013; Fewster & Gurayah, 2015; Ooi et al., 2016; Padden & James, 2017). There are many domains of family life where parents do not have access to professionals for support, such as going on outings, holidays and visiting friends (Ooi et al., 2016). Another domain of family life that is negatively impacted on is the increase in parental stress due to caring for their child, marital concerns and the lack of social ability of the child diagnosed with ASD (Becerra et al., 2017).

It is clear from the literature review that respite care is important for parents to potentially alleviate stress from caring for a child diagnosed with ASD. Most of the research focuses on temporary respite care that supports families a few hours per week and shows a positive effect on reducing stress levels with parents (Harper et al., 2013). From the limited amount of research that could be found on full-time live-in caregiving, parents report positive experiences regarding extra support and a “break from caregiving” (Harper et al., 2013, p. 2605; Hodgetts et al., 2015; Ooi et al., 2016).

The current research therefore aims to explore the impact of having a full-time live-in caregiver on the parents of children diagnosed with ASD.

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### **3.2 Research question**

The research question that this study seeks to explore is: What is the impact of having a full-time live-in caregiver on parents of children diagnosed with ASD?

### **3.3 Aims and objectives**

The primary aim of this study is to determine the impact on parents of children diagnosed with ASD's experience while having a full-time live-in caregiver. The objectives of this research are to determine the parents' perspective of the capabilities and demands related to having a full-time live-in caregiver caring for their child diagnosed with ASD.

### **3.4 Research design**

This study implemented an exploratory qualitative design. According to Teherani, Martimianakis, Stenfors-Hayes, Wadhwa, and Varpio (2015, p. 669), "qualitative research is the systematic inquiry into social phenomena in natural settings". The purpose of a qualitative design is to get a more in-depth understanding of parents' experience who have a child diagnosed with ASD and thus interviews were conducted. According to Malagon-Maldonado (2014, p. 120), a qualitative design purposefully aims to "comprehend, describe and interpret different phenomena as perceived by individuals, groups, and cultures". This type of design also seems appropriate to utilise the current study's aim to understand the capabilities and demands that parents experience. As Malagon-Maldonado (2014) explains, qualitative research is suitable to describe change and conflict as it considers the participants involved and the meaning and interpretations these participants offer to the interview questions.

### **3.5 Contextual information**

AG (a pseudonym for the organisation from which the participants of this study were selected), is an international company that specialises in support services for children diagnosed with ASD and their families. AG has two managing directors, of which I am one and the other director will be referred to as NB. AG focuses on offering live-in caregiver support to families with a child diagnosed with ASD for a period of at least six (6) months on a full-time basis. Live-in caregivers are full-time employed by the family, working with the child diagnosed with ASD and his/her family seven to eight hours a day, five days a week. All of AG's live-in caregivers have to complete training via AG. Level 1 and Level 2 training programmes of AG have been reviewed and approved by the International Board of Credentialing and Continuing Education Standards ([www.ibcces.org](http://www.ibcces.org)); PROVIDER

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#CE178559. I am one of the directors, founders and co-developers of AG and conducted this study.

AG is registered in Singapore, but the client base come from many different countries. Current clients of AG reside in Abu Dhabi, Bangladesh, Cambodia, Dubai, Ethiopia, Indonesia, Malta, Malaysia, Saudi Arabia, Singapore, Thailand and Vietnam. Thus, the families are currently living in these areas, with a live-in caregiver from South Africa, the Philippines, Zimbabwe or Italy, who is employed by AG.

### **3.6 Participants and sampling**

The inclusion criteria for this study stipulated that participants had to be a parent of a child with a primary diagnosis of ASD and a client of AG. The ASD diagnosis had to be obtained at least six months prior to initial contact to have participated in the study. Parents needed to live with their child diagnosed with ASD and have a full-time live-in caregiver, employed by AG. Participants were required to have employed a full-time live-in caregiver for three months or longer from the time of initial contact for the study. Purposeful sampling was used to recruit the participants of this study, due to participants being deliberately approached, as they possessed certain qualities. According to Tongco (2007), purposeful sampling is a kind of nonprobability sampling technique that ensures a specific population is reached.

At the time of conducting this research study, AG had fifteen (15) active clients (families) with a child diagnosed with ASD with a full-time live-in caregiver in their household for three (3) months or longer. From the twelve (12) countries that AG operated in during the study period, participants from three (3) countries (Cambodia, Indonesia and Singapore) agreed to participate in the current study. Both, mothers and fathers were invited to participate in the current study. The reason for not limiting the study one parent of a family is to give parents the opportunity to decide if they want to participate in the study. The researcher did not want to choose a specific gender for this study as she felt that it will decrease the already scarce opportunity for parents to discuss their experience of having a child diagnosed with ASD. A potential comparative study of mothers and fathers and the differences in their experiences of having a child diagnosed with ASD is a possible future study topic, but not the focus of the current study.

Data were collected from parents that agreed to participate in the study until data saturation was reached. Data saturation was reached when no new themes were identified during the interviews (Lincoln & Guba, 1986). In the current study, data saturation was reached after 11 interviews were conducted. Different developmental levels of the participants'

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children, who were diagnosed with ASD, were not excluded as ASD is a spectrum disorder and thus children with ASD vary greatly in terms of developmental age to their chronological age (DeFilippis & Wagner, 2016). Families that were not affiliated with AG were excluded to decrease variability of support services received and offered.

### 3.7 Procedure

Firstly, potential participants were identified with the assistance of the operations director of AG. The operations director is an equal partner in AG, but her duties are focused around the operational systems of running the organisation, which includes sourcing clients, maintaining legal contracts and regular feedback to the clients. Potential participants for the study were approached by me, by a phone call, to explain the study to each participant. The procedure and aims of the study were explained as well as an estimated duration of the interviews. The inclusion and exclusion criteria were also explained during the call to all potential participants. An email was then sent to potential participants who agreed to read about the current study and determine if they were interested in participating in the current study (Appendix A – Call for Research). The Call for Research document contained all information pertaining to the study. Written informed consent was requested from participants who agreed to take part in the study. All participants were notified that they could withdraw from the study at any point. All of this was stipulated in the written consent document (Appendix B – Consent Form). Once participants completed the written consent form, a demographical data form was sent to potential participants to ensure inclusion criteria were met and important demographic information was gathered, such as the participants' age, the amount of years that their child has been diagnosed with ASD and for how many months they have had a live-in caregiver working with them (Appendix C – Demographics).

A total of 11 participants were interviewed for the current study. They ranged from 37 years of age to 48 years, with a mean age of 40.6 years. Of the 11 participants, 4 (36%) were Caucasian, 2 (18%) were Indian and 5 (45%) were Asian. All 11 participants were biological parents of their child diagnosed with ASD. Of the 11 participants, 7 (64%) were the biological mothers of the child diagnosed with ASD and the remaining 4 (36%) were the biological fathers. The children diagnosed with ASD ranged from 5 years old to 11 years old, with a mean age of 7.2 years old and interviews were held regarding eight different children. Three mothers and fathers of the same child were interviewed; thus, the number of participants vary to the number of children diagnosed with ASD. Interviews were conducted separately with the mother and father of each child from the same family. Of the 8 children diagnosed with ASD,

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7 (88%) were male and 1 female (12%). All participants were married and the biological parents to the child diagnosed with ASD. Seven of the 11 participants (64%) were employed (full-time or part-time). Of the 11 participants, 4 participants (36%) were unemployed and in charge of running the household. All the participants hired a live-in caregiver for longer than 3 months.

Table 1

### *Demographical data of participants*

Participant alias	Age	Race	Gender	Employment status	Marital status	Age of child	Gender of child	Diagnosed with ASD (Amount of years since diagnosis)	Full-time caregiver hired (Number of months)
BH	37	Asian	Male	Full-time employed	Married	5	Male	2 years	12 months
EJ	40	Asian	Female	Full-time employed	Married	6	Male	1 year	9 months
IB	40	Asian	Female	Unemployed	Married	6	Male	2 years	23 months
IO	37	Asian	Female	Unemployed	Married	5	Male	2 years	18 months
LB	45	Indian	Female	Full-time employed	Married	8	Male	4 years	13 months
MD	41	Asian	Female	Unemployed	Married	11	Male	8 years	12 months
MS	40	Caucasian	Male	Full-time employed	Married	9	Male	6 years	38 months
PG	39	Caucasian	Female	Part-time employed	Married	6	Female	3 years	24 months
RD	41	Caucasian	Female	Unemployed	Married	9	Male	6 years	38 months
SB	48	Indian	Male	Full-time employed	Married	8	Male	4 years	13 months
TG	39	Caucasian	Male	Full-time employed	Married	6	Female	3 years	24 months

### 3.8 Data collection

Participants who agreed to participate were contacted via email and asked when an interview via Skype or in person would suit them. According to their availability, semi-structured interviews were scheduled and conducted in English. Interviews were conducted via Skype meetings (as all participants agreed to an online interview) and thus did not bear any financial cost, such as traveling, to participants of the study. I conducted the Skype interviews, in a private study room in Bali, Indonesia, with no one having access to the area during the call, as the room was locked. The participants were able to decide if they wanted to have a voice call or video call, but all participants agreed to a voice call.

Participants were interviewed to gather a more in-depth understanding of any benefits and challenges they experience with live-in caregiving for a child diagnosed with ASD. The

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data obtained from these interviews were recorded as all participants gave consent.

The interview schedule consisted of the following open-ended questions (Appendix D – Interview Schedule):

- When and why did you seek to find live-in caregiving support?
  - Tell me more about the process of finding a live-in caregiver.
- Tell me about the experience of having a full-time live-in caregiver in your home:
- Please describe any benefits and/or challenges you have experienced with this type of support.
- What about the benefits and/or challenges relating to:
  - Marital stress
  - Financial stress
  - Sibling interaction
  - Outings, holidays and family vacations
  - Social interaction with friends and family
  - Independent play skills at home
  - Going to school and other therapy sessions
  - Having someone from another country that lives in your home
  - Different cultures and beliefs
  - Becoming dependent on another person for caring for your child
- Besides a live-in caregiver, what other forms of support do you have with your child with ASD?
- Does your child attend school during the day?
- Are there special schools in your area?
- Who or what assists you to cope with your caregiving role?
- Who or what makes caregiving easier for you?
- Is there anything else you want to add regarding your experience of having a live-in caregiver for your child diagnosed with ASD?

### **3.9 Data analysis**

Data were analysed using thematic analysis, which refers to the identification, analysis and reporting of themes within data, as developed by Braun and Clarke (2006). This approach requires the researcher to apply six (6) steps after transcription of the interviews namely:

1. Familiarisation with the data

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2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and labeling themes
6. Producing the report.

The first step required me to immerse myself in the collected data, by familiarising myself with the audio-recordings. Re-listening to the audio-recordings made transcribing this data easier and more precise. Reading and re-reading through the transcriptions, ideas of potential themes that participants conveyed started emerging. These potential themes were then given initial codes and also notes were added of themes that were not initially part of the open-ended questions during the interviews, yet emerged through discussion. In consultation with Dr. Pretorius, who is my research supervisor and who was familiar with the transcripts, the potential themes were identified, verified and where possible, combined.

Themes were then systematically recoded as similar themes were combined. Themes were grouped together to streamline the findings that the data produced. Interesting data were documented and added into the revised themes as valuable information for rendering the findings. The identified themes and interesting data were compared and variances were resolved through discussion, which yielded the final version that is included in producing the research report. Throughout the process of thematic analysis, the themes were refined and revisited to produce exact and precise data reporting, while keeping the aims of the research study in mind.

### **3.10 Trustworthiness**

This study is qualitative in nature and employed four methods to ensure trustworthiness and soundness of the findings, namely 1) transferability, 2) credibility, 3) dependability and 4) conformability (Given & Saumure, 2008).

#### **3.10.1 Transferability**

The goal with transferability is to ensure that the findings of the research can “be transferred to other contexts and situations beyond the scope of the study context” (Jensen, 2008, p. 886). It is essential that the findings of this study be considered within the background context of the participants (the parents of children with ASD), including factors such as the geographic and socio-economic settings and organisational characteristics, and therefore a

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comprehensive description of these factors was provided in the study to ensure transferability to similar contexts.

### **3.10.2 Credibility**

This aspect is seen as the most important aspect in ensuring trustworthiness as it asks the researcher to link the findings with reality (Al-Busaidi, 2008). Two methods to improve credibility were used during the collection of data for this study.

