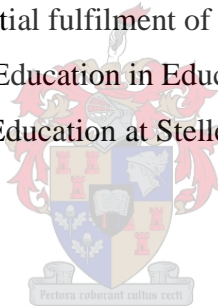# DUAL DIAGNOSIS OF AUTISM AND HEARING LOSS: CAREGIVERS' EXPERIENCE OF DIAGNOSIS AND INTERVENTION

by

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DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously, in its entirety or in part, submitted it for obtaining any qualification.

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ABSTRACT

Caregivers are central role players throughout the life span of a child with special needs and they form part of a family within the broader network of their community and social spheres. Bronfenbrenner's bio-ecological system theory provides a theoretical framework which depicts the interactive nature of this process which starts before receiving a conclusive diagnosis. This study explores the lived experiences of caregivers of three children with a dual diagnosis of autism spectrum disorder and hearing loss as they navigate the maze of intervention and support after diagnosis within the South African context.

The study is qualitative in nature and utilised a case study research design to explore the experiences of caregivers. The participants were selected by means of purposive sampling and data were collected through semi-structured interviews as well as a document study of learner files. Data was analysed through the process of thematic analysis and presented through a discussion of the findings.

Research findings confirmed the complexity of the experiences and needs, not only of children with this dual diagnosis, but also of their caregivers who were considered as the project managers of their childrens' intervention programmes. Caregiver experiences were largely influenced by their own level of participation or withdrawal, their knowledge base as well as access to services and information throughout the process of intervention. Proximal processes between caregivers and the school community served as support for the establishment of an effective multi-disciplinary team approach to offer support which will continue throughout the life span of the child with a dual diagnosis of autism spectrum disorder and hearing loss. The researcher derived from the research findings recommendations for professionals who provide services to caregivers of children with this dual diagnosis.

Key words: Caregivers; dual diagnosis; autism spectrum disorder; hearing loss; intervention; bio-ecological perspective

OPSOMMING

Versorgers word beskou as kernrolspelers dwarsdeur die lewensduur van 'n kind met spesiale behoeftes en boonop vorm hulle deel van 'n familie binne die breë netwerk van hul gemeenskap en sosiale sfere. Bronfenbrenner se bio-ekologiese perspektief verskaf 'n teoretiese raamwerk wat die interaktiewe aard van hierdie proses uitbeeld wat reeds voor die verkryging van 'n finale diagnose begin. Hierdie studie verken die geleefde ervarings van versorgers van drie kinders met 'n dubbele diagnose van outismespektrum-versteuring en gehoorverlies, soos hulle die doolhof van ingrypings- en ondersteuningsdienste binne die Suid-Afrikaanse konteks navigeer.

Die studie is kwalitatief van aard en die navorser het van 'n gevallestudie-navorsingsontwerp gebruik gemaak om die ervarings van versorgers te ondersoek. Die deelnemers is deur middel van doelgerigte steekproefneming gekies en data is deur middel van deels gestruktureerde onderhoude sowel as 'n dokumentstudie ingesamel. Die data is geanaliseer deur middel van tematiese ontleding waarna dit deur middel van 'n bespreking aangebied is.

Die navorsingsbevindinge bevestig nie net die kompleksiteit van die ervaringe en behoeftes van kinders met 'n dubbele diagnose nie, maar ook dié van hul versorgers, wie beskou word as die projekbestuurders van hul kind se ingrypingsprogram. Versorgers se ervaringe is grotendeels beïnvloed deur hul persoonlike vlak van betrokkenheid óf onttrekking, hulle kennisbasis sowel as hul toegang tot dienste en inligting regdeur die ingrypingsproses. Proksimale prosesse wat tussen die versorgers en die skoolgemeenskap geskied dien as ondersteuning vir die vestiging van 'n effektiewe, multi-dissiplinêre spanbenadering wat ondersteuning bied dwarsdeur die lewe van 'n kind met 'n dubbele diagnose van outismespektrum-versteuring en gehoorverlies. Die bevindinge verkry uit die navorsing, word vervat in aanbevelings aan professionele persone wat dienste aan ouers van kinders met 'n dubbele diagnose verskaf.

Sleutelwoorde: Versorgers; dubbele diagnose; outismespektrum-versteuring; gehoorverlies; ingryping; bio-ekologiese perspektief

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The One who planted this interest in my heart and promised to see it to completion.

Finally, this thesis is dedicated to Olin along with the research participants who opened my heart and mind as they challenged me to see a world through the lense of a dual diagnosis of autism spectrum disorder and hearing loss and thereby becoming a better teacher.

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LIST OF ABBREVIATIONS

AAC   augmentative and alternative communication

ABA   applied behaviour analysis

AN/AD   auditory neuropathy/dyssynchrony

APA   American Psychiatric Association

A;SA   Autism South Africa

ASD   Autism Spectrum Disorder

AWC   Autism Western Cape

BAER   brainstem auditory evoked responses

CMV   cytomegalovirus

DBST   District-Based Support Team

DCAP   Division of Child and Adolescent Psychiatry

DSM-IV-TR   Diagnostic and Statistical Manual of Mental Disorders Fourth Edition Text
             Revised

DSM-5   Diagnostic and Statistical Manual of Mental Disorders Fifth Edition

DTT   discrete trial teaching

EEG   electroencephalogram

EHDI   early hearing detection intervention

GRI   Galluadet Research Institute

HPCSA   Health Professions Council of South Africa

ICD-10   International Statistical Classification of Disease and Related Health Problems

IEP   Individualised Education Plans

ILST   Institution–Level Support Team

NDCS   National Deaf Children's Society

NHREC   National Health Research Ethics Committee

PDD-NOS   pervasive developmental disorder not otherwise specified

PECS   picture exchange communication system

PRT   pivotal response treatment

RDI   relationship development intervention

REC   Research Ethics Committee

SIAS   screening identification assessment and support

TACA   talk about curing autism

ToM   theory of mind

WCED   Western Cape Education Department

CHAPTER 1:
CONTEXT AND RATIONALE FOR THE STUDY

1.1   INTRODUCTION

Caregivers are considered primary role players during the process of enquiring about and seeking advice from professionals regarding unusual behaviour or concerning symptoms observed in their children. They are at the forefront of receiving the diagnoses (Keenan, Dillenburger, Doherty, Byrne, & Gallagar, 2010) and are responsible to seek intervention services according to their child's specific needs (McCloskey, 2010). Caregivers' experience of the diagnostic process has an impact on the role they have as caregiver to take the lead in the process of seeking intervention services for their child. When a communication break or "disconnect" as McClosky (2010, p.162) refers to it occurs between guiding professionals and caregivers, the role of caregivers are compromised. Research has looked at this specific phenomenon in countries with first world medical and educational infrastructure such as America, Australia, Canada and the United Kingdom and yet the body of knowledge on the process of diagnosis, intervention and support is limited (Myck-Wayne, Robinson, & Henson, 2011). What if, however, the diagnosis entails multiple disabilities in an under-resourced or first-world country such as South Africa?

In this first chapter the author provides a conceptual framework that will guide the research as it provides background to the study through highlighting the research problem and identifying the theory underlying the research question (Leshem & Trafford, 2007). An introduction of the research design and methodology is provided along with the clarification of key concepts. In conclusion of this chapter a presentation of the remaining structure of the research study is presented.

1.1.1   Background to the study

In this first stage the author proposes the need for the study (Fouche & De Vos 2011, p. 80). The researcher will provide an overview of the elements to be discussed on this topic, provide the context for the study along with the background and rationale. A mention of current literature is made to identify what is known and what is to be explored. The research area will be identified and motivation for the purpose thereof argued.

Receiving a diagnosis of ASD according to Keenan *et al*. (2010, p. 390) is "... a traumatic experience on which future care and education plans for the child with a disability depend". When children have special needs and are diagnosed with a disability caregivers' experiences have been that of shock and grief and caregivers' experience of stress is at its highest level at the time of receiving a diagnosis (Stuart & McGrew, 2009). Caregivers of children with disabilities are further known to be at a higher risk for health issues such as chronic illness and psychological difficulties (Bromley, 2004). And yet, when the diagnostic process is experienced in a positive way, it has a significant impact on caregivers' initial reaction to the diagnosis (Cottrell & Summers, 1990 in Keenan *et al.,* 2009).

Families and caregivers of children with special needs are confronted with many challenges that surpass the initial diagnosis (Baker, 2012, p. 209). These challenges evolve as the child matures and the impact of the disability is experienced within different developmental domains (Head & Abbeduto, 2007). Oluremi (2015, p. 103) is of the opinion that disability within a family serves as a "...source of severe phychological disruption to family adjustment". Baker (2012, p. 209) discusses how caregivers often require the support of counsellors and other professionals to "… reorganise their thoughts …" after receiving a diagnoses for their child and consequently getting started on the road that lies ahead.

Caregivers are often exposed to numerous assessments and opinions (Braiden *et al.,* 2010). Since caregivers' perceptions are central to both the diagnosis and the design, monitoring and modifying of treatment and service delivery, Renty and Roeyers (2005) maintain that it is vital that greater attention and investment is afforded to both their experience and their perception of the diagnostic process than is currently the case.

Getting started entails making decisions regarding their child's specific needs and intervention services suitable to the family system as a whole. Intervention could involve a team of guiding professionals such as social workers, teachers, psychologists, speech therapists, occupational therapists, physiotherapists, as well as medical doctors (Oluremi, 2015). The impact of a diagnosis of a disability stretches across the different levels of a caregiver system including family life and relationships, finances and material resources, as well as the work environment of caregivers (Markoulakis *et al*., 2012). Caregivers' experiences will therefore be unique depending on the multiple factors and their circumstances. This concept is theoretically depicted by Bronfenbrenner's Bio-ecological perspective (Sameroff, 2010).

Pearlin developed the model of caregiving stress process which offers a possible depiction of the the way in which caregivers experience a diagnosis. According to this model caregivers' experiences are further influenced by their personality, self-perception, coping repertoirs, mastery and the meaning they ascribe to life (Park & Chung, 2015).

The family is regarded as a dynamic system where the action of one member affects the family as a whole. The family forms part of a network in which all members influence the nature of the family system and is reciprocally influenced by the system (Bronfenfrenner, 1994; Brendtro, 2006). Caregivers are considered as the primary roleplayers within the family system. Caregiver responces to diagnosis influences their ability to implement the recommended treatments, seak further support and to be supportive role players in working towards stimulating their child's development (Head & Abbeduto, 2007, p. 293). Bearing this in mind, caregivers' experiences of diagnosis and intervention services will undoubtedly have a significant impact on the wellbeing and outcome of the child with a disability as caregivers navigate their way through receiving a diagnosis and consequent intervention services for their child.

Getting to the point where caregivers receive a dual diagnosis of ASD and hearing loss for their young child (Myck-Wayne, Robinson, & Henson, 2011) is an uncertain and challenging process due to the fact that making this diagnosis is considered complex. One of the reasons for this is that the symptoms of hearing loss may apprear similar to those of ASD and the communication abilities of both children with ASD and with hearing loss are affected (Easterbrooks & Handley, 2006).