Firstly, data, interpretations and conclusions were shared with participants to ensure their intended response to questions was captured. This method is known as member-checking. Although data and interpretations were shared with participants, it is possible that data can be transcribed and presented with personal bias as qualitative research allows for personal interpretation by the researcher (Malagon-Maldonado, 2014).

The second method, reflection, was implemented to enable me to reflect on the data in terms of my own thoughts. I would reflect on this by going through different scenarios that I know of for each family and spend a substantial amount of time thinking and reflecting on each family and their situation. This process is explained in Appendix E – Reflecting on Interviews. Long and Johnson (2000) found that reflecting forms a vital part of qualitative research and thus was included to further try and eliminate biased data interpretations by including my own values and views in the process. This process was also supplemented by continuous consultation with my research supervisor.

### **3.10.3 Dependability**

A comprehensive description of the methodology used in the study was included, to enable replication (Shenton, 2004). There were no changes introduced through the interview process, which may have impacted the methodology.

### **3.10.4 Conformability**

A comprehensive description of the study methodology was provided to enable the integrity of findings to be analysed (Shenton, 2004). Limitations in the scope of the study and the potential effects thereof will be described (Shenton, 2004). An onset limitation of the current study might be that the participants are all active clients of AG, of which I am one of the directors. I discussed interpretations and potential biases via the supervision process, and this will be discussed in the ethical considerations paragraphs below. As mentioned previously, qualitative research allows for biased interpretations due to the personal nature of the interview



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process. Gathering data and analysing what you, as the researcher, believes is meant can be seen as a limitation to this type of research study. All participants understood the study's intent and agreed that data can be analysed and presented in a research study.

It is standard protocol for all research proposals to be reviewed by at least two members of the Psychology Department to ensure academic merit and rigour of the research. Two staff members, who both confirmed that the study could be completed, if ethical clearance has been obtained, reviewed this study proposal.

### **3.11 Ethical considerations**

Ethical clearance for the current study was obtained prior to the commencement of the research from Stellenbosch University Research Ethics Committee (REC). The ethical clearance number awarded to the study is REC-2018-6801 (see Appendix F – Ethical Clearance). The REC members reviewed the initial ethical clearance applications and responded with questions and requirements that had to be answered and fulfilled before the study could commence. One requirement was that IBCCES ([www.ibcces.org](http://www.ibcces.org)) had to agree that their organisation can be referenced to as providers of credentialing courses that AG provides the full-time caregivers. I received a permission letter through IBCCES and the REC members provided ethical clearance for the current study (see Appendix G – IBCCES Permission). I also signed a Non-Disclosure Agreement (NDA) to ensure any information or materials related to the parents of children with a primary diagnosis of Autism Spectrum Disorder (ASD) received by me while participating in the research study, during any class-related or research-related activity, shall be kept strictly confidential (see Appendix H – NDA).

Agreement to participate in the study was sought from all participants during the first point of contact using emails and/or phone calls. Participants were advised of the purpose of the study, and that no remuneration will be provided in respect of their participation. The participants had the option to refuse to participate without any negative consequences on the services rendered to their family and children. Participants were also advised that they could withdraw from the study at any point with no adverse consequences.

After agreement to participate in this study was obtained, written informed consent was obtained to use the data generated in the current research project. Permission for an audio recording of the interviews was also requested. Further, it was established that any identifying information, such as participants' names, qualifications and any other personal information, will not be used to maintain confidentiality and anonymity. Aliases were also allocated to every participant in order to protect their confidentiality. Data collected during the study are stored

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safely and electronic files will be encrypted. The information will be kept safe for five years from the time of the research, after which it will be destroyed in an appropriate manner. AG's original name will not be mentioned in the research study. It is referred to as AG, which is a pseudonym.

Parents who are also clients of AG might have felt obliged to participate in this study as it forms part of my research study and I am one of the directors of AG. It was explained that no decision about their child's services would be based on their participation or nonparticipation. To ensure this was implemented, the other director (NB) of AG was appointed to be the person to speak to parents about their child's programme, the live-in services or any queries for the duration of the study. Parents from the same structure (family) were invited to participate in the current study. To ensure that there was no obligation towards participation, it was explained that neither, both or one parent can participate. The sensitivity of the information discussed during Skype interviewing was explained to stay confidential and the interviews would commence in a locked door with no one else being able to hear the information being disclosed.

The participants are parents of children diagnosed with ASD and are thus considered to be a vulnerable research population. In light of the factors explained, this was a medium-risk research study.

All participants had the opportunity to request counselling sessions with Clinical Psychologist, who will be referred to as BT. Participants were notified of these complimentary counselling sessions available to them before interviews commenced. Dr. BT is a clinical psychologist that practices in Cape Town, South Africa and specialises in the field of autism and family relations. Dr. BT has worked with families and children diagnosed with ASD since 1999. Participants were able to call or email Dr. BT directly if they wished to schedule face-to-face counselling and/or via phone/Skype. Dr. BT made himself available for two 30 minute sessions for each participant in this study at no cost. If at any point participants felt any unease during or after the interview process, they were able to email Dr BT to request complimentary counselling services and participants could continue counselling after the study had been completed, if they needed on-going support. As primary researcher, I took full responsibility for any costs involved if more than the two complimentary counselling sessions were required. None of the participants of this study has requested a counselling session with Dr. BT yet.

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### **3.12 Conclusion**

This chapter provided a description of the research methodology that was utilised in the current study. The chapter started with a rationale for the study, which outlined an expressed need for parents with children diagnosed with ASD to receive more ongoing support services. Challenges faced by parents with children diagnosed with ASD were discussed as a reason for this support need. Thereafter, the research question as well as the aims and objectives were reported with a specific focus on the capabilities and demands parents faced with hiring a full-time live-in caregiver to support their child diagnosed with ASD. The research design that was utilised in the current study – an exploratory qualitative design – was also described. This was then followed by a discussion of the contextual and biographical data of participants that took part in the current study, as well as the procedures that formed part of sampling and data collection. The procedures that were used to conduct thematic analysis were also outlined. The chapter concluded with a discussion of the means that were utilised to maintain trustworthiness and the ethical considerations of the current study. The next chapter will present the findings and the key findings that were obtained during the current study.

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## **Chapter 4: Findings**

### **4.1 Introduction**

The findings of the current study will be reported in this chapter. Even though there were differences in the children with an ASD diagnosis in terms of age and developmental levels, there were several common themes identified through thematic analysis of the 11 semi-structured interviews with the parents. The list of themes and sub-themes are reported in terms of capabilities and demands faced with having a child diagnosed with ASD, according to the parents.

### **4.2 Application of theoretical framework**

The current study focuses on the perspectives of parents when introducing a live-in caregiver, during a crisis period of needing consistent support and respite. The current study examined the parents' experience in terms of capabilities and demands offered by full-time live-in caregivers. According to the FAAR model (McCubbin & Patterson, 1983), a family undergoes continuous cycles of adapting to crises. The family then utilises its capabilities to balance out the demands placed on the family unit. The meaning which the family places on this apparent balancing of demands versus capabilities will determine the way in which the family adapts to the crisis.

The current study examines the demands placed on parents needing support services for their child diagnosed with ASD, which is identified as the crisis period, according to McCubbin and Patterson's (1983) FAAR model. The study also examines the capabilities that the participants report they experience during this crisis period as well as the meaning placed on this experience. In the current study, the demands include four themes, namely: (1) the experience of the parents (from diagnosis to finding a suitable live-in caregiver), (2) their family functioning, (3) social interaction and independence, as well as (4) support services currently available for their child, diagnosed with ASD. These demands are discussed during the interview with the parents, and their experience being a capability, or demanding to their specific family system. During the interviews, participants often revealed the meaning they have placed on potential stressful situations, their coping behaviours, as well as resources that have supported their family during these demanding periods. The participants of the current study reported how they reached a balanced functioning level within their family by utilising their capabilities (such as generalising skills and strategies to the home environment, the respite the live-in caregiver offered and the continuity of support) to meet the demands placed on them. This effort to balance demands and capabilities is mediated by the meanings the family assigns

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to events. According to Patterson (2002), families go through repeated cycles of adjustment (characterised by relative stability), crisis, and adaptation (characterised by discontinuous change) over time. Please see Figure 3 for a visual representation of how the FAAR model (McCubbin & Patterson, 1983) has been applied to the current study.

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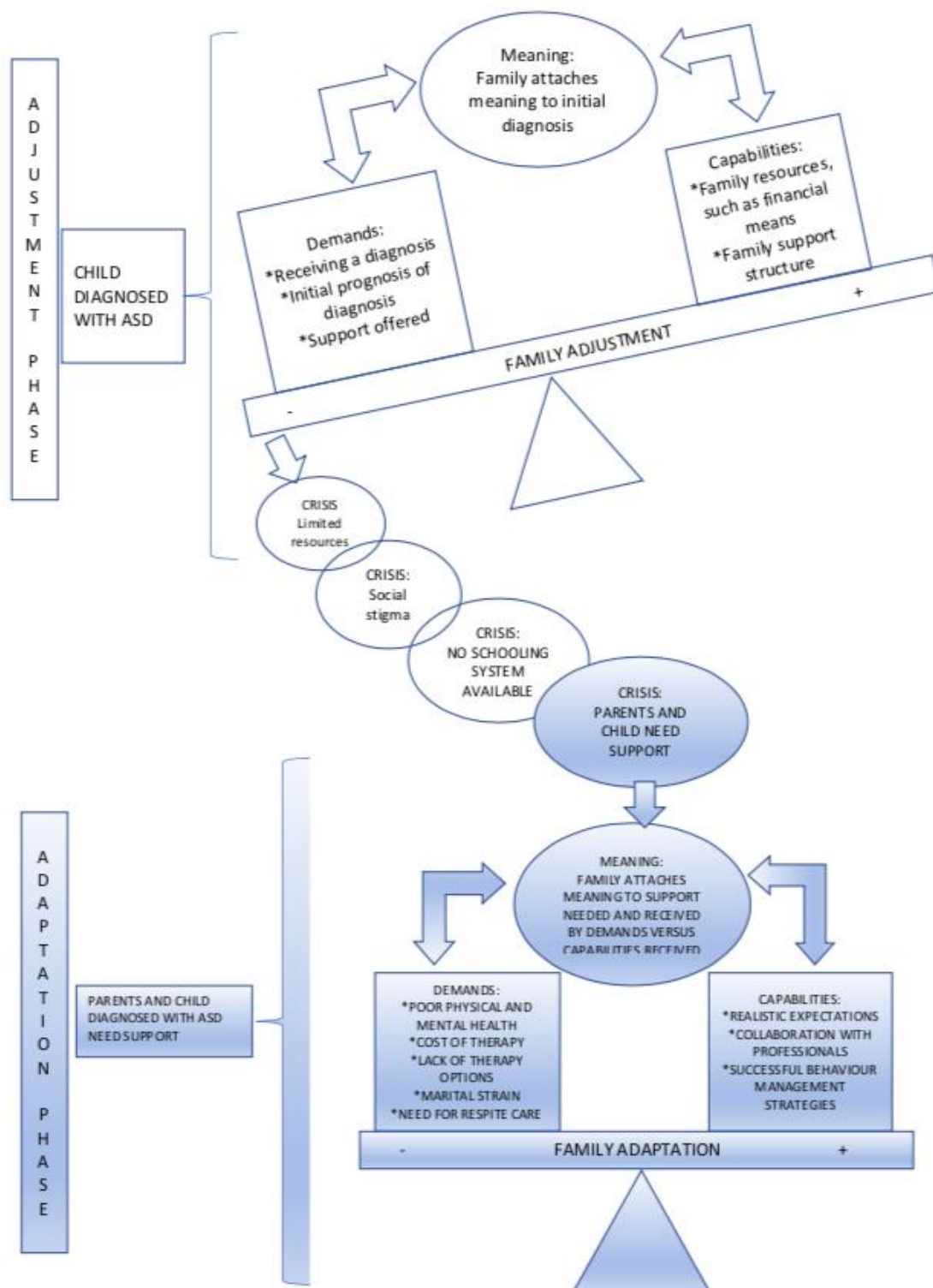


Figure 3. Visual representation of the FAAR model applied to the current study

Table 2 explains the different family systems and the main sub-themes reported as

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either a capability or demanding.