Investigating the experiences of caregivers is a very complex thing to achieve due to the subjective nature thereof and the many different factors that could influence caregivers' experiences. Caregivers cannot be considered in isolation but should rather be seen as part of this dynamic and evolving system (Selingman & Darling, 1997). Therefore caregivers should be considered within their context coming from a unique background (Head & Abbeduto, 2007). It was decided that it was best to address this topic by means of the application of the bio-ecological perspective. Culture, language, education, resources and beliefs around disability further are believed to influence caregivers' experiences of diagnosis and intervention and form the foundation of Bronfenbremmer's Model (Brendto, 2006).

All these factors considered culminate into caregivers' response to diagnosis and support, and therefore the road ahead for their child. Caregivers' experiences of diagnosis and intervention should be aimed at supporting the whole family and those providing intervention services should be mindful of the needs of the family as a whole. It is therefore necessary to investigate what the experiences of caregivers are in order to take the necessary steps to provide caregivers with an experience that allows them to take the first steps on the road ahead with their child within the context of their system.

Experiences within the South African context with its multicultural population, economic diversity, public and private healthcare and education systems will also create a unique experience. According to the Constitution of the Republic of South Africa (Act 108 of 1996) Chapter 2 of The Bill of Rights prescribes that everyone "...has the right to education, which the state through reasonable measure, must make progressively available and accessible".

Assessment and diagnosis, together with support, have traditionally been topics of high importance within the field of educational psychology. According to Head and Abbeduto (2007, p. 293) assessments are done to determine the child's diagnosis for which an intervention programme is devised, and finally to evaluate the progress made through the intervention. Caregivers seek the services of educational psychologists in instances where they experience uncertainty, and hope to get answers to questions regarding their child's behaviour or development in general. Taking a systems approach as proposed by the bio-ecological perspective will prevent too much focus on the child's needs in isolation, but rather aim to support the caregiver system as a whole. Insights gained through the completion of this research study of caregivers' experiences of diagnosis and intervention services for their child with a dual diagnosis of ASD and hearing loss, will contribute positively to the current lack of knowledge of this topic in the discipline. Knowledge of caregiver experiences could contribute to increased positive experiences of the caregivers and thus the well-being of their children. This makes the current study valuable to the field of educational psychology.

1.2   PERSONAL MOTIVATION FOR THE STUDY

"Our most evident source is our contact with the external world and the direct observation of it" (Fouché & De Vos, 2011). With this kept in mind the researcher remained mindful of her role and the influence of how her world view, shaped by her experiences and exposure, has become part of her frame of reference. These aspects consequently became involved in the process of the research.

During an 18-month period starting in 2011, the researcher taught at a school for learners with ASD. The school is situated in Cape Town and children from divergent demographic areas and diverse socio-economic backgrounds attend the school. The population of children with ASD is spread across the Cape Town Metropole and, because of the shortage of schools which are equipped to support children with ASD and their families, many children need to make use of bus transport and travel far to be able to attend school. The cost of transport is not funded by the Education Department and this expense therefore has to be carried by the caregivers of the child. Considering that approximately 60% of the children at the school received dispensation of school fees, the implication of the financial burden of transport on caregivers is significant.

Children with ASD follow an Individualised Education Programme formulated by a multi-disciplinary team on an annual basis. This team could include several therapists who are involved in providing therapeutic intervention for the child, for example a speech therapist, an occupational therapist, an educational psychologist, the child's classroom teacher, as well as his or her caregivers.

During the initial Individualised Educational Plan (IEP) discussion of a ten year old boy with autism spectrum disorder and profound hearing loss the researcher, who was his classroom teacher, met the caregivers of the child. They were his grandparents and were mature seventy year olds. The intake interview and a study of his learner file revealed the journey his caregivers had been on since his birth. Referral letters, doctor's and specialist's reports, therapist intervention and process notes, teacher reports and observation documentation mapped out the process his caregivers had gone through to receive a dual diagnosis of hearing loss and ASD, and consequent intervention services that would address his unique developmental, communication and learning needs. At the time of the IEP discussion his caregivers were hopeful that they had at last found the most appropriate school placement for their ten-year-old grandchild.

Learning about these caregivers' experiences through their personal retelling of events, along with supportive documents from the learner file, a timeline was sketched of their experiences. This process evoked a sense of concern with the researcher regarding the possibility of other caregivers going through similar experiences. Where or to whom do they get referred to for a diagnosis? Which services are available to caregivers, and where do they find appropriate school placement?

These processes lead the then teacher, after being witness to the caregivers' experience, to the question of what other caregivers' experiences of receiving a dual diagnosis of hearing loss and ASD for their child was, and which intervention services were made available or were recommended to support them. This study offered the researcher the opportunity to explore these complex issues, and gain answers to these research questions.

1.3   PROBLEM STATEMENT

Meinzen-Derr *et al*. find that children with a dual diagnosis of ASD and hearing loss constitute 4% of the deaf or hard of hearing population. Statistics generated by the Gallaudet Research institute (GRI) show that the diagnosis of children with hearing loss and ASD is on the increase. In a survey conducted in 2004 and 2005, it was found that 1% of children taking part in that particular project had a dual diagnosis of hearing loss and ASD. The researchers agreed therefore that a general increase in the population of children diagnosed with ASD suggests an increase in the population of children who have a dual diagnosis of hearing loss and ASD. If this finding is transferred to the South African context it means that according to statistics by STATS SA (2011) approximately 209 to 837 children in the Western Cape have the same dual diagnosis. Research on this topic within the South African context has not been done before.

Diagnosing the presence of both ASD and hearing loss in a young child presents challenges due to the fact that the symptoms of hearing loss and ASD in young children may appear similar. Screening items used to determine the presence of ASD and hearing loss overlap, such as responding to your name, for example. Communication impairments are inherent to both disabilities (Roper, Arnold, & Monteiro, 2003). ASD, however, is diagnosed much later, at approximately 66.5 months (Meinzen-Derr *et al*., 2014) in individuals with hearing loss compared to hearing children (Myck-Wayne *et al*., 2011, p. 379). These aspects make early identification, and subsequent early intervention, unlikely. The co-occurrence of ASD and hearing loss is a reality for some families, yet the appropriate intervention remains unknown to those affected by this dual diagnosis (Szymanski *et al*., 2012, p. 2028).

The literature consulted argues collectively that research investigating the dual diagnosis of ASD and hearing loss is severely lacking (Meinzen-Derr *et al*., 2014, p. 113). Words used to describe the shortage of research include "meagre" and "scattered". Limited information on the diagnostic process, intervention and support offered to caregivers is available (Easterbrookes & Handley 2005). Meinzen-Derr *et al*. (2014) propose that the first step to

gain understanding and building a foundation for improved identification and intervention for these children's communication needs is to have a clear understanding of the characteristics of a dual diagnosis of hearing loss and ASD.

Specialised intervention methods are used for children with hearing loss and for children with ASD respectively. There is, however, no available research on effective therapy for children with a dual diagnosis (Malandraki & Okalidou, 2007, p. 23).

Caregivers have the earliest contact with the child and this makes early intervention and therefore better long-term outcomes possible. Therefore the role of the primary caregivers is invaluable throughout the process of diagnosis of a disability and the implementation of the necessary intervention. They become key members of a multi-disciplinary team whose function is to formulate and implement a unique and specific intervention plan to support and develop the child diagnosed with ASD and hearing loss.

Through the completion of the current study the researcher hoped to gain knowledge of caregiver experiences and thus information to service providers in order to address caregivers' specific needs and address concerns and problematic experiences of navigating the medical and educational maze of having a child with a dual diagnosis of ASD and hearing loss.

Insight gained could potentially inform practices of professional staff or therapists who work with caregivers and their children and allow therapists understand the specific needs and concerns of caregivers in the Western Cape regarding their children, as well as their personal well-being. Insight into caregivers' lived experiences and improved support services could facilitate earlier diagnoses and thus earlier intervention.

Throughout the literature study the researcher was confronted with divergent perspectives and limited and scarce recommendations regarding best practices for intervention for children with this dual diagnosis. Guidelines to support caregivers of these particular children were found only when studying recollections and first person reports by caregivers themselves. The researcher quickly learnt that a limited body of research exists on this topic. Having personally been challenged to teach a child with ASD and hearing loss the researcher was aware of the concerns caregivers had and the challenges they faced in receiving appropriate intervention services. A researcher's personal interest and intellectual curiosity certainly comes into play in all research, but sometimes it is driven by it (Flick, 2006).

1.3.1   Purpose of the study

The purpose of this study was to explore and gain insight into the lived experiences of caregivers of children with a dual diagnosis of ASD and hearing loss. The researcher specifically focused on the process that occurred from when caregivers first became aware of the need to seek support and answers for what they experienced as problematic or challenging behaviour, up to when caregivers received the dual diagnosis and subsequent intervention and services provided by practitioners, healthcare professionals and therapists.

Through the exploration of caregivers' lived experiences of the diagnostic process and consequent intervention services and resources available within the community context the researcher gained insight and possible understanding of existing systems to address the complex and multiple needs of the specific caregivers.

Denscombe (2000) in Fouché and De Vos (2011) identifies three primary reasons for presenting a clear purpose for the research study. The researcher found this conceptualisation to be a true reflection of her research process.

The research purpose made provision for the reader to understand the intention of the research, what served as the motivation for the research, as well as what it was that the researcher hoped to discover. The second reason for a clear and concise research purpose as experienced by the researcher was that it provided the reader with an understanding of the criteria to evaluate whether or not the researcher achieved the goals set out. The purpose of the study, as defined by the author, is that it served as a platform from which the researcher would conduct the research.

The purpose of this study was to explore and gain a deeper understanding of the experiences of caregivers on becoming aware of their child's specific presentation of hearing loss and ASD, seeking a diagnoses, and subsequent intervention.

1.3.2   Research questions

Obtaining a conclusive ASD diagnosis in children, who have hearing loss and gaining consequent appropriate services, is challenging. Children with hearing loss and ASD are often placed in inappropriate educational settings with inappropriate interventions (Myck-Wayne *et al*., 2011, p. 380). Caregivers and professionals are challenged by the lack of information and resources to support children with this dual diagnosis.

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The study was guided by a primary research question:

What are the experiences of primary caregivers of children with a dual diagnosis of hearing loss and Autism Spectrum Disorder?

The following sub-questions were explored:

1. *What were caregivers' experiences of identifying signs and behaviours presented by their child that were unusual and alerted them to the fact that their child could possibly require special intervention? (When did caregivers first notice that something was different about their child?)*
2. *What influences caregivers' experiences of intervention and support services after diagnosis?*
3. *What process did this experience take on in relation to caregivers' needs at the time?*

1.3.3 Research goals

When considering caregivers' experiences of receiving a diagnosis and intervention, the influence and interaction between the different systems as well as a range of factors related to their context were considered and reviewed. This included the community environment, the availability of resources (financial and emotional), and the support from family and friends. Therefore, in order to explore caregivers' experiences, the researcher listened to and recorded the detailed recollections of their personal experiences.

Caregivers' experiences of these interacting systems were recorded, transcribed and studied in order to gain deeper understanding of the experiences, which would include their needs throughout these processes of diagnosis, intervention and support. Roadblocks to effective support and intervention, factors considered as stressors, helpful, meaningful etc. were discovered and understood in order to gain knowledge of what caregivers go through as they embark on this journey of having a child with hearing loss and ASD.

The overarching goal of this study was therefore to provide a meaningful description of caregivers' experiences throughout the process which could inform policy for practices and training to support caregivers according to the shortcomings of current services.

The rationale was that if greater awareness was realised interventionists such as doctors, nurses, therapists, etc. could more clearly understand caregivers' needs during their process of seeking the best way forward for the child, therefore caregivers' needs could more

effectively be met with the available resources at hand. It was acknowledged that each caregiver's experience would be unique due to the context etc. but services could be adjusted and needs addressed specifically.

1.4   CONCEPTUAL FRAMEWORK

In the following presentation of the conceptual framework the researcher provides a description of the process that was followed to successfully attend to the research goals and questions. This research process entails consideration of the researcher's theoretical framework, research paradigm, research process, research methodology, research design, research methods and data analysis.

1.4.1   Theoretical framework

As a result of the researcher's ontological and epistemological stance being that there is no "real truth" except a "narrative truth" (Schurink, 1998, p. 246) that can only be known by those who experienced it personally, this study was embedded in social constructionism and guided by two complementary theories. These were the bio-ecological theory, developed by Bronfenbrenner, and the principles of family-centered theory, stemming from Carl Rogers' client-centered work. The combination of these theories formed an effective lens through which the complex experiences of caregivers could be viewed and unpacked in order to attempt to gain a deeper understanding.

Throughout the caregiver's journey from when they first observed something different in their child to seeking advice or intervention, receiving a diagnosis and consequent intervention and support, complex interactions occurred. The nature of these interactions are dynamic and occur between the caregiver and the child, extended and close family, caregivers' work environment, financial and emotional resources within the environment, and cultural beliefs. All these experiences took place across the dimension of time.

Bronfenbrenner's bio-ecological theory conceptualises each caregiver as a unique and complex organism within a number of interconnected systems. The individual could not be separated from any of the systems and therefore all systems, which includes the caregiver, are considered as parts of a whole (Rogoff, 2003).

1.4.2   Research paradigm

According to the interpretivist paradigm reality is socially constructed with no single observable reality (Merriam, 2009, p. 8). The researcher tried, as described by Creswell

(2007, p. 20), to understand the reality of the caregivers as they have gone through the process of receiving a dual diagnosis of ASD and hearing loss, and seeking intervention for their child. The researcher went with the assumption that the caregivers' reality could only be interpreted through the meaning they ascribe to their life world (Fouché & Schurink 2011, p.309). These experiences were viewed according to the understanding that the meanings shared by caregivers were subjective and often negotiated socially. Caregivers were asked to share their experiences as they perceived it, and to share the meaning and interpretation ascribed to these personal experiences with the researcher. These meanings could only be discovered through the vehicle of language (Schwandt, 2007, p. 314).

1.4.3   Research process

Research questions were triggered by a process of formulating a conceptual framework, specifically by a model and theory which initiated the research process (De Vos & Strydom, 2011, p. 39). The research process which was underpinned by a theoretical framework entailed what was to be researched, how it would be done and the way data would be analysed and interpreted in order to answer the research question. Here is a brief discussion of the process. An in-depth discussion takes place in Chapter 3.

1.4.4   Research methodology

Qualitative research and a case study design were applied in this study as the aim of the research was to gain insight into the experiences of caregivers of children with a dual diagnosis of ASD and hearing loss. The researcher immersed herself in the caregivers retelling of their experiences in order to obtain an intimate familiarity with their social worlds and to look for patterns in the caregivers' retelling of their experiences (Fouché & Schurink, 2011, p. 320).

In producing the product of this qualitative enquiry as Merraim describes it (2009, p.16) the researcher hoped to provide rich descriptive data on caregiver experiences. The in-depth study of individual caregivers' experiences aimed to serve as the basis from which the development of appropriate practice and intervention programmes for caregivers of children with a dual diagnosis would sprout in the future (Babbie, 2007).

A brief overview of the research methodology to be employed for the purpose of the study is provided in Table 1.1 below. A detailed description and motivation for this procedure appears in Chapter 3.

Table 1.1: Summary of the research methodology

RESEARCH METHODOLOGY	
Research design	Case study design
Selection of site and participants	Identification of research sites • Special schools in the Cape Town Metropole which facilitate learning by children with multiple disabilities. • Purposive sampling of participants • Primary caregivers of three young children who have been diagnosed with hearing loss and ASD and who attend a special-needs school situated in the Cape Town Metropole.
Data collection methods	• One-on-one interviews • Study and analysis of documentation of current or past individual educational programs (IEDPs), audiograms, medical reports, developmental assessments, reports from psychologists, and behaviour management plans to create a visual representation of caregiver experiences on a time-line.
Data capturing through documentation	• Audio recordings and transcriptions • Summary and conceptualisation of documentation of current or past individual educational programs (IEDPs), audiograms, medical reports, developmental assessments, reports from psychologists, and behaviour management plans.
Data analysis	Thematic analysis as proposed by Braun and Clarke (2006)
Criteria to ensure rigour	Credibility, transferability, dependability and confirmability as developed by Lincoln and Guba in 1985.
Ethical considerations	Informed consent, voluntary participation, the right to discontinue, confidentiality, anonymity.

1.4.5   Research design

The type of qualitative research that was applied in this study was a case study. Yin's (2009) consideration of the case study design as a comprehensive strategy of inquiry to study a particular case within a real life situation or contemporary context, addressed the researcher's question of what was to be studied. The case study considered a *concrete entity,* as Yin puts it, and this case was then described within certain parameters. Thus the researcher explored the experiences of caregivers of diagnosis and intervention of their children with a dual diagnosis of hearing loss and ASD. Caregivers' experiences of diagnosis and intervention were the studied phenomenon. The researcher wanted to explore this specific issue and, true to the hallmark of a good qualitative case study, wanted to present an in-depth understanding of the case (Stake, 1995).

1.4.6   Research methods

Research methods relat to the specific tasks at hand and focus on the research process. These methods were therefore considered as the tools and procedure used in order to address the research questions. The point of departure in this section was sampling of participants, data collection and data analysis. The researcher now focuses on motivating the individual steps taken in the research process and discusses briefly what was considered as the most objective procedures to be employed.

1.4.6.1   Selection of participants

According to Denzin and Lincoln (2000, p. 87) the qualitative researcher seeks out individuals where the specific phenomenon or process being studied are most likely to have occurred. Data in qualitative research is often derived from one or two cases. The qualitative researcher believes that no individual is ever only an individual. Each case must be studied against the background of more universal social experiences and processes. Purposive sampling was chosen as it was the most relevant technique to use in order to collect the richest data. Purposive sampling allowed the researcher the opportunity to select participants who were known to be caregivers of a child with a dual diagnosis of hearing loss and ASD and therefore would be able to provide rich information about the phenomena being studied (Hays & Singh, 2012).

1.4.6.2   Method of collection

Individual interviews and document collection were the primary means of the two-phase data collection process. In-depth interviews were either conducted during scheduled home visits or took place at the venue of the school involved, whichever was more convenient for the caregivers. The interviews were conducted with the caregivers without disturbing school activities. The caregivers were requested to agree to audio recordings of the individual interviews and to give informed consent for the researcher to view relevant educational and medical documents. These included current or past Individualised Educational Plans (IEPs), audiograms, medical reports, developmental assessments, reports from psychologists, and behaviour management plans. Pseudonyms were used for all participants.

Open-ended interview questions focused on the diagnostic process for hearing loss and ASD, service delivery and interventions that had been offered to the participants related to hearing loss, ASD, and hearing loss and ASD combined. Caregivers were encouraged to share their perspectives on the process of obtaining services and the types of services made available to

them. The purpose of the individual interview was therefore for caregivers to describe their experiences in their own words. This constituted the first phase of data collection.

These methods are described in depth in Chapter 3. An example of the interview guide is attached as Addendum D.

1.4.7   Data analysis

Patton (2002, p. 432) explains that qualitative analysis transforms data into findings. The purpose of this data analysis was to reduce the raw information provided by the participating caregivers in order to identify significant patterns and finally to communicate to the reader what the data revealed (Schurink *et al*., 2011, p. 397). The researcher made use of thematic analysis and was guided by the authors Braun and Clarke (2006).

1.5   ETHICAL CONSIDERATIONS

The researcher was intentional in her practices to uphold ethical standards throughout the research process. The first implication of an ethical approach to research, as referred to by Allan (2011, p.288), came into play prior to commencement of the study and stipulated that it has scientific merit, the applied methodology is appropriate for the purpose of the study, and that the study is feasible. Ethical principles such as non-maleficence, beneficence, fidelity, confidentiality, autonomy and justice were strictly adhered to throughout the research process as the researcher strived to uphold ethical standards. The researcher aimed to employ the following competencies in her research project, based on Merriam's guidelines (2009, p.17). She strived to ask *good questions* and was a *careful observer* who had a high tolerance for ambiguity in the ebb and flow of qualitative research whilst trusting the process. She aimed to think inductively and considered the "whys" in her work and life context.

The researcher adhered to all requirements formulated by the Research Ethics Committee. Ethical clearance with reference number, REC-050411-032, was consequently obtained from The National Health Research Ethics Committee. The means by which the researcher upheld principles of ethical research will be discussed in more detail in Chapter 3.

1.6   TRUSTWORTHINESS AND QUALITY OF DATA

Criteria for the thrustworthiness and quality of data are credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). In essence credibility refers to the believability and internal validity of the data. Transferability refers to the generalisability and external validity while dependability refers to the consistency and reliability, and

confirmability to the neutrality of the researcher (Hays & Singh, 2012). An in-depth discussion of the process followed in this research study is presented in Chapter 3.

1.7   CONCEPT CLARIFICATION

In order to explore the lived experiences of caregivers it was required that we first explored concepts that are basic to this research topic and the specific context of the research. Especially relevant to this explorative study, are the concepts of *autism spectrum disorder*, *hearing loss*, *dual diagnosis*, *caregivers*, and *intervention*. Concept clarification serves to sharpen and enrich the reader's understanding and to form a common ground with the reader audience. A detailed discussion and a critical reflection on the literature will follow in Chapter 2.

1.7.1   Autism spectrum disorder

Autism spectrum disorder is a complex and changeable condition. It is referred to as a pervasive developmental disorder and is characterised by disorganised neurological development (Koudstaal, 2011). ASD is regarded as a social and developmental disorder and not a psychiatric or intellectual disability. Children with ASD experience difficulties in all aspect of daily life (Szymanski & Brice, 2008) and are affected in three main areas within the first three years of their lives, namely behaviour and imagination, social interaction, and language, and communication (American Psychiatric Association [APA], 1994). The features of this developmental disorder present uniquely in each child, therefore no two children on the autism spectrum will be the same.

1.7.2   Hearing loss

The term used throughout this thesis is children with hearing loss and refers to children who are culturally deaf, who are hearing impaired, who use sign language, or who use an auditory-based spoken language to communicate (Duncan, 2012).

Hearing loss, as described by Sattler (2014) may be in one ear (unilateral) or both ears (bilateral), the same in both ears (symmetrical) or different in each ear (asymmetrical), progressive or sudden, fluctuating or stable, and mild (resulting in minor difficulties with conversation) or severe (resulting in complete deafness).