Table 2

*The main capabilities and demands experienced by parents of a child diagnosed with ASD within the Family Adjustment and Adaptation Response (FAAR) model*

Theme	Sub-theme	Level of system: Adaptation phase
Theme 1: Live-in caregiver experience	1.1 Process in finding a live-in caregiver	Capability
	1.2 Experience of having a live-in caregiver	Capability
	1.3 Having someone from a different country living in your home with different cultures and different beliefs	Capability
Theme 2: Family functioning	2.1 Marital implications	Capability
	2.2 Financial implications	Capability
	2.3 Becoming dependent on another person caring for your child	Capability
	2.4 Parents learning from the caregiver	Capability
Theme 3: Social interaction and independence	3.1 Sibling interaction	Capability
	3.2 Outings, holidays and family vacations	Capability
	3.3 Social interaction with family and friends	Capability
	3.4 Independent play skills at home	Capability
Theme 4: Support services	4.1 Going to school and other therapy sessions	Capability
	4.2 Other forms of support	Capability
	4.3 Lack of sufficient support in the country	Demand

### 4.3 Capabilities and demands

Although McCubbin and Patterson's (1983) Family Adjustment and Adaptation Response (FAAR) focuses on three levels of systems (individual, family and community), the main area of focus is on the family system and its ability to adjust and adapt within a crisis. The current study focused on the second phase of the FAAR model, namely the family adapting to a crisis as a family unit. The levels of systems that are discussed are the individual's reported ways of either being capable or finding it demanding throughout the crisis as it relates to the experience of having a full-time live-in caregiver. Four themes and thirteen sub-themes emerged from the thematic analysis as capabilities to the individual (the parent) and the family.

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The main themes include the live-in caregiver experience, family functioning, social interaction and independence and lastly, support services. One sub-theme (lack of sufficient support in the participants' countries) emerged from the thematic analysis as challenging to the individual and the family. Each of these themes and sub-themes will be discussed in the next section.

### **Theme 1: Live-in caregiver experience**

This theme falls into the category of the family system, as it requires the entire family to adjust and adapt to finding a well-suited caregiver, living with this caregiver and adjusting to potential cultural, religious and personality differences.

#### ***Sub-theme 1.1: Process of finding a live-in caregiver***

The majority of the participants (8 out of 11) agreed that finding a live-in caregiver was a relatively easy process. One participant mentioned that referral occurred from a professional as well as a friend that was already utilising AG's services. The following quote illustrates the ease of this participant's decision from needing extra support to hiring a full-time live-in caregiver:

...it was fairly easy, because we already had a referral and a recommendation from a friend who was actually with AG already. (PG)

Another capability that was expressed by participants was that the caregiver was an immediate good "fit" for the family and became "part of the family" (IB). The following quotes illustrates these findings:

Finding them (AG) is very, very easy. We started off very smoothly and things set off just like that, not even a month. In two, three weeks. (BH)

I knew about "AG" so I Googled it and then "AG" started the process. The caregivers have capable backgrounds and they have so much experience with handling kids with ASD. That's why I want to try "AG" and the process is very easy. I met the caregiver, did an interview with her. I then spoke to the director and the process was done simply like that. (EJ)

It was an easy process. It was something that if it went well, it really went well. I mean we spoke to (caregiver), our therapist, and when we emailed her and did a few calls, we immediately felt "okay, this is okay". It could have gone the other way as well, that we



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didn't feel a connection or that the call didn't go well. Or if she eventually got here, we didn't feel a connection, but actually with (caregiver), as soon as she arrived, we felt that she was part of the family. It was a really good fit and I think also personally, (caregiver) is very dedicated and a very nice person. (IB)

### *Sub-theme 1.2: Experience of having a live-in caregiver*

All the participants agreed that the experience of having a live-in caregiver is a capability to their child and family. The capabilities of having a live-in caregiver included their child showing progress in a variety of developmental areas, generalising skills to different environments, the parents having more time to interact with the child's sibling(s) and the unique approach that "AG" offers, in terms of the number of hours of support offered and the novel idea of a full-time caregiver, living with the family. The participants also reported feeling less stressed. These capabilities are illustrated in the following quotes:

...when he comes back from school and he has to complete his homework, there is continuity. And the way the person is handling Sammy at home and at school, there is continuity of that at home as well when he's doing homework with the person or doing any kind of therapy with that person or even just playing simple games. (LB)

Obviously, it's easier, of course. I am less stressed and I have more time for myself also and since we have not only one child, but three children it is much easier for me to also give attention to the other children. So, it is better, actually our life is getting much better. I just want to add that having a caregiver and then also doing therapies with him constantly gives amazing results... (MD)

The company called "AG" and us were formulating this idea to take what was a unique approach to the treatment of ASD and who we were familiar with and then sort of build on our needs specifically... You know there is a lot of stressors there and actually I felt that having a live-in therapist reduced the stress...(MS)

...we are not nearly as exhausted and we are certainly not as reliant on having a resource... His interpersonal skills and communication, while not yet a hundred percent, has certainly improved exponentially... (MS)

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I think what was quite instrumental was to get the live-in therapist to see him in all aspects of his life. From the second he wakes up to the second he goes to sleep, because it is basically more of a holistic approach really. It is looking at the whole child as opposed to looking at a child in a session, in a bedroom. (RD)

### ***Sub-theme 1.3: Having someone from a different country living in your home with different cultures and different beliefs***

All participants agreed that having a live-in caregiver from a different country was not a challenge for their family. Some participants agreed that people from specific countries suited certain cultures better, but all participants felt that their caregiver fit in well with their family's cultural and religious beliefs. One participant expressed an extent of trust towards AG to find the best-suited candidate for his child and family. Participants also reported feeling at ease as they are used to having a full-time, live-in nanny in their homes. The following quotes illustrate the participants' experience of having a live-in caregiver from another country in their home:

Since (caregiver) is from the Philippines and it is still Asia. I mean, because we are both from Asia, the culture is almost the same. So, I don't have any problem whatsoever with (caregiver). (MD)

...we had a lot of trust and faith in the due diligence of "AG" – the company we used. That their sourcing methodology ensured not just strong therapists, but individuals that could fit into the home, because they knew the family dynamics pretty well. (MS)

Not an issue, not at all. The (caregiver) is very understanding. So, these interpersonal issues for us have never been an issue. (Caregiver) is very understanding, I would like to say that we feel very welcoming and so far, it is going really well for us. So, we have been used to that kind of environment where we are accepting of other cultures. (Helper) has gelled with us from day one and I think (caregiver) also had the same comfort level and she gelled with us, our family, home environment from day one. (SB)

### **Theme 2: Family functioning**

According to McCubbin and Patterson's (1983) Family Adjustment and Adaptation Response (FAAR), the family's ability to maintain balanced functioning during the adaptation stage when a crisis arises is of utmost importance. The way in which a family sustains a balanced functioning is through utilising their capabilities (resources and coping behaviours)

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when presented with the demands (stressors and strains) of a potential, yet inevitable crisis (McCubbin & Patterson, 1983). As already explained, the crisis in this study can be seen as having a child that was diagnosed with ASD and finding the appropriate support (consistent) for this child and respite for the family. The capabilities and demands were presented through the interview process by participants explaining different areas in their personal and family life, that they have experienced as beneficial or challenging the support of a live-in caregiver. In general, participants found the support of a live-in caregiver to be a positive coping skill for their family unit to manage the demands and support a child diagnosed with ASD presents.

### *Sub-theme 2.1: Marital implications*

The majority of participants (7 out of 11) found having a live-in caregiver to be beneficial to their family functioning and specifically their relationship with their partner. Reasons for this alleviating of marital strain included having another person in close proximity that was able to find solutions from a different perspective. Participants also reported alleviation of stress in their relationship as the caregiver provided an “extra pair of hands” (MS), they did not feel alone in the management of their child anymore and were offered a solution to challenging behaviours that was “always present” (PG). Participants also reported having more time and thus feeling less stressed. The following quotes illustrate the experiences of participants regarding marital implications of having a live-in caregiver in their homes:

It is different when she is with us. Let me put it this way; there is someone that sees it from another perspective, right? If it’s just the two of us, we tend to argue about my son and also, we don’t really see how the other person is dealing with things. The therapist sees it from a different perspective and gives us a solution on how to handle him and how to deal with his behaviour. So, yes, it is helpful. (IB)

I have more time for myself. (MD)

...having a live-in therapist reduced the marital stress exponentially, because you knew that you weren’t alone and in real time you had an extra pair of hands. Most importantly, in real time, you can troubleshoot. And you’re learning through the process all the time, both in real time and also, you can sort of recalibrate and debrief at more appropriate times and continue your learning. So, for me it actually caused less stress in the home environment. (MS)

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...point is it's really hard not to sometimes let the resentment filter in if you've had a tough day and you can't be there in the way you want to for the child. That kind of being able to have that third-party come in and almost take that away from you. So that the guilt that you obviously feel, rightly or wrongly, or the kind of availability that you might want to give dissipates with having a live-in person. Life just gets in the way because either work or other siblings are involved. And you can actually have more of a balanced role in your child's life as opposed to always taking turns with your husband. (PG)

### *Sub-theme 2.2: Financial implications*

Although most participants (9 out of 11) mentioned strain due to cost implications of having a child diagnosed with ASD, they also mentioned that certain therapies were “worth” the cost and needed support that “AG” offered (EJ). This is demonstrated with the following quote:

...the challenge of having an ASD kid is that it takes more time and extra money, extra effort and everything. But I think it's worth it, so for “AG” I know it is a financial challenge, but then again it is worth it. I mean, you ask for an experienced (caregiver), you get an experienced (caregiver), for that kind of money. In (country) sometimes we pay, but the services can't compare to the price, so I'm satisfied with “AG”. (EJ)

Another participant mentioned that although the service is “worth it”, it is not sustainable (IB):

It is high, but it is worth it. But it's also not very sustainable. (IB)

One participant mentioned that cost is not a factor if there is an end goal in sight:

...knowing that it (caregiver's full-time presence) has a purpose and we're moving towards that and that the end goal is much more manageable and it makes it more comforting to know that. (TG)

In general, participants felt that the financial implications would have been present in any case having a child diagnosed with ASD and that the cost for their current live-in caregiver was either similar to the cost of other therapies or lower:

...the benefit of it is more than what we spend, so I think it is really worth it to have a caregiver from “AG”. (MD)

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Well, for us personally, (country) is a really expensive place for an education and particularly for special needs education. Although we weren't necessarily "better off" I suppose with "AG" coming in, we would definitely be worse off and in fact richer for the month. We feel that the value for money that we gained in terms of, not only emotional and academic support for the child, but also the intimacy of having an "AG" therapist every single day as part of our lives was worth more than the kind of therapies that we were putting in... (PG)

...when we took away all of (child's) extra therapies, all the school and all the extra stuff that really wasn't necessary, I think it (AG) was definitely financially viable. (RD)

***Sub-theme 2.3: Becoming dependent on another person caring for your child***

The majority of participants (6 out of 11) did not feel that they would become dependent on the support a caregiver offers their family. They expressed that they feel comfortable in detaching from this type of support at a later stage. Some participants were still concerned about their current understanding of managing their child's challenging behaviour. They did, however, explain that they did not feel this will be a problem for them once they fade support services out at a later stage. The following quotes illustrate what participants reported regarding becoming dependent on their caregiver:

Yes, I see that problem, but it's only when the child has anxiety issues. Sometimes we might not know or we might not have enough practice to be able to calm the child down and to handle the situation. So, those kinds of situations, we do foresee for now with (child), especially at school. Even outside, we do feel that we kind of sometimes struggle. (LB)

Of course, I'm always worried about that but (caregiver) only comes from Monday to Friday now, so Saturday and Sunday (child) is usually only with us and then we do not see any problem with that. Hopefully when (caregiver) has to go and we have to, we can continue what he's doing perfectly. Without any problem whatsoever. (MD)

***Sub-theme 2.4: Parents learning from the caregiver***

All participants reported that they were able to learn a variety of strategies in managing their child's challenging behaviour better through having a live-in caregiver. They also

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reported being able to put strategies in place to increase their child's coping skills during transition periods and reported feeling supported by the caregiver's presence in their home and implementing these strategies. Participants reported that they felt more susceptible to advice when it is given from a professional rather than from their partner or family member. They also reported feeling a sense of consistency in maintaining the different strategies in place as well as a stable routine, which they credited the caregiver's presence with. The following quotes illustrate the positive feelings parents reported by learning from the caregiver:

She (caregiver) showed us quite a lot. She helped us, she told us the issue, she showed us what the problem was and then she told us what we need to change. She (caregiver) implemented a routine that (child) had to follow, even us, as the parents and the nanny had to all follow the routine. We had to observe and change. (BH)

It would be less welcoming if I told my partner: "look, that's what you have to do with him", than if it comes from a professional that says: "look this is how you have to do this or this is the strategy for you and your child". It's more welcoming when it comes from a professional, I think. (IB)

To generalise the strategies that the therapist is using should be the ideal situation. So that when you're on an outing, he listens to you, just like he's listening to the therapist. (IB)

You're learning through the process all the time, both in real time and also, you can sort of recalibrate and debrief at more appropriate times and continue your learning. So, for me it actually caused less stress in the home environment. (MS)

### **Theme 3: Social interaction and independence**

As mentioned before, Patterson (2002) explains that families go through repeated cycles of adjustment (characterised by relative stability), crises and adaptation (characterised by discontinuous change) over time. In this current theme (social interaction and independence) the participants were asked about the meaning they have placed on different community and social situations (such as interactions with a variety of people and their child in a variety of settings) and how well they have coped with these potential stressors. Four sub-themes emerged from the thematic analysis, namely: (1) sibling interaction, (2) outings, holidays and family vacations, (3) social interaction with family and friends, and lastly (4) independent play

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skills at home. These sub-themes are discussed below in terms of the participants' reported views of these situations being either beneficial or challenging.