He explains that there might be a considerable delay between when caregivers first suspect some difficulty and when a conclusive diagnosis is reached (Sattler, 2014; p. 578). Profound hearing loss at birth affects not only language development, but also cognitive, social and

intellectual development (Leigh, 2008, p. 24). Approximately one in four children with hearing loss also have additional developmental disabilities (including intellectual disability) and experience delays in reaching early developmental milestones (Meinzen-Derr *et al*., 2014). Infants born with hearing loss do however follow a normal pattern of vocalisation until about seven months of age where after spoken production is reduced.

1.7.3   Dual diagnosis

Dual diagnosis in this study refers to the presence of hearing loss and ASD in young children of the caregivers who were interviewed. It is estimated that autism spectrum disorder co-occurs in 4% of children with hearing loss (Meinzen-Derr*et al*., 2014, p. 112). Such a dual diagnosis is complex (Meinzer-Derr *et al.,* 2014*)* as it is required to determine whether the communication and social delays experienced by the child is better accounted for by their hearing loss or whether it is indeed symptomatic of ASD.

1.7.4   Caregivers

Caregivers in this study, refer to the primary caregivers of the child regardless of their biological relationship to the child. This person or persons assume responsibility for the child's needs and upbringing (Stuart & McGrew, 2009, p. 86). Within the South African context caregivers are often the child's grandparents or other relatives.

1.7.5   Intervention and support

Intervention and support refers to measures put in place to address challenges experienced as a result of the dual diagnosis of hearing loss and ASD. Within the South African context on an educational level, support takes place through various support teams depending on the level of support required by the child. These are the class support team, institution-level support team (ILST), district-based support team (DBST) and lastly, informal sources of support drawing from the community, organisations and caregivers. Support from these teams is available from the child being school-going age and included in the schooling system (Jooste & Jooste, 2012, p. 427). Intervention and support however is necessary prior to this stage. Implementation of early intervention is essential (Ellis-Gonzales, 2008, p. 24) through provision of occupational therapy to address the child's sensory needs, speech and language therapy to address communication challenges, and caregiver support to address the emotional needs of the family system that forms the basis for optimal development of the child with a dual diagnosis of hearing loss and ASD.

1.8   STRUCTURE OF THE PRESENTATION

This research study will be presented according to the following structure:

Table 1.2: Structure of the presentation

Chapter 1: Introduction	An introduction and contextualisation of the study, research problem, research questions, concept clarification, outline of the study and conclusion to the chapter.
Chapter 2: Literature review and conceptual framework	An in-depth review of current literature on autism spectrum disorder, hearing loss and other relevant content, the formulation of the conceptual framework for the study and conclusion to the chapter.
Chapter 3: Research methodology	A detailed description of the research process that was followed, research methodology and design, research paradigm, ethical considerations and conclusion to the chapter.
Chapter 4: Research findings and discussion	A presentation of the data, data analysis, discussion of the findings and integration of relevant literature, summary of the findings, conclusion to the chapter, strengths and limitations of the stydy and recommendations to professionals.

1.9   CONCLUSION

The researcher's objective for this first chapter was to provide an orientation to the research study. She specifically presented the purpose and rationale through a description of the background to the study, as well as a brief discussion of the proposed methodology. The researcher clarified key concepts derived from current literature, relevant ethical issues for consideration were mentioned and an outline for the study was provided. In Chapter 2 the researcher will provide an in-depth literature investigation of concepts relevant to dual diagnosis of hearing loss and ASD through a critical discussion against a backdrop of a preferred conceptual framework for the study.

CHAPTER 2:
LITERATURE REVIEW

2.1   INTRODUCTION

The purpose of this chapter lies in the establishing of the theoretical framework for the research (Bak, 2004, p.18). The researcher aims to identify the body of literature relevant to the research study, to indicate the relationship of the study to literature and to demonstrate where this particular study fits into the broader arguments, and to justify the relevance of the current study. Grinnel and Unrau (2005, p. 424) identifies four purposes of the literature review which the researcher worked towards presenting.

First to demonstrate an understanding of the research issues related to caregiver experiences (ASD, hearing loss, diagnoses and interventions). Secondly, to point out in which way the current research study is different to or similar to other studies on the topic. Thirdly, to fit the research into present knowledge, and fourthly, to conceptualise the constructs used throughout the study.

This overview of the literature creates the context for the exploration of caregivers' lived experiences of receiving the dual diagnosis and subsequent intervention services for their children. ASD and hearing loss were explored individually and studied systematically. Ultimately the literature review makes the careful consideration of the impact of having a child who is on the autism spectrum and has hearing loss on the life world of the caregivers possible.

Themes covered in the literature review are the characteristics, prevalence and aetiology of ASD and hearing loss respectively. The diagnostic processes, associated challenges and disorders, and known intervention services for each condition are investigated respectively.

2.1.1   Caregiver experiences of diagnosis and intervention for their child with ASD and hearing loss: a theoretical framework

The theoretical framework underpinning this study and through which the data will be interpreted and discussed is based on the theory of human development by Urie Bronfenbrenner (1917-2005), also known as the ecology of human development or the bio-ecological perspective. Bronfenbrenner was a pioneer in the field of the behaviour of children

against the backdrop of what he referred to as their "natural life space" (Brendtro, 2006, p. 162). The researcher chose to make use of this theory because Bronfenbrenner was honoured as one of the most distinguished scientist in the world for his extraordinary ability to put theory into practice. The following aspects addressed by this theory are discussed in relation to its relevance to the research.

Ecological models encompass an evolving body of theory and research concerned with the processes and conditions that govern the lifelong course of human development in the actual environments in which human beings live. Bronfenbrenner, Kessel, Kessen and White (1986) theorise that throughout the life course, human development takes place through processes of progressively complex reciprocal interaction between an active, evolving, biopsychological human organism and the persons, objects and symbols in its immediate environment.

His theory of human development has been well researched and applied within the field of educational psychology since its development in the 1970s. Before the development of Bronfenbrenner's theory specialists such as sociologists, educators and anthropologists studied isolated aspects of a child's world. However, Bronfenbrenner's bio-ecological theory offers researchers within the field of social sciences the perspective to combine all of these areas through the consideration of all the aspects of a person's life world and the influence thereof on their development (Brendtro, 2006).

Central to this theory is the belief that human relationships are key vehicles that take the lives of children on a pathway to either problematic or positive outcomes (Brendtro, 2006). However, the researcher was interested in how caregivers experienced diagnosis and interventions for their child within their natural life space, or otherwise referred to as the lived experience of caregivers. This theory offered the researcher the foundation to study caregiver experiences at the different levels of interaction between systems.

Bronfenbrenner's most basic belief was that the most powerful force in positive youth development is trusting bonds (Brendtro, 2006, p.163.) and therefore "… every child needs at least one adult who is irrationally crazy about him or her." He also emphasised that throughout the process of raising children caregivers require the support of another adult in their lives as they face the tremendous task of parenting.

The bio-ecological theory was used to study the experiences of real-life caregivers in real-life settings with real-life implications, as Bronfenbrenner hoped it would achieve

(Bronfenbrenner *et al*., 1986, p. 38). According to this theory caregivers' behaviour will reflect the transactions within these immediate circles of influence. Circles of influence are regarded as the most powerful influences and make up the relationships within the "immediate life space of the family, school and peer group" (Brendtro, 2006, p. 163). In order to gain an understanding of the caregiver experiences it is necessary to investigate the transactions within the family, peer group and neighbourhood. Therefore thorough information needs to be gathered on these interactions in order to get an understanding of caregivers and their experiences.

According to Swart and Pettipher (2012) the bio-ecological perspective explains by means of contextual analysis and synthesis, the implications for the interactions between the different levels of the context in which a caregiver of a child with a dual diagnosis of ASD and hearing loss finds him or herself. This context consists of the microsystem, mesosystem, exosystem, macrosystem and chronosystem. In order to consider the development of a person holistically, biological resources and attributes pertaining to the person should also be considered. This perspective proposes a combination of intrinsic and extrinsic causality of disorders, and hints towards the concept of epigenetics which refers to genes affected by the environment which contribute to the development of epigenetic disorders (Batshaw, 2011, p. 3).

Proximal processes are considered as the core within the bio-ecological model. They are described as the person-environment interaction and constitute the point of interaction between the five levels of the model. Proximal processes involve progressively more complex reciprocal relationships and interactions between an active individual and the persons, objects and symbols in his or her immediate environment (Swart & Pettipher, 2012). For these interactions to be effective, or as Bronfenbrenner (1994) refers to it the quality thereof, they must occur on a regular basis over extended periods of time. Proximal processes have the potential of "reducing" or "buffering" against environmental differences (difficulties) in developmental outcomes. Developmental outcomes for caregivers would be finding resolution after the diagnoses of ASD and hearing loss, as well as navigating available resources in the environment in order to receive appropriate intervention services for their child and family. The effects (influence) of proximal processes are considered more powerful than those of the environmental contexts in which they occur (Bronfenbrenner, 1994, p. 39).

Considering caregivers' lived experiences according to Bronfenbrenner's bio-ecological theory will aid in the systematic understanding of caregivers' experiences and allow a careful study of the proximal processes that occur within and across the different levels. Caregiver experiences will be a result of interactions on these levels and will take into consideration human development as pertaining to the children with hearing loss and ASD, as well as that of the caregivers. These levels will now be described according to Bronfenbrenner's conceptualisation.

Bronfenbrenner (1994, p. 39) defines the microsystem as a pattern of either direct activities, social roles and interpersonal relations experienced by the individual at any given point in time through "… particular physical, social and symbolic features that invite, permit or inhibit engagement in interaction". This engagement in sustained interaction and activity could become progressively more complex. Examples of these settings are the family, school, peer group and workplace. Proximal processes work to produce and sustain development. However, the ability of proximal processes to produce development depends on the content and structure of the microsystem.

When referring to the mesosystem, the interactions and linkages that occur between two or more of these settings of microsystems which involve the developing caregiver are considered. A mesosystem is therefore a system of microsystems as Bronfenbrenner refers to it (1994, p. 40). One example of a mesosystem of caregivers of children with a dual diagnosis of ASD and hearing loss would be the relationship between the home and the caregiver's work environment.

The exosystem is the next level and involves interaction and linkages that occur between two or more of these settings where the caregiver is not necessarily actively involved but where interactions directly influence the caregiver within their direct setting. An example would be the relationship between the child's school and the neighbourhood peer group. Prominent exosystems which have been found to have a significant indirect influence and therefore affects the development of children indirectly have been the parent's workplace, family social networks and neighbourhood community contexts (Eckenrobe & Gore, 1999).

The macrosystem consists of overarching patterns of micro-, meso- and exosystem characteristics of the relevant culture or subculture with reference to the belief systems, material resources, and bodies of knowledge, customs and life styles, opportunity structures,

hazards and life-course options that are embedded in each of these broader systems. Bronfenbrenner refers to these as the social blue-print for a particular culture or subculture. Bronfenbrenner considers it necessary to search beyond simple labels of class and culture to identify more specific social and psychological features at the macrosystem level that ultimately affects the particular conditions and processes occurring in the microsystem (Bronfenbrenner *et al*., 1986). This would, for example, be the dominant beliefs around ASD and hearing loss within a specific cultural group, for example the "Deaf culture".