### ***Sub-theme 3.1: Sibling interaction***

All families that formed part of the current study consisted of more than one child in their household. According to the majority of participants (6 out of 11) sibling interaction of a neuro-typical child and their sibling, who has been diagnosed with ASD, is beneficial if a live-in caregiver is present. Participants reported that they see a positive change in sibling interaction due to inclusion of games and activities during the caregiver's sessions with the child diagnosed with ASD. Participants reported that due to the inclusion of games, the sibling appeared appreciative of the involvement. Participants also mentioned that the child with an ASD diagnosis seems calmer and thus interaction with their siblings becomes more natural and leads to siblings learning from each other. These views are demonstrated by the following quotes:

...in fact maybe in some ways "that" (sibling interaction) has improved because sometimes (caregiver) involves (child's sibling) in some of the activities. (LB)

So, (child), is usually calmer when (caregiver) is present and the brother can interact better with him. (MD)

I think it's great. (Child) shares a room with her younger brother (child's sibling), and that made for some fantastic interactions. And (caregiver) encouraged this interaction by taking them on trips together and used that as a framework to understand a-typical social interaction. It just allows them to have someone that she (child) can play with and interact with in real time without having to arrange playdates to try to recreate that. So, that's been fantastic. And it's been great and that's worked incredibly well. (TG)

### ***Sub-theme 3.2: Outings, holidays and family vacations***

According to all participants, having a live-in caregiver that accompanies them on outings, family holidays and vacations makes it less challenging and more beneficial for the family members involved, including the child diagnosed with ASD. Participants reported that generalising strategies from one environment to another becomes easier as well as having one consistent person that implements these strategies. Participants also reported being less stressed having "another pair of hands" that can help with respite care whilst they had to divide their

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attention to either the sibling of the child diagnosed with ASD or other people in their family or environment. The following quotes demonstrate what participants reported during the interview:

Okay, so if the therapist is not with us, then it's as challenging as it ever is, as always. If the therapist is there, then yes, it becomes easier. (IB)

Yes, absolutely. Right, so it's the continuity of using the same strategies, the same tools to work with (child) and the generalisation of course of having the same person. (LB)

It is easier, of course. It is easier now, than before (caregiver) was around. (Caregiver) helps me, so she takes a little bit of my job by taking care of (child), so I can divide my attention also to my other children. During family outings or vacations, I also have to give attention or do something with my other children so it's definitely easier with (caregiver) around. (MD)

When we had a full-time caregiver, there was no challenge. I think it was just great. You know, the initial therapist could be here, travel and see different parts of the world with us and certainly again reduce the stress on the family. It allowed us, as parents, to have a little bit of respite. It also permitted us to have another pair of hands on our outings and when we are at family gatherings, out of our home country and visiting family from where we are from, in (country), it allowed us to actually be participants and be present in the situation. Whereas, without a therapist one of us is always "on" and not really immersed in the situation. (MS)

### ***Sub-theme 3.3: Social interaction with family and friends***

All participants agreed that social interaction of their child diagnosed with ASD and family and friends improved with a live-in caregiver's support. The general theme that emerged through participants' reports was that the consistency of having one person following through with strategies in a variety of settings and with different people in the child's life, lead to a positive change. This is illustrated by the following quotes:

At the end of the day, the best person to take with you (on family vacations) would be a therapist, because that helps (child) and it keeps (child) busy and entertained. It doesn't mean that he's not doing stuff with us, but it just means, like for example, we go out to the park and we go as a whole family and let's just say one of the therapists



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comes with us, it just means that if we bump into people in the park we can actually chat with them while (child) is being looked after by the therapist. (RD)

(Caregiver) comes and helps manage them (children). (Caregiver) also joins in conversations with our friends. She sits at the table with us when we have friends over and so on. So, it's been beneficial... (SB)

### ***Sub-theme 3.4: Independent play skills at home***

The majority of the participants (6 out of 11) felt that their child's independent play skills at home improved, since hiring a live-in caregiver. This is a major improvement for parents who have children diagnosed with ASD as previously mentioned, parents express a need for their child to occupy themselves. From the quotes below, it is evident that participants in the current study expressed that having a live-in caregiver has improved their child's ability to play in a more natural setting:

Yes, absolutely. Her imagination has just completely blossomed. She has so many more ideas and the kind of building blocks of play that you might consider a child to have sort of earlier on, you can really see happening now and how she's making sense of the world through play. (PG)

I think it's made a big difference in that you are able to see (child) in her natural environment. (TG)

Participants added that they still believe too much "screen time" was present playing on iPads or smartphones. These reported feelings are reported in the quotes below:

...he will play independently, but it's when he's playing with a screen. Which is not really independent play. (IB)

...where he we will go into his room and he will get out of piece of paper and write or he will read a magazine, but the fall back is always to, to technology. (MS)

### **Theme 4: Support services**

Another theme that participants have reported that they have to manage, in terms of adapting to having a child diagnosed with ASD, is other support services available in their country. This theme emerged through interviews and was not specifically part of

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any question asked. Three sub-themes emerged from the thematic analysis, namely: (1) the caregiver going to school and other therapy sessions with the child, (2) other forms of support available, and lastly (3) the lack of sufficient support available in the participants' country of residence. These sub-themes are discussed below in terms of the participants' experiences of these situations being either beneficial or challenging.

### ***Sub-theme 4.1: Going to school and other therapies available***

The majority of participants (9 out of 11) believed that a live-in caregiver accompanying their child to school and other therapy sessions is beneficial for their child. Some of the capabilities that were reported by participants included consistent generalisation of strategies from one environment to another and learning as well as teaching from the other therapists in the child's team. It was reported that the school of some of the children diagnosed with ASD felt satisfied and grateful for these strategies put in place by the caregiver. The quotes below illustrate these reported feelings that emerged through the interviews:

Because she is able to take him there and she also learns from the OT some of the strategies that he's using. So, there is again continuity, because what he's using, she also tries to incorporate at home. And the strategies that she uses to work with (child), she generalises to other environments. That helps to build continuity. And she also helps us as she is able to take him in (to sessions and school), because otherwise I would have had to take him. So, that's a big help as well. (LB)

...the most challenging thing about being a special needs parent is that loneliness in decision-making. The fact that you don't know. You're doing everything in good will, but you're not necessarily sure that it's the right decision. So, to have that kind of neutral, objective stance, is very useful and the only way we can really manage that is if she's actually pivotal to all of our strategies. (PG)

The school finds (caregiver's) presence in school to be beneficial. That's the feedback we got from the school teachers, and he definitely works better when (caregiver) is going to school with him. (SB)

Absolutely – it has been great, so (caregiver's) been there in some of the occupational therapy, she either picks (child) up or, is sometimes there with her. Being able to support us and learns first hand, seeing some of the different occupational therapy styles

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herself and some of the therapists we use. I think that's worked very well. (TG)

***Sub-theme 4.2: Other forms of support***

Most participants (9 out of 11) reported that they have sufficient alternative forms of support. The majority of participants listed a nanny or helper as their main form of support, in addition to the live-in caregiver. Some participants listed their parents or the parents of their spouse as forms of support for their family and specifically with their child diagnosed with ASD. Participants reported a need for more affordable support systems, where their child receives more therapy hours but are not charged per hour as this works out to be too costly. Participants also mentioned that they struggle to trust people with their child. Although participants listed reasons for struggling to find adequate support, they did report a need for after-hours help and respite and one participant reported feeling lonely in their journey with a child diagnosed with ASD. The following quotes illustrate participants' needs and support system or network they have:

I think of the nanny or maybe the therapist as outside support. I have my mom, my mom-in-law, every one of us really attends to the kids. (IO)

So, I think the primary person who has made it easier for me is (helper) of course, because she has been more or less there all the time since birth and she has always been a huge help to me. And then of course now, since (caregiver) has come she has been able to handle (child) very well as well. These two persons I would say I am confident with. (LB)

...we were spending an enormous amount of money on various disciplines and therapies because everyone has their idea of what would work best and what's appropriate. You want to do the best within your financial means that you can for your child and what ends up happening or at least in our case, at one point we had too much going on. And so, this (hiring a full-time caregiver) allowed us to sort of cut back enormously, add structure, work and consistency, which is all things that our son needed. (MS)

...when her flare-ups happened, rather than it just being in a therapy session you had once a week, so we needed that constant interaction and that constant care. Within obviously the parameters of "AG's" kind of remit. (PG)

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Yes. So, we also have (nanny's name), who is our nanny. So, (nanny) also helps in terms of caregiving for (child). So, it's the parents, (caregiver), and (nanny). (SB)

One participant also expressed that one of the reasons their family changed from some support to full-time support via a live-in caregiver was the disjointed hourly sessions from one therapy to another in a single day. The following quote illustrates this:

...we would send our son to an OT or any other specialist, with a sort of school-like environment and he was only being seen for a couple of hours at a time. It wasn't really a holistic overview from morning till night so that drove this sort of whole process that we should think about someone that lives in. (MS)

### ***Sub-theme 4.3: Lack of sufficient support in the country***

Some participants (2 out of 11) felt that there were not enough support services in their country of residence. Participants stated that the options of therapists and therapy centres in their current country of residence are not readily available and offer too few hours for therapy and not adequately trained support for their child diagnosed with ASD. These statements are illustrated by the quotes below:

My wife and I also went around a lot to look for a local therapist. A centre to help us and (child). They do not have enough therapists and every client only gets one or two hours. I said "don't waste my time". I am looking for a full-time therapist, I am not looking for one or two hours. There were kids that we know who actually spent three years of their time, with these centres, with only one or two hours a week and the progress was like nothing. (BH)

In (country), there is a lack of international or national (services) plus local schools. There is a lack of learning support. It's very difficult. (IB)

Yes, because near my area or in (country) there are not any schools that have the support system to accept kids on the spectrum. (IO)

Yes, because (child) is nonverbal, so at the moment there are no support services available in my country. (MD)

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One participant also expressed a need to train local therapists that can speak the local language as well as offer their services at more affordable rates:

I mean train locals to be a therapist. It would be cheaper. (BH)

### **4.4 Conclusion**

The findings of the study were reported according to the second phase of McCubbin and Patterson's (1983) Family Adjustment and Adaptation Response (FAAR), namely, adapting to a crisis. This study focused on the effect a child diagnosed with ASD has on the family who hired a full-time caregiver. Various themes and sub-themes were identified during analysis of the semi-structured interviews that were conducted with the caregivers involved in the current study. These themes consisted of the capabilities and demands that influenced the participants. The four main themes that emerged through thematic analysis included (1) the live-in caregiver experience, (2) family functioning, (3) social interaction and independence, and (4) other support services offered. In general, participants found having a live-in caregiver as beneficial for their child diagnosed with ASD as well as their entire family. In the final chapter to follow, the findings of this study will be integrated with the existing literature on this topic.