The final system parameter extends the environment into a third dimension (Sameroff, 2010). It is called the chronosystem and refers to the dimension of time which relates to the interactions between the systems at a specific time to influence individual development (Swart & Pettipher, 2012). According to Bronfenbrenner the chronosystem encompasses change or consistency in characteristics over time, related to the individual as well as the environment (Bronfenbrenner, 1994, p.40). Due to the belief that the ecology of a person is not fixed, but that it changes over time, the chronosystem becomes of particular importance in considering caregiver experiences. Bronfenbrenner (2005) proposes that a "… longitudinal perspective on growth and development …" be maintained. As caregivers are faced with challenging situations related to their child's disabilities, they acquire skills to deal with these situations and their perspective evolves as a result of going through these experiences.

There are three main theories hypothesised that relate to ASD. These three theories are: the theory of mind, the theory that relates to executive functioning, and the theory of information processing (Pellicano, 2007). Unfortunately these theories fail to provide a full understanding of the child with ASD and therefore, regardless of one's theoretical convictions, it is important to consider the child with ASD and his or her family first holistically. Fortunately the bio-ecological perspective does this. The bio-ecological perspective takes into account the impact or role of genetic inheritance and biological factors on development.

The concept of a family structure is dynamic and each family has a unique composition (Turnbull & Turnbull, 2001). In order to understand the complex, yet unique structure (Orelove, Sobsey, & Silberman, 2010) of a family system and how it functions, it is important to consider the family's narrative. A family system reflects the composition, socio-economic status, resources, personal attributes, and special challenges of each particular family (Shelton & Traub, 2004, p. 49). These characteristics influence each member's role and responsibility within the family, how decisions are made, and communication within and

outside the boundaries of the family. Each member within the family has a specific role in a changeable family system (Turnbull & Turnbull, 2001, p. 49).

Receiving a diagnosis of the combination of ASD and hearing loss will influence every aspect of a caregivers' life world. Based on their research Head and Abbeduto (2007) recommend that clinicians take a systems approach to the assessment, diagnosis and intervention process by being aware of the way in which caregivers are being cared for.

2.2   AUTISM SPECTRUM DISORDER

Autism spectrum disorder (ASD) is a complex and changeable condition characterised by disorganised neurological development (Koudstaal, 2011). ASD is a life-long condition and until now no cure has been found. It is referred to as a pervasive developmental disorder that appears within the first three years of childhood (American Psychiatric Association [APA], 1994). ASD represents a spectrum of complex, neurological, and developmental disorders characterised by deficits in reciprocal social interaction and communication. They are a group of biological disorders resulting from abnormal brain development during early childhood, and the causes of ASD are still largely unknown (Ming & Pletcher, 2014). ASD is therefore referred to as a group of brain-based, whole-body disorders with organic causes. ASD is not considered a mental illness or a psychiatric disorder. ASD is a medical and developmental disorder which involves physical and chemical aspects of the brain (Doyle & Doyle, 2004). Therefore it is a neurological disorder and not an emotional one.

2.2.1   Characteristic features of autism spectrum disorder

Characteristic features of ASD are defined by the American Psychological Association in the DSM-5 (2013) as impaired social interaction and communication, repetitive and restrictive patterns of behaviour and interest. However, the features of this developmental disorder presents uniquely in each child. No two children on the autism spectrum are the same. Therefore the particular features presented by a child that leads caregivers to seek help are different. However, ASDs are biologically distinct groups of disorders that exhibit similar abnormal behavioural and developmental features (Ming & Pletcher, 2014).

Currently ASD is regarded as a social and developmental disorder and not a psychiatric disability as previously proposed. When considering the characteristic features of ASD it is important to understand that ASD is not a mental illness, behavioural disorder, nor an emotional disturbance (Ming, 2014). Pellicano (2007) explains that there are three primary

theories that stand out most prominently when considering ASD. These are the theory of mind (ToM), the theory that relates to executive functioning and the theory of information processing and provides us with important information when considering the characteristic features of ASD. Brunson *et al*. (2015) explain that the behavioural symptoms associated with ASD are thought to be a result of underlying cognitive differences in individuals with ASD. Cognitive accounts of ASD can be divided broadly into domain-specific and domain-general theories. A domain-specific theory, such as the theory of mind, identifies the primary area of deficit of a child with ASD as social processing and thus explains social and communication difficulties. The child with ASD experiences difficulty related to representing mental status. On the other hand, domain-general explanations of the difficulties children with ASD experience propose that the primary deficit or area of challenge lies in executive functioning.

Generally speaking characteristic features of ASD could thus present in some or all of the following ways. The child with ASD could display a marked difficulty in socialising and initiating shared social interactions due to a perceived inability to understand pragmatic language (Reid & Lannen, 2012). He or she displays a poor understanding or knowledge of unwritten social rules and experiences difficulty in participating in symbolic play. The child with ASD could also experience difficulty in achieving joint attention and display an interest in or intense fascination with a particular subject. Inflexible or ritualistic behaviours are observed in children with ASD (Kutscher, 2014; Ming & Pletcher, 2014).

Kutscher (2014) explains that when a child experiences difficulties with understanding social pragmatics, and consequently struggle to interact socially, the child could appear anxious, insist on sameness, display concrete and literal comprehension of language, appear inattentive or rude, seem to be interested in objects rather than people, appear out of it or odd, and become socially unwelcome.

2.2.2   Classification and diagnostic process of autism spectrum disorder

Receiving the diagnosis of a chronic illness or disability is a significant source of heightened stress for caregivers (Feliciano, 2008). Moore (2008) maintains that caregivers should experience the diagnostic label as a passport to relief if it goes hand-in-hand with receiving appropriate support and intervention. However, this is not always the case. Caregivers often associate their children's diagnosis with a sense of loss and trauma characterised by bereavement reactions similar to those that a person experiences when losing someone

through death (Feliciano, 2008, p.20). The way in which each caregiver experiences the diagnoses of ASD is unique and will affect the entire family as well as the diagnosed child (Williams, 2000). According to Feliciano (2008), the diagnosis of children with ASD drastically alters the caregivers' own psychological process of cognition, emotion and behaviour.

One mother described their family's experience of receiving a diagnosis as having their dreams for their daughter shattered (Ellis-Gonzales, 2008). According to Ellis-Gonzales (2008, p. 20) her perspective of her child's world was instantly redefined when they received the diagnosis of ASD.

> Our many dreams for her were shattered.
> We needed time alone in our desperate grief.
> We were shaken to the core; our souls were racked with grief. We were terrified of what lay ahead of us. Everything seemed so unknown, so foreign to us – even our own daughter.
> Ellis-Gonzales, 2008.

The clinical diagnosis of children displaying features of ASD depends on the quality of clinical evaluations (Thomas, Morrissey & McLaurin 2007). There is also no simple diagnostic test that can provide definite answers for a diagnosis. Diagnosing ASD is a challenging task for professionals, because their professional opinion for diagnosing children is formed based on caregivers' reports and observations as well as their own professional judgment (Ming & Pletcher, 2014). Diagnostic issues do arise due to norms for social interaction within different cultural groups, for example, nonverbal communication and relationships. But even with these differences, individuals with ASD are markedly impaired compared to the norms for their cultural context (Thomas *et al*., 2011).

It is important to note that the diagnosis of ASD is not simply done by describing physical symptoms. There are no biological markers to indicate the presence of ASD and therefore no medical tests that determine conclusively whether a child is on the autism spectrum, or not (Sattler, 2014). The diagnostic process includes observations of the child's development, learning, behaviour and communication. Specific behaviours are observed when assessing a child with possible ASD. These include the use of eye contact, facial expressions, gestures and vocalisations, interactions with others and caregivers, the use of language, play, motor behaviour, the ability to make transitions from one activity or environment to another, attention and activity level, and awareness of social cues and expectations.

Difficulties associated with ASDs such as difficulty establishing social relationships, impaired communication and unusual responses to sensory stimuli presents specific challenges to the clinician administering a formal evaluation of a child with suspected ASD (Sattler, 2014). Sattler (2014) recommends that the clinician consult with the child's caregivers and teacher about his or her communication ability, but also to inquire about suggestions they might have for engaging with the child prior to the assessment. Questions considered important to ask caregivers relate to the child's eye contact, response to his or her name, whether or not they point or gesture to indicate a response, use of signs, words, phrases or sentences.

According to the Diagnostic and Statistical Manual of Mental Disorders IV-TR this developmental disorder affects three main areas of the child's functioning, namely behaviour and imagination; social interaction; and language and communication. This is known as the Triad of Impairments, first conceptualised by Lorna Wing and Judith Gould in 1979. Considerations of the sensory modalities and related sensory-motor development in children with ASD have since become increasingly relevant within the field of ASD (Koudstaal, 2012). Sensory-motor development relates to the ability to integrate and process sensory, motor and perceptual experiences.

2.2.2.1   DSM-5 and ICD-10

According to the latest edition of The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013):

> The essential features of ASD are persistent impairment in reciprocal social communication and social interaction (Criterion A), and restricted, repetitive patterns of behaviour, interests, or activities (Criterion B). These symptoms are present from early childhood and limit or impair everyday functioning (Criterion C and D).

> The stage at which functional impairment becomes obvious will vary according to characteristics of the individual and his or her environment. Core diagnostic features are evident in the developing period but intervention, compensation and current support may mask difficulties in at least some contexts. Manifestations of the disorder also vary greatly depending on the severity of the autistic condition, developmental level and chronological age; hence the term spectrum.

> ASD encompasses disorders previously referred to as early infantile autism, Kanner's autism, high-functioning autism, atypical autism, pervasive developmental disorder not otherwise specified, child disintegrative disorder, and Asperger's disorder.

Impairments in communication and social interaction specified in Criterion A are pervasive and sustained. Many individuals have language deficits, ranging from complete lack of speech through language delays, poor comprehension of speech, echoed speech, or stilted and overly literal language. Deficits in social-emotional reciprocity (i.e., the ability to engage with others and share thoughts and feelings) are clearly evident in young children with the disorder, who may show little or no initiation of social interaction and no sharing of emotions, along with reduced or absent imitation of others' behaviour. What language exists is often one-sided, lacking in social reciprocity, and used to request or label rather than to comment, share feelings, or converse.

The diagnostic criteria whereby ASD is diagnosed are set out in the DSM-5 above (American Psychiatric Association, 2013). With the reviewed set of criteria for diagnosis in The DSM-5 it has entailed significant changes in the categorisation of Asperger Syndrome as part of the autism spectrum and no longer being a separate diagnosis umbrella term, once again looking at language pragmatics. The DSM-5 has thus combined all three pervasive developmental disorders (autistic disorder, Asperger disorder and PDD-NOS) into a single ASD diagnosis while adding severity specifiers depending on the presentation of each individual child (Ming & Pletcher, 2014).

The DSM-5 (2013) specifies that diagnoses are most valid and reliable when based on multiple sources of information, including a clinician's observation, caregiver history, and, when possible, self-report. Verbal and nonverbal deficits in social communication have varying manifestations, depending on the individual's age, intellectual level, and language ability, as well as other factors such as treatment history and current support.

ICD-10

The International Classification of Disease (ICD-10) developed by the World Health Organisation is a classification system and serves the same purpose as the DSM-5 in the diagnosis of ASD. Although there are some variations in the diagnostic criteria in the DSM-5 and the ICD-10 mental health professionals, neurologists and other medical professionals are generally in agreement about the diagnosis of ASD as the reflection of the standards of both these classification documents. Diagnostic terms are however used in different ways and have different meanings (Wing & Potter, 2002).