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## **Chapter 5: Discussion**

### **5.1. Introduction**

This chapter aims to provide a discussion of the most significant findings that emerged in the current study. This will be achieved by linking the themes and sub-themes that were identified and interpreted through the lens of the theoretical framework with those that have been identified in the existing literature. Limitations to the study, recommendations for future research regarding this topic and concluding remarks will thereafter be presented.

### **5.2 Discussions of findings of the study, theoretical framework and literature**

The current study aimed to explore the capabilities and demands experienced by parents who have a child diagnosed with ASD and have hired a full-time live-in caregiver as a form of support. According to the FAAR model, individuals go through continuous cycles of, firstly, adjusting to the demands and the meaning placed on these demands by utilising capabilities. Secondly, families experience crises and again, the meaning the family unit places on these demands during a crisis leads into the family's way of adapting (McCubbin & Patterson, 1983). This process is seen as a cyclical event, where once adjustment has been attained, another stressor or challenge presents itself and it is then up to the family to adjust and ultimately, through a crisis, to adapt. Using the FAAR model (McCubbin & Patterson, 1983) as a means to interpret the findings of the current study, the main and sub-themes that were identified during analysis were grouped according to the crisis. In the current study, the need for support in terms of more frequent and consistent respite can be seen as the crisis period. The meanings that participants have placed on this needed support were explored during the interviews and subsequently analysed and reported in the findings chapter in accordance with the themes and sub-themes that emerged.

The available literature indicates that supporting a child diagnosed with ASD presents a variety of challenges for parents (Bluth et al., 2013; Fewster & Gurayah, 2015; Ooi et al., 2016; Padden & James, 2017). Researchers suggest that raising a child diagnosed with ASD might be more challenging than not only raising a neuro-typical child, but also a child with a different diagnosis, such as Down Syndrome or Learning Difficulties (Baker-Ericzen, Brookman-Frazer, & Stahmer, 2005; Dabrowska & Pisula, 2010). A study conducted by Baird et al. (2003) suggests that there is a need for parents of children diagnosed with ASD to receive more respite.

According to the literature on respite for children diagnosed with ASD and their families it seems that most respite offered is not full-time (Fewster & Gurayah, 2015). Parents

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have expressed, in a variety of studies, their needs to receive more consistent and continuous support (Baird et al., 2003; Fewster & Gurayah, 2015; Hodgetts et al., 2015). Having a full-time caregiver may be one example of such support. Participants in the current study reported that having a full-time caregiver contributed to alleviating stress in multiple environments, such as marital, sibling interaction and social functioning due to receiving consistent support.

The following sections will focus on the most prominent themes that emerged during this study according to the second phase (adaptation) of the FAAR model (McCubbin & Patterson, 1983) after a crisis presents itself (in this case a child diagnosed with ASD needing more support services). This will be achieved by discussing the themes that were identified during the current study. These themes will then be linked with available literature and determining if the theme or sub-theme was initially reported as challenging or beneficial by the participants of the current study. The experiences reported by participants will determine the meaning placed on these situations and ultimately the family unit's ability to ultimately adapt to these situations or events.

### **5.2.1 The live-in caregiver experience**

Basnyat and Chang (2016) found during their study that people who have a child diagnosed with ASD are often overwhelmed by the amount of support that their child needs, which impacts other areas of their lives as well, such as poorer physical and mental health (due to an increase in stress levels) compared to parents of neurotypical children (Padden & James, 2017). According to Hodgetts et al. (2015), parents have reported feeling obligated to proceed with limited options of services providers or information received by pediatricians. These families often require full-time support in the form of live-in caregiving, which is most often not part of the recommendation from a pediatrician. This unmet need in turn affects their personal and social life as well as their emotional state in other aspects of their lives, due to added pressures on their family unit (Harding et al., 2012).

Contrary to the literature described above, the process of finding a live-in caregiver was an easy process, according to the majority of the participants of the current study. This relatively easy process was due to referrals from a friend or a pediatrician that has worked with AG before. One participant found AG online, by searching on "Google" for a live-in caregiver. In general, this shows the importance of having a network of people being informed by the variety of support services available. According to Cowen and Reed (2002), additional supports and services, such as referrals for different types of assistance, is crucial in alleviating stress parents might experience when having a child diagnosed with ASD.

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According to Hodgetts et al. (2015), parents often feel distrust towards professionals during the diagnosis process as well as the ongoing time period of securing appropriate service providers for their child. The current study's findings have shown that parents have trust in AG to find an experienced caregiver. This trusting relationship also continues after the caregiver is placed with the family, as some participants expressed that they trust the caregiver more with managing their child than other professionals or family members. According to a study conducted by Emira and Thompson (2011), parents noted that changes in therapists are particularly challenging for children diagnosed with ASD. This changing of therapists usually occurs with short term therapies (Emira & Thompson, 2011). This is different to signing an employment contract with a full-time live-in caregiver for a minimum time period of twelve (12) months, which is AG's policy. The continuity of having the same person to work with their child over a long period of time might contribute to the trust that parents reported in AG.

Fewster and Gurayah (2015) state that parents experience intense emotions of isolation, confusion and frustration during the path of a diagnosis and finding appropriate support services for their child. Again, this is different to the reported feelings of relief that participants in the current study expressed when they reported their experiences of having a full-time live-in caregiver. According to Betsy (2002), parents of children diagnosed with ASD feel at ease when appropriate support services have commenced as this process usually takes longer than expected. Betsy (2002) continues to state that most empirically proven interventions require parental involvement of some sort in the support they offer. In this case, having a live-in caregiver who is with the family for most of the day seems to offer relief to the parents, because the caregiver can stand in for them when they cannot be involved in the interventions.

As mentioned in the literature review of the current study, pediatricians typically refer parents to ABA, Speech and Occupational therapists to serve as support services for children diagnosed with ASD. A well-documented limitation of ABA and other forms of short-term therapy is the ability for parents to generalise specific skills learnt in these environments to the home environment (DeFilippis & Wagner, 2016; Fewster & Gurayah, 2015). In the current study, participants expressed feeling less stressed due to the generalisation and continuity of skills by one person (full-time caregiver) accompanying their child to different therapeutic settings, social settings as well as school settings. The reported feelings of alleviation of stress combined with the confidence of the caregiver generalising skills from different environments to the home environment are beneficial in the adaptation process of the family unit to the crisis of needing more support services for the child diagnosed with ASD. According to Drasgow,



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Halle, and Phillips (2001), children diagnosed with ASD frequently struggle with generalising skills from a therapeutic environment to the home or social environments.

Basnyat and Change (2016) conducted a study with the partners of patients diagnosed with dementia and reported that the partners felt at ease with having a caregiver from a different country in their home. This result is similar to the current study where all participants felt at ease with the caregiver being from a different country to their own, which is another capability to the family unit's ability to adapt to the novel situation of a person living in their home.

Successfully finding a live-in caregiver and the initial period of the family to familiarise with a foreign person in the family's home have been reported as beneficial to the participants of the current study. McCubbin and Patterson (1983) explain that the family adaptation process weighs on the family unit's ability to utilise the capabilities and the demands placed on it during a crisis. The meaning the family places on the event of finding a live-in caregiver and familiarising a new person in their family home in turn affects the way in which this family adapts to the new situation within the crisis of needing support services for their child diagnosed with ASD. The live-in caregiving process and experience in the current study can be seen as the family unit's ability to turn potential demands into capabilities through the meaning they have placed and positive experience they have experienced during these events.

### **5.2.2 Family functioning**

From a family perspective, parents with a child diagnosed with ASD have expressed their concerns about the increase in marital strain. According to Bluth et al. (2013), parents with children diagnosed with ASD have a higher divorce and separation rate than families with neuro-typical children. Ooi et al. (2016) found a direct link of higher levels of parental stress to children diagnosed with ASD who engaged in more challenging behaviours.

According to the study conducted by Harper et al. (2013), parents reported a positive correlation between the amount of respite care that they receive and the quality of their marriage. Similarly, the current study found that parents reported that they were less stressed due to the extra support from an alternate perspective and an "extra pair of hands". Participants of the current study also reported that having a person in "real time" alleviated some of the stress as there was an immediate feedback loop, especially during behavioural outbursts, from the caregiver to the family. Receiving respite care on the functioning of the family is seen as a capability in the current study as it alleviates stress within the marriage according to these findings.

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The cost of therapy for a child diagnosed with ASD can deter some parents from seeking full-time support though. According to Wang et al. (2013), most therapies that are recommended by pediatricians are privately covered by parents, which makes it unsustainable and increases the stress and demands placed on parents (Horlin et al., 2014).

Participants in the current study reported that hiring a full-time caregiver is costly, but they believe that it is valuable due to the progress their child is making with the support of the caregiver and the ability of both the parents to work part-time or even full-time. According to the FAAR model (McCubbin & Patterson, 1983), the ability for a family to turn a demand into a capability is the way in which a specific meaning (reported feelings of full-time caregiving being valuable) is placed on the situation. One participant agreed with literature that the cost of therapy (including full-time caregiving) was not sustainable. According to Horlin et al. (2014), the cost of various forms of therapy combined with parents (or one parent) needing to resign from their jobs in order to help generalise skills to the home environment is not a sustainable, long-term solution for families. In the current study the meaning of progress observed and having more time for themselves and their career might be outweighing the initial burden the cost of support services places on the family, although it seems that the findings of the current study agrees with the unsustainability of full-time support as an ongoing option. Literature suggests that parents are able to sustain support services for a limited amount of time before the cost of therapy affects them in a negative way by increasing stress in the family unit (Hoefman et al., 2014; Horlin et al., 2014). The majority of participants saw the presence of the caregiver as an important foundation to assist them to cope effectively and to assist them to ultimately be able to function as a family without the assistance of a full-time caregiver.

Participants of the current study reported not being concerned about over-dependence on the caregiver as they involved themselves in their child's programme and development. Some participants reported that they believe fading services at a later stage might become challenging for their family to manage. The meaning that participants placed on the support services of having a full-time caregiver seems to increase the anxiety that they reported regarding the future of potentially not having a full-time caregiver. According to Imms and Fossey (2004), parents go through two phases, firstly adjusting to the situation of their child being diagnosed with ASD, and secondly, becoming active participants in their child's home therapy. This study concludes that parents take an average of two years to become active participants in their child's home therapy, which might suggest that a live-in caregiver is valuable for at least the initial two year period from when the diagnosis is confirmed (Imms & Fossey, 2004).

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This leads into a way for participants to increase their capabilities by learning strategies from their caregiver. According to Harding et al. (2012), parents prefer formal respite care of an experienced individual guiding them with strategies. One participant believed that the strategies that were put in place by the caregiver were beneficial as it was an experienced and full-time caregiver. The meaning that participants placed on the quality of advice given by the caregiver and the company (AG) suggests that they adapted to the crisis (needing support services) easier with the strategies that were put in place. According to one participant, the caregiver implemented a consistent routine that he and his wife were able to generalise easily. The generalisation and continuity of the strategies introduced and utilised by the full-time caregiver was again mentioned as one of the most important capability gained from this type of support service. As mentioned before, multiple studies have shown the importance of skills and strategies learned in therapy being generalised to more natural settings, such as the home environment and during outings with parents (Brentani, et al., 2013; Drasgow et al, 2001; Fewster & Guraya, 2015).

### **5.2.3 Social interaction and independence**

According to Nealy et al. (2012), parents report sibling(s) of children diagnosed with ASD might receive less attention than their brother or sister with the ASD diagnosis. This unequal distribution of attention and time can be seen as a demand on the family of a child diagnosed with ASD. Participants of the current study reported progress and maturity of their child diagnosed with ASD due to caregivers involving the sibling in games and activities. Thus, the caregiver utilised the capabilities of the family by involving the sibling in the sessions with the child diagnosed with ASD and the family was able to adapt more positively due to this. Another desire for siblings of children diagnosed with ASD, according to Welch et al. (2012), was to spend more time with their parents. In the current study, participants reported that they were able to spend more time with their neuro-typical child, due to the care that the full-time caregiver offers. According to a variety of studies done on the value of respite, it is evident that an increase in respite alleviates not only parental stress and pressures, but also the stress on the siblings of children diagnosed with ASD (Becerra et al., 2017; Fewster & Gurayah, 2015; Harper et al., 2017; Hodgetts et al., 2015).

According to Fewster and Gurayah (2015), parents find it difficult to generalise behavioural management skills and techniques from therapy to social environments when they are without a trained professional. Participants of the current study reported feeling relieved and supported having a caregiver to constantly support them during outings, holidays and

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family vacations. Another capability to a caregiver being present in a variety of environments is the generalisation of skills, targets and strategies. Participants also reported that the extra support enabled them to participate more on a social level with family and friends. According to Ooi et al. (2016), parents reported higher levels of stress if a child engaged in more challenging behaviours, which often occurs during a change in environment or a structured routine. Again, the family utilised their capabilities (the caregiver's presence) during changes in the environment and reported a positive experience.

Ooi et al. (2016) states that the social stigma of the general public not understanding meltdowns in children who might not look distinctively different still exists. According to Kinnear et al. (2015), parents often report feeling isolated when they are not invited to social events due to what they believe might be a judgement of their child's challenging behaviour. In the current study, participants reported progress of their child and his or her behaviour in social settings due to the constant presence of the caregiver in a variety of settings and thus being able to attend more social settings since employing a full-time caregiver.

Again, it was reiterated that a major capability for participants in the current study was the consistency of the full-time caregiver, the support and strategies that he or she offered and the ability to persevere with the reliability thereof.

Brentani et al. (2013) explain that one of the main goals of an Individual Educational Plan (IEP) for a child diagnosed with ASD should be in adaptive skills. Bluth et al. (2013) similarly state that a major concern for parents is their child's future and ability to function independently. Participants of the current study reported definite progress in independent play skills of their children with the support of the caregiver. The child's natural environment and the capabilities of working within that setting was reported as a reason for this progress. Some participants believed that their child still gravitates towards technology too frequently instead of playing with physical toys. Ganz et al. (2012) argue that for a child diagnosed with ASD a form of technology, such as an iPad with a loaded communicative programme, can be beneficial. This is however beyond the scope of this study and a topic that should be investigated more thoroughly.

The family was able to utilise its capabilities with the caregiver working on independent skills and sibling interaction within the natural setting of the child's home and during social outings as well as holidays with family and friends. The meaning that the family placed on the progress shown in these situations led to the adaptation of the crisis of needing their child to become more independent as part of the support required.

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### 5.2.4 Support services

As previously mentioned, Fewster and Gurayah (2015) state that parents who do not have a full-time live-in caregiver find it difficult to generalise strategies that Speech-, Occupational-, and Behavioural therapists implement during their session to the home environment. Participants of the current study reported feeling supported by the caregiver going to school and other forms of therapies with their child diagnosed with ASD. The generalisation from one environment to another was again reported as being beneficial to parents. Two participants reported that they felt the caregiver was able to learn from the other professionals to generalise targets or skills to the home environment. It was also reported in the current study that the caregiver was able to alleviate stress from parents needing to take their children to different therapies. The consistency through the transitions from one environment to another was seen as another capability to the participants of the current study. It can be argued that participants of the current study placed a positive meaning on the support (capability) they received from a caregiver in terms of school facilitation and generalisation from one therapeutic environment to another. This led to the participants managing their demands (taking their child to different forms of therapies and generalising the strategies implemented in these sessions) by utilising the caregiver in order for the family to adapt to their stressful situation.

Brentani et al. (2013) mentioned that a focus area of children diagnosed with ASD should be on generalisation to natural environments and that goals should be re-evaluated on a consistent basis. This re-evaluation of goals can potentially be completed more frequently with the support of a full-time live-in caregiver and goals can potentially be generalised and reached more quickly by the caregiver accompanying the child to all the different therapies and environments.

Other forms of support were discussed with participants of the current study as participants all reported that they felt supported by their caregiver. When probed to elaborate about other forms of support, all participants reported that, other than the caregiver, their nanny or helper supported their child and their family. Another form of support that was reported was the help of the grandparents of the child diagnosed with ASD. Participants did not feel that, apart from what has been reported, any other forms of support were readily available and/or it was too costly for them to include. According to Nealy et al. (2012), parents feel unsupported after therapy hours (when they do not have a full-time, live-in caregiver). One participant reported that a parent support group, where parents with similar challenges can support each other, is needed.

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Participants utilised their capabilities, which might include the caregiver, nanny or helper and grandparents and placed a positive meaning to adapt to the lack of support services for their child diagnosed with ASD and their families. The need for a support group, according to the one participant, is an example of a demand that he has not been able to adapt to, perhaps as there have not been enough capabilities for him to do so.

The lack of support services in three (3) countries (Cambodia, Indonesia and Singapore) were discussed in the current study with participants that had varying sources of support. Some participants reported a need for more experienced caregivers, such as the caregivers of AG as well as a need for locally trained caregivers that might be more affordable and speak the local language. The financial element and strain have been discussed, but it was mentioned again by participants that an alternative form of support might be less costly – such as training caregivers that might be less experienced but willing to learn. According to Hebert (2014), parents often feel obliged to try a variety of therapeutic modalities that were recommended by professionals as they do not feel qualified to filter through the different therapies and choose the most important ones for their child. This is an area where the demands placed on a family might not be supported by the caregiver in their home. This is a subject that should be explored in more depth in future research.

The findings of this study are consistent with qualitative research that has examined parents' perspectives of ASD-related services in general (Brookman-Fraze, Baker-Ericzén, Stadnick, & Taylor, 2011). Brookman-Fraze et al. (2011) highlighted the shortcomings of accessing information about the available support ASD services, the lack of consistency of these support services and the challenges regarding collaboration between parents and professionals in particular. The limitations of this study will be presented in the next section.

### **5.3 Limitation of the current study**

The current study has several limitations that have to be discussed. Firstly, the sample comprised of eleven participants from three different countries who differed on demographic characteristics, such as the age of the child being cared for, the type of support needed and the years of the caregiving experience of the caregiver. The total participant group was therefore not representative of the broader population of each of these countries or other countries not included in the current study. This limitation was further confounded by the fact that a small sample of predominantly mothers and fathers of the same family was used as a source of data collection. However, it should be noted that the aim of qualitative research is not to generalise the findings, but rather to provide an in-depth description of the experiences of the participants.

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Secondly, the themes and sub-themes that were identified in the current study through thematic analysis were not verified. The preliminary findings of thematic analysis could have been verified by sending the transcripts of the interviews as well as the initial themes that were identified through the data analysis to the participants to ensure the themes were accurately deducted from the interviews. Focus groups could also have been conducted with the participants in order to verify emerging themes by presenting the analysis thereof. This was however not possible, due to the time and geographical constraints as participants were located in various locations in multiple countries. Member checking was, however, utilised during interviews to ensure a clear understanding of what the participants conveyed to the researcher.

Thirdly, the researcher is one of the directors of AG, which makes potential biased answers from participants relevant. The responses of the participants were overwhelmingly positive. Although this might have been their real experiences, it is also possible that they were hesitant to report challenges, because of the close connection of the researcher to the company from which they receive caregiver support services. Although the researcher made participants aware that their answers will not determine any decisions of their child's programme, it is a possible limitation to the study that cannot be overruled.

### **5.4 Recommendations for future research**

Given its exploratory nature, the current study has provided an avenue for future research of parents' experience of full-time live-in caregiving support on an international level. Since this study focused on describing the capabilities and demands of hiring a full-time caregiver from the family's perspective, it is recommended that future research also include the perspective of the caregiver. This might provide guidelines of where training could be improved and also give the means of how to improve training not only for caregivers, but also for parents of children diagnosed with ASD.

A recommendation of one participant of the current study was to create support groups for parents, which is another potential area that can be researched in future studies. A support group might serve as a network where parents can receive recommendations by other parents.

The extremely high cost of therapy seems to be a challenge for not only the parents of the current study, but in general if a child is diagnosed with ASD. It is recommended that more studies should focus on interventions related to more affordable therapy that might be more sustainable.

Another general theme that became apparent that parents of children diagnosed with ASD are struggling with is the ability to filter through recommendations from professionals,

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such as paediatricians, to determine which support services are absolutely necessary and which ones are not worth the cost of the therapy. There is a need to study this further in more depth to help parents with this very important first step towards receiving the most appropriate support for their child in a very crucial stage for them and their child.

### **5.5 Conclusion**

This study aimed to explore the experiences of a group of parents regarding the capabilities and demands related to hiring a full-time live-in caregiver to assist with their child diagnosed with ASD. This exploratory qualitative study revealed that parents encountered a number of demands in the search for appropriate support services for their child diagnosed with ASD. These challenges included receiving adequate information about support services available by pediatricians, choosing therapies appropriate for their child and generalising skills from the therapeutic setting to the home environment. Additional challenges included the family's ability to function in their usual social setting with friends, family and during holidays. These challenges lead to feelings of helplessness that in effect leads to a family crisis of needing support for their child diagnosed with ASD as well as their family system.

AG was a trusted source for participants in finding experienced caregivers to support their child and family in the current study. The trusting relationship the parents experienced with the caregiver and their child in a variety of environments alleviated stress previously experienced. The ability of parents to trust a support service is a definite advantage to parents that can feel intensely isolated during the process of finding and securing support services for their child, when they receive an ASD diagnosis (Fewster & Gurayah, 2015).

One of the overarching themes of hiring a full-time live-in caregiver was the fact that they provided the participants with consistent and continuous support. This type of support service in the form of a full-time live-in caregiver has various capabilities.

Firstly, although participants reported hiring a full-time caregiver to be costly, the capabilities seemed to outweigh the financial cost implication. Participants reported that the value in hiring a full-time caregiver is more important than the cost. Some of the capabilities that were reported include the progress that their child was making, the ability for the parents to spend more time with their other children and for them to receive some respite. It does however seem as if the cost of having a full-time caregiver does not make it sustainable for an indefinite period of time.

Secondly, the respite that participants received is an important consequence of employing a full-time live-in caregiver. Participants had the time and confidence to attend more



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social outings, such as excursions to grocery stores and parks as well as going on family vacations. Reasons for this increase in social interaction varied from having the caregiver accompany their child on the outings or providing the participants with time without their child to engage in these activities. Participants were also able to spend more time with the sibling or siblings of the child diagnosed with ASD due to the respite offered, which was beneficial not only for the participants, but also for the sibling or siblings. The caregiver was able to include the sibling or siblings into interactive games with their child diagnosed with ASD, which was mutually beneficial to the children. In general, the increase in respite was positively related to quality of marriage.

Thirdly, the consistency of accompanying the child to a variety of environments, that the caregiver provided to the participants and their child, were particularly valuable. The caregiver would take their child to the various therapies, school and other environments, such as outings to stores, which was beneficial to the child and the family and thus became a capability. The child was able to have the same person that implemented the same strategies in various environments. It might be suggested that the child is then also better prepared for the expectations of these various environments, due to the consistency of the strategies put in place by the caregiver. Another capability of having a caregiver accompanying a child to various environments, including the home environment, is the immediate consequence and management of behavioural coping strategies.

Fourthly, the ability for the caregiver to generalise skills and strategies from one environment to another was invaluable. This includes strategies and skills that the caregiver generalised from their own time spent with the child diagnosed with ASD, but also from other professionals. Due to the fact that caregivers accompanied the children to the various therapeutic settings, they were able to generalise what other professionals were implementing to the home environment. This in turn offered the participants the opportunity to, once again, learn from the caregivers and generalise skills and strategies from other professionals, which they might not have been able to observe and learn from, to the home environment. In general, this generalisation of skills and strategies to the home environment on a consistent basis seemed to provide the participants with the most significant form of respite and, ultimately, alleviated stress in all the families of the study.

This study is one of the first of its nature to be conducted in various countries with a variety of families. The findings serve as a starting point for future studies on this topic. It is hoped that these findings will increase the awareness of the value of employing a full-time live-in caregiver, that might be required for parents and their children diagnosed with ASD.

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### **List of Appendices**

The following documentation is attached and included in support of the current research project:

- A. Call for Research Invite
- B. Consent Form
- C. Demographics
- D. Interview Schedule
- E. Reflecting on Interviews
- F. Ethical Clearance
- G. IBCCES permission
- H. Non-Disclosure Agreement
- I. Plagiarism Declaration
- J. Turnitin Report

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## **Appendix A – Call for Research**

To whom it may concern,

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This study has been approved by the **Research Ethics Committee at Stellenbosch University**.