Within the ICD-10 classification system autism is classified as a *Disorder of psychological development* under F84, the pervasive developmental disorders category. Pervasive developmental disorders is a category that comprises of childhood autism (F84.0), atypical

autism (F84.1), Rett's syndrome (F84.2), other childhood disintegrative disorders (F84.3), overactive disorder associated with mental retardation and stereotyped movements (F84.4), Asperger syndrome (F84.5), other pervasive developmental disorders (F84.8), and pervasive developmental disorder, unspecified (F84.9). These disorders are categorised by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities. According to the criteria these characteristics should be a pervasive feature of the child's functioning in all situations. This system of categorisation also allows for the diagnosis of additional medical conditions and mental retardation.

2.2.2.2   *Other diagnostic tools*

Sattler (2014, p. 605) advises clinicians that the assessment of children for possible ASD entails the description of the child's symptoms as well as the degree or severity thereof, along with any associated features. If a child has any other condition such as epilepsy it should be considered along with the child's intellectual level when conducting the assessment. Filipek *et al*. (2000) in Batshaw reiterates the importance of a multi-disciplinary team approach and knowledge of development in this process and "… it follows directly from the [DSM- 5] diagnostic criteria that focus on impairments in social reciprocity, language, and restricted patterns of behaviour". Areas of development that should be assessed include receptive and expressive language, cognitive function, hearing, fine and gross motor function, social and emotional skills, and finally adaptive skills (Batshaw, 2013, p. 353).

Table 2.1: Screening and diagnostic tools for ASD

Screening tests for ASD in toddlers	*Standardised test that support a clinical diagnosis of ASD*
Modified checklist for autism in toddlers (M-CHAT; Dumont-Mathew & Fein, 2005): ages 18-36 months	Childhood autism rating scale (CARS2; Schopler, Van Bourgondien, Wellman & Love, 2010): older than two years of age
Screening tool for autism in two-year-olds (STAT; Stone, Coonrod, Turner & Pozdol, 2004.)	Gilliam autism rating scale, Third Edition (GARS-3; Gilliam, 2006); older than age three
Pervasive developmental disorder Screening Test (PDDST II; Siegerl, 2004.)	Autism diagnostic interview (ADI-R; Rutter, LeCouteur & Lord – revised, 2003): semi-structured interview with the caregiver that allows for scoring whether ASD is present
Autism observation scale for infants (AOSI; Bryson; Zwaigenbaum, McDermott, Rombough, & Brian, 2008.)	Autism diagnostic observation schedule (ADOS; Lord, Rutter, DiLavore, Risi, Gotham & Bishop, 2012)

Screening test for older children
Social communication questionnaire (SCQ; Rutter, Mailey, Lord, 2003); older than 3 years of age
The autism spectrum rating scale (ASRS; Goldstein & Nagliery, 2010); 2–18 years of age.
The autism spectrum screening questionnaire (ASSQ; Ehlers, Gillberg, & Wing, 1999).
The checklist for autism spectrum disorder (Mayes,Calhoun, Murray, Morrow, Yurich, Mahr, Cothren, Purichia, Bouder, & Peterson, 2009).

(Combination of Hayman and Levy in Batshaw 2013 & Sattler 2014)

2.2.3   Prevalence and aetiology of autism spectrum disorder

In 2001 autism spectrum disorders were on the increase worldwide, with international statistics implying that it affects one in every 158 children under the age of 8 years. Only eight years later, in 2009, the prevalence of ASD was estimated at 1 out of 110 children (A;SA, 2009) and the statistics presented by Talk About Curing Autism (TACA, 2012), Autism Speaks and the American Academy Paediatrics Report respectively stated that one in every 88 children were diagnosed with ASD in the United States (Centre for Disease Control and Prevention, 2012). Based on these reports the rate of ASD diagnoses documented around the world has shown a sharp increase in the last three decades (Lord & Bishop, 2010). A report by Autism South Africa (A;SA) on the prevalence of ASD in South Africa, reflects these findings. In South Africa a child affected by ASD is born every hour (A;SA, 2011). Males are affected more than females by a ratio of 4:1.

The DSM-5 (American Psychiatric Association, 2013) however reports the frequency of ASD to be approximately 1% of the total population across the United States and non-U.S. countries. The American Psychiatric Association remains uncertain as to whether the previous higher rates are a reflection of the expanded diagnostic criteria of the DSM-IV-TR, increased awareness of ASD, differences in research methodology, or a true increase in the frequency of ASD. The debate about the prevalence of ASD and the reason for the recent reported increase therefore continues. Although the prevalence rates have varied the fact remains that the reported rate in 2011 is tenfold what it was reported a generation ago (Hyman & Levy, 2013).

Due to the many varied manifestations of ASD unravelling the exact causes are difficult. Researchers suggest a combination of a possible genetic predisposition along with impacting environmental and biochemical factors (Doyle & Doyle, 2004). ASD was first considered a biological disorder at the start of the new millennium and the previous grossly incorrect theory of a "refrigerator mother" has since been rightfully rejected (Ming, 2014). Therefore it is not the effect of a disrupted mother-child relationship. It is not caused by caregivers nor is it a consequence of parental behaviour prior to or after birth (Doyle & Doyle, 2004). With this being said, associated behavioural challenges have significant effects on caregiver experiences.

According to Batshaw (2002, p. 371) evidence exist that pervasive developmental disorders are the product of developmental brain abnormalities with a significant genetic influence (Batshaw, 2002, p. 371). Genetic evidence in ASD is compelling and comes from both twin studies as well as more extensive family studies. Research shows that the rate of ASD amongst identical twins ranges between $70 - 90\%$ whereas the rate of ASD amongst fraternal twins is 0%. Sternberg (2006) who agrees that ASD is biological in its origin stated that the gene responsible for ASD has not yet been conclusively identified. However, according to research by Sternberg (2006) children with ASD show abnormal development in different areas of the brain. Abnormalities have been identified in the frontal and parietal lobes, cerebellum, brain stem, corpus callosum, basal ganglia, amygdala and the hippocampus.

Factors within the environment that could contribute to the risk of ASD are nonspecific but may include, for example, higher parental age, low birth weight, and fetal exposure to valproate (APA, 2013). On a genetic and physiological front heritability estimated for ASD have ranged from $37\% - 90\%$ based on twin concordance rates (APA, 2013).

Due to the increase in ASD diagnosis in the past three decades (Lord & Bishop, 2010) research has focused on formulating a body of knowledge and gaining understanding of biological and genetic markers of ASD relating to the aetiology and manifestation of ASD. Research on interventions designed to support individuals with ASD and their caregivers has been comparatively more limited, specifically research aimed at assessing how ASD treatments influence caregivers and families. This neglects the crucial role caregivers play in the intervention process (Karst & Van Hecke, 2012).

2.2.4   Associated disorders

ASD is known to coexist or have co-occurring symptoms or conditions (Levy *et al*., 2010). These co-occurring conditions are broadly divided into three categories, namely neurological disorders, psychiatric disorders and biologically based disorders which include genetic disorders and conditions (Ming & Pletcher, 2014). These include intellectual disability, learning disabilities, epilepsy, tic disorders, sleep disorders, gastrointestinal symptoms, and psychiatric conditions such as attention deficit hyperactivity disorder (ADHD), anxiety, depression and mood disorders. There are also specific genetic disorders that have been associated with ASD such as tuberous sclerosis, fragile X syndrome as well as Chromosome 15 deletion (Hyman & Levy, 2013).

ASD and learning disability, as described by the ICD-10, the DSM-IV, and now DSM-5, are co-associated (O'Brien, 2004). ASD is more common among individuals with learning disability, with higher numbers of children with ASD that have lower IQs. ASD influences the child's ability to learn and therefore all areas of development. This is then the reason for the use of the term *pervasive* to describe its nature. O'Brien (2014) states that in general the severity or degree of symptomatic display or symptomatology will vary according to the level of the child's learning disability.

ASD and intellectual impairment have long been associated. Individuals with an IQ score of less than 50 will have significant language impairment and may be nonverbal (Reiss, 2010).The best established prognostic factors for an individual outcome within ASD are the presence or absence of associated intellectual disability and language impairment. Epilepsy, as a comorbid diagnosis, is associated with greater intellectual disability and lower verbal ability (APA, 2013).

> Many individuals with ASD also have intellectual impairment and/ or language impairment (e.g. slow to talk, language comprehension behind production). Even those children with average or high intelligence have an uneven profile of abilities. The gap between intellectual and adaptive functional skills is often large. Motor deficits are often present, including an odd gait, clumsiness, and other abnormal motor signs e.g., walking on tiptoes. Self-injury (e.g. head banging, biting the wrist) may occur, and disruptive or challenging behaviours are more common in children and adolescents with ASD than in children with other disorders, including intellectual disability. Adolescents and adults with ASD are prone to anxiety and depression (APA, 2013).

The co-occurrence of specific conditions will inevitably have a significant influence on the behaviour and every day functioning of a child with ASD. An example of this is the co-occurrence of anxiety or obsessive compulsive disorders with its known associated behaviours, as well as gastrointestinal disorders with symptoms such as encopresis, abdominal pain or bloating (Monteiro, 2014). Amongst these numerous conditions which are associated with ASD is hearing loss.

2.2.5   Interventions for autism spectrum disorder

While children with ASD might display similar characteristic features, each individual with ASD is unique, often making it difficult for caregivers and professionals to fully understand the child's complex needs and therefore finding ways to support these unique needs sufficiently (Doyle & Doyle, 2004). There are specific factors that need to be considered when deciding on intervention for a child with ASD (Reid & Lannen, 2012). These factors relate to education, the home environment, social, and other issues that arise after school and will be family and situation specific. However, treatments could consist of "… a variety of therapies and possibly medications" (Hayes Rosen, 2014).

Interventions available to caregivers of children with ASD are considered as either evidence-based practices or alternative therapies. Deciding on interventions is determined by caregivers' available resources as therapies can be costly. There is significant emotion attached to caring for a child with special needs and wanting the best possible outcome for your child is a natural occurrence. Caregivers are often desperate to see results and therefore vulnerable to opting for therapies that promise results. The current debate over ASD aetiology and definition, in conjunction with the overabundance of interventions available for ASD often leaves caregivers feeling unsure and confused about the optimal course of treatment for their child (Mackintosh, Goin-Kochel, & Myers, 2012).

Notwithstanding the difficulties caregivers face when raising a child with ASD, and the negative effects that these stressors inflict on the outcomes of interventions, these interventions are primarily focused on achieving outcomes related to the child and therefore neglect to consider or incorporate caregiver and family factors that could have an influence on immediate and long term effects of intervention therapy (Karst & Van Hecke, 2012).

More than 70% of children on the autism spectrum also have an intellectual disability (Szymanski *et al*., 2012). These statistics have significant implications for educational and

psychological support in schools internationally, also in South Africa. Within the educational context issues speak to the provision and extent of available services and the level of specialist expertise.

It cannot be assumed that even significant improvements in the diagnosed child will ameliorate the caregiver and family distress already present, especially as the time and expense of intervention can add further family disruption (Karst & Van Hecke, 2012).

Diversity amongst individuals could further be applied to the process of deciding on the most appropriate intervention. Karst and Van Hecke (2012) have proposed the necessity to consider five specific areas when attempting to determine the range of effects of ASD. These are the child's cognitive functioning or intelligence, the severity of the characteristic features of ASD, the child's verbal or non-verbal communication ability, the child's age and the level of exposure to learning experiences. It is understood that the lived experiences of caregivers of children with features of ASD will therefore be affected by the range of these affects.

Therapies that have demonstrated significant evidence of positive outcomes include speech therapy, occupational therapy, sensory integration therapy, physical therapy, as well as behavioural therapy and social skills training. Behavioural therapy includes applied behaviour analysis (ABA), discrete trial teaching (DTT) and pivotal response treatment (PRT). Behavioural therapies with an increased focus on the development of relationships include the DIR/Floortime model and relationship development intervention (RDI) approach. Social skills training focusing on increasing social and communicative skills are further considered as a core intervention strategy for children with ASD (Kutcher, 2014; Ming & Pletcher, 2014).

Biomedical interventions are provided by medical doctors and address specific concerns unique to each child with ASD, but could be related to comorbid sleep disturbances, symptoms of ADHD as well as anxiety or aggression (Ming & Pletcher, 2014).

2.2.6 Diagnosis and intervention for autism spectrum disorder in South Africa

In order to gain insight into the experiences of caregivers with a child with ASD the researcher consulted an educational psychologist who works at a special school in Cape Town for children with ASD. This conversation provided the researcher with valuable information regarding caregivers' experiences as they seek support and intervention for their children. The researcher formulated questions related to caregivers' queries to the school, a

protocol for screening and diagnosis, placement procedures, and support offered to caregivers by the school. The following information was shared by the educational psychologist at a special needs school for children with ASD (personal communication, June 30, 2016):

According to her experience the process of receiving a diagnosis of ASD, specifically in the Cape Town Metropole, seem to differ depending on who they receive the diagnosis from. Doctors, psychiatrists and psychologists who have experience in the field of ASD appear to have more insight and are able to offer parents more support and direction after an initial diagnosis. The neuro-paediatric division at Red Cross Hospital, Cape Town, offer insight and advice to parents and are able to refer parents to relevant schools. Doctors and specialists at the Division of Child and Adolescent Psychiatry (DCAP) at Red Cross Hospital are able to diagnose ASD. There are a few well-known psychiatrists and psychologists in the Cape Town Metropole whom parents are often referred to if they can afford to consult with doctors in private practice. According to her experience there are parents at this particular school who report that they moved to the Western Cape in order to access public services.

There are specific measures and diagnostic tools used to diagnose ASD. Prior to being admitted to the school, a trans-professional team (which includes a psychologist, occupational therapist, speech therapist and experienced educator) initially screens every learner in order to identify signs and symptoms of autism and autistic traits. Their observation is based on knowledge and experience of working with learners with ASD on a daily basis. It is also based on the diagnostic criteria set out in the DSM-5. Furthermore, an in-depth history of the child's development is obtained from the caregivers and all previous assessments and referral information is taken into account. Observation checklists guide their monitoring of each individual learner. Assessment and diagnostic tools used at this school, as well as the professionals who conduct them, are set out in the table below.

Table 2.2: Measures and diagnostic tools for ASD and the professionals qualified to administer them

Measures and diagnostic tools	Professionals qualified to administer these measures and tools
Informal observation	Educators and therapists
PEP-3: Psycho-educational profile – Third edition	The trans-professional team
ADOS-2: Autism diagnostic observation schedule, Second edition	A psychologist trained in using the ADOS

CARS-2: Childhood autism rating scale, Second edition	The tans-professional team
ASIEP-3: Autism screening instrument for educational planning – Third edition	The trans-professional team
Specific assessments conducted by the speech therapist	Speech therapist
Specific assessments conducted by the occupational therapist	Occupational therapist

When caregivers who are concerned about their child due to developmental delays and possible features of ASD contact this particular school the educational psychologist guides them and offers direction as follows. She explains to them that admission to a special school for children with ASD governed by the WCED is a lengthy process and that learners often wait for years to be placed. She explains that the first step in getting this process started is a referral to the school by a specialist, for example a psychologist, psychiatrist or speech therapist. The learner is then placed on a centralised waiting list and when there is a place available the learner is invited to a screening interview at the special school for children with ASD closest to where the learner lives. After the screening interview a two-week observation period follows during which a diagnosis and recommendation for school placement at a special school for children with ASD will be made if appropriate. The learner then waits for placement at the school or is referred elsewhere if an ASD school is not deemed to be the correct placement.

At present, according to legislation from the WCED, priority is given to learners who are of school-going age and therefore caregivers are encouraged to seek early intervention while waiting for placement at a school or for intervention by the WCED, as learners' names may be on the list from the age of three years. Examples of possibilities include placement within a small playgroup for socialisation, communication and the development of socio-emotional skills. Further recommendations include intervention by a psychiatrist, speech therapist or occupational therapist trained in working with learners with ASD. If caregivers cannot afford private therapy they are referred to a state Developmental Clinic such as found at Tygerberg Hospital or Red Cross Children's War Memorial Hospital. Caregiver training and skills development is sometimes provided by the school or caregivers may be referred to Autism Western Cape (AWC) as a resource. The use of an augmentative and alternative communication system (AAC) is sometimes advised.

The main concerns reported by caregivers when they contact a special school for children with ASD are related to observed speech and communication delay, the inability to express their needs effectively, lack of social-emotional reciprocity, and a concern over whether their child will fit into a mainstream school. Caregivers first report these concerns to specialists who then refer them to a special school for children with ASD. Caregivers may also contact the specific school due to developmental or social concerns expressed by their child's preschool. When caregivers contact this special school for children with ASD regarding their concerns information is provided to them based on the unique needs and challenges of their child. If the school is not able to provide services to the caregiver and their child the school tries to refer the caregivers to professionals with experience in working with children with ASD.

The diagnostic process is explained to caregivers when they inquire. They are told that the school does a thorough assessment of the child within the school context during the observation period and that both formal and informal assessment measures are used within the school context while considering the developmental history of the child. Caregivers are told that the team will try to ascertain which behaviours are consistent and that sufficient time is needed to make these observations. For this reason it is not possible to confirm a diagnosis at a screening interview as this interview is an informal observation session and there is not sufficient time and information gathered on which to base a diagnosis. The caregivers' role in the diagnostic process is considered important as they are vital members of the trans-disciplinary team and form part of all aspects of management, diagnosis and intervention.

Intervention services available to caregivers of children with ASD outside of ASD specific schools include Division of Child and Adolescent Psychiatry at Red Cross Hospital, Autism Western Cape, specific inclusive preschools and private therapists with experience in working with children with ASD.

Special schools for children with ASD strive to offer services to caregivers of children with ASD by presenting some training which provides glimpses into the life of a learner diagnosed with ASD (ABC training), Makaton training (language programme using signs and symbols to help people to communicate, designed to support spoken language) and PECS training (picture exchange communication system).

Suggestions to caregivers of a child with a dual diagnosis of ASD and hearing loss would be the use of an augmentative and alternative communication system (AAC) such as sign language, along with the opportunity for socialisation in a small, structured setting.

2.2.7   Caregivers of children with autism spectrum disorders

The impairments associated with ASD not only affects the diagnosed child, but also his caregivers and family (Karst & Van Hecke, 2012). Caregivers face common challenges in their daily lives, as well as challenges specific to their child's diagnosis and the unique characteristic features of ASD. When reflecting on the reported experience of raising a child with ASD it is described in the literature as being overwhelming for caregivers and families (Ming & Pletcher, 2014).

The effects of having a child with ASD on caregivers are, like the disorder itself, multifaceted and pervasive (Karst & Van Hecke, 2012). Approximately 85% of individuals with ASD present with cognitive and or adaptive limitations that impair their ability to live independently. Consequently these children need some measure of care or assistance from their caregivers for the duration of their lives (Volkman, 2011). Caregivers therefore have a lifelong responsibility to care for their child with ASD. The burden of this responsibility has the potential to exacerbate the difficulties they encounter due to the characteristic features of ASD. Caregivers experience a sense of concern over their diagnosed child's future along with their own. Caregivers report that they feel less optimistic about their ability to provide effective parenting (Karst & Van Hecke, 2012).

Autism spectrum disorders are constantly being reconceptualised which means that the aetiology is uncertain and the conceptualisation changes all the time Meinzer-Derr *et al.,* 2014. Caregivers experience this uncertainty as it influences their conceptualisation of their child, for whom they are constantly concerned. The caregivers have to find the appropriate and best-suited interventions despite these uncertainties (Rutter, 2011; Karst & Van Heck, 2012).

Due to the many difficulties and challenges as a result of the pervasive and severe nature of "deficits'" associated with ASD, caregivers are known to experience a sense of decreased parenting efficacy. This relates to "... a sense of not knowing what to do or how to deal with or resolve a situation" (Karst & Van Hecke, 2012).

Parenting self-efficacy may be uniquely affected by having a child with ASD. Caregivers with a broader autism phenotype or sub-threshold characteristics of autism often seen in parents of children with ASD in (Karst & Van Hecke, 2012) may lack confidence to help their child address difficulties. The caregivers experience this as social anxiety or difficulties with non-verbal communication.

Desai, Divan, Wertz and Patel (2012) describe the lived experiences of caregivers of children with ASD with reference to their context. This means the historical unfolding of the lives. These findings were divided into four temporal phases. They found that within these four phases there were three constituent processes that were regarded as important in caring for their child: (a) Engaging in an open-ended process of parenting by learning to meet new and unfamiliar challenges; (b) Ensuring that the child's basic needs are met; and (c) Finding an engaging niche to create a sense of belonging for their child in the everyday milieu including social relationships, education/work, maintaining family values etc. These concerns described by Desai *et al*. (2012) were present from the earliest period and continued to develop as time went on.

2.2.7.1   *Effects on mental and physical health*

Higher levels of parenting stress and an increase in mental and physical health problems are reported compared to caregivers of typically developing children, as well as other developmental disorders. Caregivers of children with ASD may experience more maternal stress and caregiver burden when raising the child, according to Hsien and Lo (2012). This relates to the challenges of teaching daily tasks or introducing them to new environments or dealing with behavioural challenges relating to the features of ASD. The experience of on-going stress includes negative physical and psychological effects such as low frustration tolerance, anxiety and hypertension.

Challenges are not static and experiences of caregivers are subject to growth and development. Throughout the developmental stages of the child experiences develop and evolve. Each developmental stage brings new and unique experiences. Caregivers experience doubt and feelings of uncertainty related to parental self-efficacy (Weiss & Lunsky, 2011; Karst & Van Hecke, 2012). They experience significant levels of financial strain and time pressure. Unfortunately, high rates of divorce amongst spouses with children with ASD are a reality, and generally lower family wellbeing is reported. With a closer look at the lived experiences of caregivers of a child with ASD, the burden and responsibility placed on

caregivers becomes comprehensible. The need for subsequent comprehensive support and intervention to address this need becomes clear.

Caregiver affects, reciprocally and negatively impact the child diagnosed with ASD (Karst & Van Hecke, 2012). It is essential for service providers, involved individuals, care workers and psychologists to consider the influence of caregiver experiences as this can diminish the positive effects of intervention that are proposed and implemented.