**TITLE OF THE RESEARCH PROJECT: The Impact of the presence of a full-time live-in caregiver on the parents of a child diagnosed with ASD**

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR: Miss Karla Pretorius**

**ADDRESS: Jalan Umpeng Sari II, Labuhan Sait, Pecatu, Kuta, Badung, Bali, Indonesia, 80361.**

**CONTACT NUMBER: +62 821 4082 0182**

### **1. What is this research project all about?**

This study aims to explore the perspectives of parents of children with Autism Spectrum Disorder (ASD) regarding the challenges and support offered by full-time live-in caregivers.

Although many studies have examined ASD, very little research has been done on the perspective of parents with live-in support services. I could not locate any studies about this topic. It is possible that themes that emerge in this study could identify not only the challenges that parents of children with ASD face, but also the factors that assist them in coping.

The study will take place at a time and place that suits you best. The first step in the interview process will be filling out the biographical questionnaire. I will then ask you a number of open-ended questions about your experiences of having a child with ASD and a live-in caregiver. The interview will be conducted one-on-one, in-person interview or via a Skype meeting (online) and should last between 30 and 60 minutes. Your permission will be required to record the interview. This will allow me to later transcribe the data accurately and this will allow me to analyse the data accurately.

### **2. Who can participate?**

Parents of children between the ages of 3 and 12 with a primary diagnosis of Autism Spectrum Disorder.

The diagnosis had to be obtained at least 6 months ago.

Parents between the ages of 35 and 45 years.

Parents need to live with their children.

Parents need to have a live-in caregiver (employed by AIMS Global) who works with their child on a full-time basis for 3 months or longer.

Parents need to be clients of AIMS Global.

### **3. What will your responsibilities be?**

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You will only be expected to take part in one semi-structured in-person or Skype interview that should last more or less 30-60 minutes. During the interview, we will discuss some of the challenges you face, as well as some of the factors that assist you by having a live-in caregiver for your child with ASD.

**4. Will you benefit from taking part in this research?**

There is no direct benefit to be gained from participating in this study. This research will however contribute to the existing knowledge in the field of ASD. The study addresses a gap in the literature and as such, the findings could be published in a peer-reviewed journal. This in turn could lead to a greater understanding of the experiences of parents of children with ASD who have a live-in caregiver.

**5. Are there any risks involved in your taking part in this research?**

Participating in the study holds no anticipated risks. However, due to the personal nature of the study, it is possible that the questions discussed in the interview may lead to emotional distress. If this happens, and counselling services are required, Dr. BT (Clinical Psychologist) is available for two 30-minute counselling sessions. Dr. BT has offered two 30-minute sessions to all participants, free of charge. If you need any additional support after this, an arrangement will be made with Dr. BT and the Primary Investigator will be responsible for the cost implications.

Dr. BT can be reached via email: [ben@paarlpractice.co.za](mailto:ben@paarlpractice.co.za) or via phone: +2721 200 8327.

**6. Who will have access to your medical records?**

Any information that is obtained in this study will be treated as confidential and any information that can be connected to a participant will not be disclosed without their permission. The identity of participants will be protected by assigning an alias instead of using your name. Only myself (the primary investigator) and my supervisor will have access to the information obtained during the study. Written consent (via filling out an online form, signing it and emailing it back) will be obtained to use the data generated in the current research project. All the data collected during the interviews will be encrypted with a password and will be stored for 5 years after my study has been completed. It will then be appropriately destroyed and discarded.

**7. Will you be paid to take part in this study and are there any costs involved?**

You will not receive any money for taking part in this study, however, the study will not cost you anything as interviews will be conducted at your home (if appropriate) or via a Skype meeting.


**8. Is there anything else that you should know or do?**

If you are eligible and wish to participate in the study, please contact me via email: [karla@startupautism.com](mailto:karla@startupautism.com) or by phone: +62 821 4082 0182

Further enquiries may be directed to Dr. Chrisma Pretorius at [chrismapretorius@sun.ac.za](mailto:chrismapretorius@sun.ac.za) or at +2721-808- 3453.

Thank you,

The impact of a full-time live-in caregiver on the parents of a child diagnosed with ASD

A handwritten signature in black ink, appearing to read 'K Pretorius', with a stylized, cursive script.

Karla Pretorius

The impact of a full-time live-in caregiver on the parents of a child diagnosed with ASD



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## Appendix B – Consent Form

### STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

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You are invited to take part in a study conducted by Karla Pretorius, a Masters student from the Psychology Department at Stellenbosch University. You were approached as a possible participant because you are a parent (between the ages of 35 years and 45 years) with a child diagnosed with Autism Spectrum Disorder (ASD), a client of AIMS Global and has employed a live-in caregiver for your child.

#### 1. PURPOSE OF THE STUDY

This study aims to explore the impact of the presence of a full-time live-in caregiver on the parents of a child diagnosed with ASD.

#### 2. WHAT WILL BE ASKED OF ME?

If you agree to take part in this study, you will be asked to answer questions in a semi-structured interview. These interviews will be conducted in-person (if appropriate) or via Skype meetings. The interviews are estimated to last for 30–60 minutes and you are able to withdraw at any time or decline answering any question(s).

#### 3. POSSIBLE RISKS AND DISCOMFORTS

Possible risks include an emotional response to some of the questions, as the subject matter will be about your child, his/her diagnosis and support or lack thereof experienced by yourself. Should you feel uncomfortable or under distress during or after the interview process, you have the opportunity to schedule two 30-minute counselling sessions, free of charge, with Dr. BT (Clinical Psychologist) that has been working in the field of autism and specifically with parents diagnosed with ASD since 2002. Dr. BT can be reached via email ([ben@paarlpractice.co.za](mailto:ben@paarlpractice.co.za)) or via phone (+2721 200 8327). If you need any additional support after this, an arrangement will be made with Dr. BT and the Primary Investigator will be responsible for the cost implications.

#### 4. POSSIBLE BENEFITS TO PARTICIPANTS AND/OR TO THE SOCIETY

There is no direct benefit to be gained from participating in this study. This research will however contribute to the existing knowledge in the field of ASD. The study addresses a gap in the literature and as such the findings could be published in a peer-reviewed journal. This in turn could lead to a greater understanding of the experiences of parents of children with ASD who have a live-in caregiver.

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## **5. PAYMENT FOR PARTICIPATION**

You will not receive any form of payment for taking part in this study, however, the study will not cost you anything as interviews will be conducted at your home (if appropriate) or via a Skype meeting.

## **6. PROTECTION OF YOUR INFORMATION, CONFIDENTIALITY AND IDENTITY**

Any information you share with me during this study and that could possibly identify you as a participant will be protected. This will be done by assigning an alias to you, instead of using your name. Only myself (the researcher) and my supervisor will have access to the information obtained during the study. Written consent (via filling out an online form, signing it and sending it back to the researcher) will be obtained to use the data generated in the current research project. All the data collected during the interviews will be encrypted with a password and will be stored for 5 years after my study has been completed. It will then be appropriately destroyed and discarded.

## **7. PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you agree to take part in this study, you may withdraw at any time without any consequence. You may also refuse to answer any questions you don't want to answer and still remain in the study.

## **8. RESEARCHERS' CONTACT INFORMATION**

If you have any questions or concerns about this study, please feel free to contact Karla Pretorius at [karla@startupautism.com](mailto:karla@startupautism.com) or +62 821 4082 0182 and/or the supervisor Dr. Chrisma Pretorius at [chrismapretorius@sun.ac.za](mailto:chrismapretorius@sun.ac.za) or at +2721-808- 3453.

## **9. RIGHTS OF RESEARCH PARTICIPANTS**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research participant, contact Ms Maléne Fouché [[mfouche@sun.ac.za](mailto:mfouche@sun.ac.za); 021 808 4622] at the Division for Research Development.

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### **DECLARATION OF CONSENT BY THE PARTICIPANT**

As the participant I confirm that:

- I have read the above information and it is written in a language that I am comfortable with.
- I have had a chance to ask questions and all my questions have been answered.



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- All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.

By signing below, I \_\_\_\_\_ (name of participant) agree to take part in this research study, as conducted by Karla Pretorius.

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

\_\_\_\_\_  
**Date**

**DECLARATION BY THE PRINCIPAL INVESTIGATOR**

As the **principal investigator**, I hereby declare that the information contained in this document has been thoroughly explained to the participant. I also declare that the participant has been encouraged (and has been given ample time) to ask any questions. In addition I would like to select the following option:

	The conversation with the participant was conducted in a language in which the participant is fluent.
	The conversation with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this “Consent Form” is available to the participant in a language in which the participant is fluent.



\_\_\_\_\_  
 20/09/2019

\_\_\_\_\_  
**Signature of Principal Investigator**

\_\_\_\_\_  
**Date**

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## Appendix C - Demographics

### Biographical information

Instructions: Please fill in your biographical information. Indicate your choices by circling the correct option.

Name and Surname:	
Age:	
Gender: Male/ Female / Other* If other, please specify	
Ethnicity: Caucasian / Person of colour / African / Indian / Other* If other, please specify:	
Marital Status:	
Home language:	
Email address:	
Contact number:	
D.O.B of child diagnosed with Autism Spectrum Disorder (ASD):	
How long has your current full-time live-in caregiver been with your family?	
What was the official diagnosis of your child?	

## The impact of a full-time live-in caregiver on the parents of a child diagnosed with ASD

### **Appendix D – Interview Schedule**

#### **Questions for Participants**

1. When and why did you seek to find full-time live-in caregiving support?
  - 1.1 Tell me more about the process in finding a full-time live-in caregiver.
2. Tell me about the experience of having a full-time live-in caregiver in your home:
  - 2.1 Please describe any benefits and/or challenges you have experienced with this type of support.
  - 2.2 What about benefits and/or challenges relating to:
    - Marital stress
    - Financial stress
    - Sibling interaction
    - Outings, holidays and family vacations
    - Social interaction with friends and family
    - Independent play skills at home
    - Going to school and other therapy sessions
    - Having someone from another country live in your home
    - Different cultures and beliefs
    - Becoming dependent on another person for caring for your child
3. Besides a full-time live-in caregiver, what other forms of support do you have with your child with ASD?
  - 3.1 Does your child attend school during the day?
  - 3.2 Are there special schools in your area?
  - 3.3 Who or what assists you to cope with your caregiving role?
  - 3.4 Who or what makes caregiving easier for you?
4. Is there anything else you want to add regarding your experience having a full-time live-in caregiver for your child diagnosed with ASD?

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### **Appendix E - Reflecting on Interviews**

This is a document that was created to reflect my personal views on each interview conducted and “what stood out” as I was listening to each participant.

**BH**

BH is a 37 years old male, who lives with his wife and two children. He seemed cheerful, by frequently making jokes in the interview. This was an easy interview for me to conduct as BH did not seem to become emotional and negative when asked about his child. He seemed to understand that his son will need some support, but that it will not be an ongoing process, that services will be able to be faded out. This was what BH noted in the interview and he seemed to be excited that he found the appropriate support that was needed at the time for his child as he mentioned how much his child has improved.

**EJ**

EJ is a 40 years old female that has recently given birth to her third child. She is a very involved mother who seems to be in tune with what her child needs. EJ was lovely to interview as she showed genuine gratitude to the services that she is receiving. She also seemed to understand that services will end at some point and this seemed to give her hope and keep her positive. EJ kept her answers short and on point, but when asked to explain, she would. It was another easy interview as EJ was easy-going and would understand the open-ended questions easily and was positive about receiving adequate support services. It seemed that EJ felt in control of her son’s programmes and therapies. She seemed to understand him and his needs really well.

**IB**

IB is a 40 years old female who is professionally trained as a dentist. She resigned from her job when her second son was diagnosed with ASD. This interview was a bit more difficult for me. The only reason I could think of that it was more difficult for me to conduct this interview was that IB seemed to feel somewhat frustrated with some of the questions asked. It felt as if it was difficult for IB to assess what her child needs at this stage of his life and also that she was not as involved with the programme or therapies as some of the other participants I interviewed. IB seems to occupy herself with many different activities, such as lunch dates, her phone and other meetings as a coping skill to manage her feelings of her son being diagnosed with ASD.

## The impact of a full-time live-in caregiver on the parents of a child diagnosed with ASD

### IO

IO is a 37 years old female and the mother of two children, one diagnosed with ASD. IO answered all questions very short and it seemed that she did not want to go into too much detail with her answers. This could be due to a language barrier as she mentioned that she does not speak English well. The interview was considerably shorter than the other interviews and I felt that I needed to probe to get more information on specific questions. Generally, the interview did not have an emotive tone to it and I felt that IO was happy when it was completed. It must be said though that IO also did not feel that her son would need services for much longer. She felt that he would “graduate” the programme within the next 6 months. He has consequently “graduated” from therapy, meaning that he no longer required support services.

### LB

LB is a 45 years old female that has 2 children – one diagnosed with ASD. Her husband, SB also participated in this study by having a separate interview with me. LB was very forthcoming and gave a lot of information on her child, his situation and the way in which she felt supported by the caregiver. This was an easy interview for me as LB was approachable and she seemed comfortable to speak about her son and his diagnosis. Although I did feel a bit of sadness when LB spoke about his future and her being unable to imagine him without support services. In general, LB seemed to manage her family life well and she seemed involved in her son’s development and programme. She works full-time as a Professor at a University and has to ensure that there is always support for her son.

### MD

MD is a 41 years old female with two sons. Her one son is diagnosed with ASD and is currently nonverbal (unable to expressively communicate his needs and wants). MD seemed like a loving mother that truly loves her children and wants what is best for them. She seemed to not always know what her son was working on and where he was in terms of his development or what the next step would be. Her son’s prognosis is not as clear as some of the other children’s parents I interviewed. It seemed that the parents who were interviewed whose children needed more support seemed a bit less involved and aware of the specific programme and goals for their children. This might be seen as people going through different stages of acceptance, but also as a potential coping skill. Nonetheless – this was a lovely interview and MD shared a lot of information on her family and their way of coping with their son’s diagnosis.

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### MS

MS is a 40 years old male that lives with his wife (RS) and two children, one of which has been diagnosed with ASD. I have known MS for six (6) years and have found his relationship with his wife extremely difficult to manage. They usually engage in blame-shifting behaviours and this affects the children, but especially the son that was diagnosed with ASD. The interview was relatively easy and straightforward as MS is an intelligent man that speaks easily about his family and issues or challenges that they might have. He opened up about his fears for the future and wanted to ensure the easiest road ahead for not only his son, but for him and his wife too. MS elaborated on each topic with ease and understood the interview process with ease.

### PG

PG is a 39 years old female and the wife of TG. They have three children, one of which is diagnosed with ASD. PG speaks openly about her daughter's disorder and has even appeared on some radio and TV shows to create awareness of autism and other disorders. She speaks with ease about her daughter's difficulties and the fact that the full-time live-in caregiver gave her a lot of freedom and lessened her anxiety. This interview was another easy process as PG wanted to elaborate on a variety of topics without being asked to do so. PG also mentioned that she does not believe that her daughter will need services for much longer, but that she is always willing to relook at full-time services if needed. She seemed positive about her daughter's future.

### RD

RD is a 41 years old female that is married to MS with two children, one of which is diagnosed with ASD. RD was a bit more negative in her views for her son's future, but she seemed to have "needed" the full-time support services. RD also did not want to speak about any marital challenges and was hesitant to open up with the frustrations she felt regarding her son, her husband and her family life. This was a challenging interview as I know the family well and had to be unbiased and not probe with questions that RD did not want to answer. I felt myself feeling a bit frustrated during this interview, but I do feel that I had the integrity to keep a professional tone throughout.

### SB

## The impact of a full-time live-in caregiver on the parents of a child diagnosed with ASD

SB is a 48 years old male and husband to LB. They have two children – one of which is diagnosed with severe ASD. SB is a professional man (Professor at a University, as is his wife) and was able to answer each question with ease, precision and in depth. He was easy to talk to, but did not denote any emotional tone to his answers. He was straight forward and friendly, yet elaborated where he felt he wanted to give more information. There was no need for me to probe for more information and I felt that he really understood each question easily and was willing to answer more questions, if needed. It was an easy interview to conduct and I felt that SB did not want to open up regarding his family matters on an emotional level, but definitely on a professional level where he was able to tell me what he felt was positive about the support and where he felt he was still needing support.

### TG

TG is a 39 years old male and husband to PG. They have three children – one of which has been diagnosed with ASD. TG was easy to talk to and opened up regarding the experience having a full-time live-in caregiver. He was extremely positive about the experience and the future of his daughter. TG also mentioned that he does not believe that she will need services for much longer. It was an easy interview to conduct as TG was willing to share details without me needing to probe for more details.

### In general:

The interviews were difficult to schedule as most parents seemed to be occupied with work and their family lives. Once interviews were scheduled it was a relatively easy process, I felt, for the participants and myself. The one thing that stood out that was not part of the themes that were discussed was that parents with children with a more difficult prognosis to determine or with higher supportive needs seemed to come across as more unsure of not only their child's future, but also their current developmental stage, details on their educational programme and their child's specific needs. Personally, I got the sense that these parents needed more time to manage their own feelings of perhaps denial, before they could fully open up about their situation, although all participants were happy to engage in the conversations. One potential limitation to this study that I noticed was that most of the interviews were convincingly positive in nature. A reason for this might be that I am one of the directors of the company, AG, and that participants felt they needed to keep their answers positive. Although I tried to account for this by reiterating that decisions of their child's programme would not be affected by any answer, it cannot be ruled out as a potential limitation to the current study.

## The impact of a full-time live-in caregiver on the parents of a child diagnosed with ASD

**NOTICE OF APPROVAL**

REC Humanities New Application Form

15 October 2018

Project number: 6801

Project Title: The Impact of the presence of a full-time live-in caregiver on the parents of a child diagnosed with Autism Spectrum Disorder

Dear Ms Karla Pretorius

Your REC Humanities New Application Form submitted on 17 September 2018 was reviewed and approved by the REC: Humanities.

Please note the following for your approved submission:

**Ethics approval period:**

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
15 October 2018	14 October 2019

**GENERAL COMMENTS:**

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

**If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.**

Please use your SU project number (6801) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

**FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD**

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

**Included Documents:**

Document Type	File Name	Date	Version
Recruitment material	Appendix A - Call for research invite	14/09/2018	1
Research Protocol/Proposal	Proposal Karla Pretorius 2018 (13)	14/09/2018	13
Informed Consent Form	Appendix B - Consent form Karla Pretorius 2	14/09/2018	1
Data collection tool	Appendix D - Interview schedule Karla Pretorius	14/09/2018	1
Default	Appendix C - Demographics Karla Pretorius	14/09/2018	1
Default	Appendix E - plagiarism declaration	14/09/2018	2
Default	NDA Karla Pretorius	14/09/2018	1
Default	MODIFICATIONS REQUIRED REC Humanities New Application Form	14/09/2018	1
Default	AIMS Global - IBCCES Permission Letter	14/09/2018	1



## The impact of a full-time live-in caregiver on the parents of a child diagnosed with ASD

If you have any questions or need further help, please contact the REC office at [cgraham@sun.ac.za](mailto:cgraham@sun.ac.za).

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Human Research (Humanities)

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.  
The Research Ethics Committee: Humanities complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2<sup>nd</sup> Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.

# The impact of a full-time live-in caregiver on the parents of a child diagnosed with ASD

## Investigator Responsibilities Protection of Human Research Participants

Some of the general responsibilities investigators have when conducting research involving human participants are listed below:

**1. Conducting the Research.** You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research. You must also ensure that the research is conducted within the standards of your field of research.

**2. Participant Enrollment.** You may not recruit or enroll participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use.

**3. Informed Consent.** You are responsible for obtaining and documenting effective informed consent using **only** the REC-approved consent documents/process, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (5) years.

**4. Continuing Review.** The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the REC approval of the research expires, **it is your responsibility to submit the progress report in a timely fashion to ensure a lapse in REC approval does not occur**. If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.

**5. Amendments and Changes.** If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the REC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written REC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

**6. Adverse or Unanticipated Events.** Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research related injuries, occurring at this institution or at other performance sites must be reported to Malene Fouche within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the REC's requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Research Ethics Committee Standard Operating Procedures. All reportable events should be submitted to the REC using the Serious Adverse Event Report Form.

**7. Research Record Keeping.** You must keep the following research related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the REC.

**8. Provision of Counselling or emergency support.** When a dedicated counsellor or psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.

**9. Final reports.** When you have completed (no further participant enrollment, interactions or interventions) or stopped work on your research, you must submit a Final Report to the REC.

**10. On-Site Evaluations, Inspections, or Audits.** If you are notified that your research will be reviewed or audited by the sponsor or any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.

## The impact of a full-time live-in caregiver on the parents of a child diagnosed with ASD



**To Whom It May Concern:**

*University of Stellenbosch*

This letter is to confirm that Karla Pretorius (student number: 21477957) has presented a proposal: "The Impact of the presence of a full-time live-in caregiver on the parents of a child diagnosed with Autism Spectrum Disorder" to the International Board of Credentialing and Continuing Education ([www.ibcces.org](http://www.ibcces.org)).

AIMS Global Level 1 and Level 2 training has been reviewed and approved by the International Board of Credentialing and Continuing Education Standards ([www.ibcces.org](http://www.ibcces.org)); PROVIDER #CE178559. The AIMS Global Level 1 and Level 2 training options are accepted training hours for the IBCCES autism certification program.

IBCCES gives permission to be referenced in the study proposal "The Impact of the presence of a full-time live-in caregiver on the parents of a child diagnosed with Autism Spectrum Disorder" and other content.

If you need any additional details regarding the intent of this letter, please contact IBCCES.

Thank you,

Amanda Casey  
Professional Development Director | IBCCES  
[amanda@ibcces.org](mailto:amanda@ibcces.org)  
877.717.6543

The impact of a full-time live-in caregiver on the parents of a child diagnosed with ASD

Appendix H - Non-Disclosure Agreement (NDA)

Between  
Karla Pretorius

and  
Dr. Chrisma Pretorius  
(for) The University of Stellenbosch

In consideration of my participation conducted by the Department of Psychology in fulfillment of the requirements for the degree of M.A. in Psychology Research in the Faculty of Arts at Stellenbosch University, under the supervision of Dr. Chrisma Pretorius, in a capacity in which I may receive confidential information on which the success of the project depends, I acknowledge and agree that:

Any information or materials related to the parents of children with a primary diagnosis of Autism Spectrum Disorder (ASD) received by me while participating in the research study, during any class-related or research-related activity, shall be kept strictly confidential. I will not disclose to any person (including all employers or employees of AIMS Global), either during or subsequent to, my participation, any confidential participant-related information, including the names of participants or their children.

I will not permit any person to examine or make copies of any reports, memoranda, or other documents related to the research study.

Upon the completion of my participation in the research study, I will deliver to Dr. Pretorius any records or material of any nature whatsoever related to the program, including all copies thereof.

The above understanding shall survive the termination or cancellation of the Agreement.

This Agreement shall be binding upon my heirs, legal representatives, and assigns.

Signed this 27th day of August 2018.

By Karla Pretorius

\_\_\_\_\_  
(Type or print name)

\_\_\_\_\_  
(Signature)



## Appendix I

### Plagiaatverklaring / *Plagiarism Declaration*

1. Plagiaat is die oorneem en gebruik van die idees, materiaal en ander intellektuele eiendom van ander persone asof dit jou eie werk is.

*Plagiarism is the use of ideas, material and other intellectual property of another's work and to present is as my own.*

2. Ek erken dat die pleeg van plagiaat 'n strafbare oortreding is aangesien dit 'n vorm van diefstal is.

*I agree that plagiarism is a punishable offence because it constitutes theft.*

3. Ek verstaan ook dat direkte vertalings plagiaat is.

*I also understand that direct translations are plagiarism.*

4. Dienooreenkomstig is alle aanhalings en bydraes vanuit enige bron (ingesluit die internet) volledig verwys (erken). Ek erken dat die woordelike aanhaal van teks sonder aanhalingsstekens (selfs al word die bron volledig erken) plagiaat is.

*Accordingly all quotations and contributions from any source whatsoever (including the internet) have been cited fully. I understand that the reproduction of text without quotation marks (even when the source is cited) is plagiarism.*

5. Ek verklaar dat die werk in hierdie skryfstuk vervat my eie oorspronklike werk is en dat ek dit nie vantevore in die geheel of gedeeltelik ingehandig het vir bepunting in hierdie module/werkstuk of 'n ander module/werkstuk nie.

*I declare that the work contained in this assignment is my original work and that I have not previously (in its entirety or in part) submitted it for grading in this module/assignment or another module/assignment.*

Studentenommer / <i>Student number</i>	Handtekening / <i>Signature</i>
K. Pretorius Voorletters en van / <i>Initials and surname</i>	04/04/2018 Datum / <i>Date</i>