Karst and Van Hecke (2012) for this reason, propose that when intervention and support is being planned and formulated within the multi-disciplinary team (or by doctors, etc.) it cannot primarily be evaluated in terms of outcomes observed in the child. For this reason, intervention and support should address factors relating to the caregivers and the family as it will influence immediate and long term effects of therapy, etc. This concept of reciprocal relationship and influence resonates with the bio-ecological theory which guided this research study.

Amongst the disorders often associated with ASD is hearing loss. Hearing loss "… is reported more frequently in people with neurological and developmental disorders (Malandraki & Okalidou, 2007, p. 23)". Marschark (1993) has attributed the high incidence of secondary disorders in children with hearing loss to neurological risk factors associated with the cause of hearing loss. When referring to neurological risk factors Szymanski *et al*. (2012) consider "medical conditions that are severe enough to cause a child's deafness".

2.3   HEARING LOSS

Störbeck (2016, p. 430) explains that the definition of hearing loss or deafness (as she refers to it) is derived from two opposing schools of thought. The first defines deafness in audiological terms and regards deafness as a deficit or the inability to hear. The second paradigm refers to the Deaf and defines Deaf people and their deafness as a linguistic and cultural minority group with a strong identity. Störbeck (2016) alludes to the fact that these two definitions respectively represent the medical model and the social model. However, there has recently been a positive shift away from the polarisation of these two schools of thought towards an inclusive perspective namely the bio-ecological approach. The bio-ecological approach to hearing loss allows for the convergence of the medical and social models. According to this model the person with hearing loss is considered as a whole being

consisting of, but not equal to, physical, cultural, social and economic aspects and accepted accordingly (Storbeck, 2016).

There are four categories of information that need to be considered when defining the physical audiological component of hearing loss. These are the *level of hearing loss*; the *type of hearing loss*; the *cause or aetiology of hearing loss*; and the *age of onset of hearing loss* (Storbeck, 2016). These will be discussed in more detail below.

2.3.1   Parameters of hearing loss/manifestations of hearing loss

2.3.1.1   *Levels or degrees of hearing loss*

Batshaw (2013) identifies the purpose of determining the child's level or degree of hearing loss in order to predict to what extent a child will be able to understand speech through hearing alone in order to acquire language and information through hearing. Degrees of hearing loss is categorised from minimal to profound according to a classification scale. The following table illustrates the different degrees of hearing loss and is taken from Störbeck's chapter in *Addressing Barriers to Learning, Educating the deaf and hard of hearing learner* (2016, p. 432). Sounds that we hear have a specific frequency which is measured in hertz, whilst its intensity or loudness is measured in decibels (dB). The degrees of hearing loss are classified as follows:

Table 2.3: Levels of hearing loss

Hearing person	0-15dB
Slight hearing loss	16-25dB
Mild hearing loss	26-40dB
Moderate hearing loss	41-55dB
Moderately severe hearing loss	56-70dB
Severe hearing loss	71-90dB
Profound hearing loss	91dB+

2.3.1.2   *Types of hearing loss*

Hearing loss is categorised according to four types; conductive, sensorineural, auditory processing disorder (also known as central hearing loss), and auditory neuropathy/dys-synchrony (AN/AD) (Störbeck, 2016). The most common types are conductive and sensorineural hearing loss. Northern and Downs (1991, p. 13) explain that when a

combination of conductive and sensorineural hearing loss occurs it is referred to as mixed-type hearing loss. Störbeck (2016, p. 432) explains that each of these types of hearing loss manifest in different kinds of hearing difficulties which affect a child's development in specific ways. Conductive hearing loss involves a problem in the actual process of conducting the sound waves in the outer or middle ear and can be caused by blockages in the ear canal as a result of wax or fluid build-up. Conductive hearing loss affects the volume of sounds heard and can be improved through the use of medication, surgery or amplification.

Sensorineural hearing loss is caused by a problem in the inner ear or in the auditory nerve. The outer and middle ear could be in perfect working condition, but if the inner ear is not able to convert sound vibrations into electrical signals required by the auditory nerve the brain will not be able to interpret the sounds. Amplification might improve sensorineural hearing loss. However, it is often associated with auditory distortion which is not correctable.

In auditory processing disorder the sound reaches the beginning of the auditory nerve but the processing of the sound along the nerve to the brain does not occur as it should. It is caused by head injury or damage to the central auditory nervous system and thus results in the inability to interpret sound effectively. There are no medical treatments available for this type of hearing loss except speech therapy that focusses on sound discrimination which has yielded positive results (Morin, 2017).

The fourth type of hearing loss is called auditory neuropathy or dys-synchrony (AN/AD) and is particularly complex to diagnose. Audiologic testing indicates outer hair cell function within the normal range with abnormal auditory nerve and or inner hair cell function. The child with AN displays fluctuating hearing loss, for example good hearing days and poor hearing days with accompanying challenges with word recognition.

When the peripheral hearing mechanism which consists of the conductive mechanism (outer and inner ear) and the sensorineural mechanism (inner ear and auditory nerve) are within normal limits, but auditory dysfunction is present this type of hearing loss is categorised as a central auditory problem (Northern & Downs, 1991, p. 10).

Hearing loss is further defined by the time of onset, time course of the impairment, and whether one or both ears are involved or affected. Hearing loss can be unilateral or bilateral, meaning that either one ear or both ears are affected (Stach, 1998). The time of onset of hearing loss is categorised as being congenital (which means that it was present at birth or it

can be acquired or obtained after birth) or adventitious (acquired after birth). Störbeck (2016) refers to a more useful classification of hearing loss in terms of the impact it will have on the child's development, and considers whether it was developed before the age of two years, before language is developed (prelingually). The other class of hearing loss is after language has developed (postlingually). Hearing loss developed in each of these stages will have a different impact on the child's language development and therefore Störbeck (2016) highlights the fact that intervention will consider these factors accordingly. When hearing loss is classified by an audiologist it is done in terms of its degree or level, type and laterality.

2.3.2   Prevalence and aetiology of hearing loss

Hearing loss is regarded as the most common birth disorder (American Academy of Otolaryngology, 2017). Each year more than 718 000 babies worldwide are born with or acquire early-onset, permanent bilateral hearing loss (Olusanya & Newton, 2007; Swanepoel, Störbeck, & Friedland, 2009). This figure translates into approximately 2000 babies born with or acquired permanent bilateral infant hearing loss per day worldwide. According to Stats SA (2011) there are 20 944 children with hearing loss under the age of 18 years in the Western Cape alone. Due to the fact that hearing loss can either be present at birth or be acquired after birth, the prevalence of childhood hearing loss increases with age. At nine years of age the prevalence of hearing loss is double that of what it was at birth (Fortnum et. al., 2001; Olusanya, 2005).

Causes of hearing loss are associated with genetic, biologic and environmental risk factors (Batshaw, 2013). Prelingual hearing loss which is either congenital or acquired prelingually and as a result from maternal illness such as rubella syndrome, measles and cytomegalovirus (CMV), genetic deafness, birth complications or premature birth, and hyperbilirubinaemia or jaundice. Postlingual hearing loss is caused primarily through ear infections and meningitis but can also be as a result of head injuries, high fevers, mumps and measles, or as a side effect of ototoxic medications (Störbeck, 2016).

2.3.3   Screening programs and diagnostic process of hearing loss

Specific symptoms or signs of hearing loss observed at a specific age within a specific context will determine the diagnostic process of hearing loss. Within a developed context, when it is suspected that a child is at risk of having hearing loss, the child is clinically tested to determine whether he or she is capable of hearing sound at different frequencies and volumes. This is done through administering a baseline audiometric peripheral hearing test

(Kutscher, 2014). This is followed by a brainstem auditory evoked responses (BAER), which is similar to a mini-EEG (electroencephalogram).

In the United States of America early hearing detection intervention (EHDI) systems have been established by governmental agencies. These systems emphasise the importance of newborn hearing screening, diagnoses of hearing loss, family support, early intervention and medical home services (Buethe, Vohr, & Herer, 2013). According to this plan infants should be screened by the age of one month, diagnosed by the age of three months and intervention started by the age of six months of age. This is referred to as the 1-3-6 goal.

Identifying hearing loss soon after birth is comparable to the need for early detection of vision loss as the brain pathways are immature at birth and develop normally only when they are stimulated. Evidence shows that identifying hearing loss early and implementing family-centred intervention services prior to the age of six months, regardless of the degree of hearing loss, can result in significantly better vocabulary, speech intelligibility, general language ability, as well as improved parental bonding and social-emotional development for deaf and hard of hearing children between the ages of one and five years (Yoshinaga-Itano, 2001). These intervention goals are considered equally important regardless of the level of the child's hearing loss. Unfortunately (Sattler, 2014) the reality is that there often is a significant delay from when caregivers first suspect something is amiss with their child to when they receive a conclusive diagnosis of hearing loss. Similar experiences have been reported by caregivers of children with ASD.

Hearing loss significantly impacts the cognitive, linguistic, socio-emotional and educational development of a child (Störbeck, 2016) and therefore early identification is crucial to mitigate or manage the influence thereof through implementation of early intervention strategies. Internationally significant improvements have occurred during the last two decades as screening of new born babies have increased (Wilson & Avt, 2006).

In comparison to other congenital or early-onset disabilities infants with hearing loss have the prospect of achieving outcomes similar to their hearing peers provided that their hearing loss is identified early on and intervention is initiated by six to nine months of age (Swanepoel, Störbeck & Friedland, 2009). Early identification requires screening with objective electrophysiologic equipment such as otoacoustic emissions and auditory brainstem

responses (Swanepoel *et al*., 2009) and screening and identification is administered by a pediatric audiologist (Van der Spuy & Pottas, 2008).

According to Fitzpatrick *et al*. (2007) the universal newborn hearing screening has become a normative procedure after birth. However, the concern expressed by Yoshinaga-Itano and Gravel (2001) is that until hearing health-care service delivery could be guaranteed for all children, the process of screening newborns before hospital discharge, is seen only as a reasonable outcome in addressing the challenge of early identification.

Internationally research findings in the field of early intervention have clearly illustrated the significant benefit of early identification of hearing loss and the consequent access that early intervention services have on the development of a child's speech, language and vocabulary, as well as social-emotional development. The main aim of early intervention for children who have been identified as having hearing loss is the fitting of appropriate amplification devices and access to early intervention services.

2.3.4   Associated challenges and disorders of hearing loss

According to McClay *et.al*. (2008) children with hearing loss are at an increased risk of medical and educational diagnosed disorders. They are heterogeneous in nature for a range of factors, including aetiology, the potential for a coexisting disability and family or environmental characteristics. Approximately 40% of children with hearing loss are known to have one or more disabilities in addition to hearing loss. These findings were made by the Gallaudet Research Institute based on a study done in 2003 which included 42 361 children with hearing loss. The following conditions made up this 40%: learning disability 10.7%; intellectual disability 9.8%; attention deficit disorder 6.6%; blindness and low vision 3.9%; cerebral palsy 3.4%; emotional disturbance 1.7%; and 12.1% other conditions. ASD is considered one of these "other conditions" (Ewing & Jones, 2003). Although children with hearing loss and ASD make up a small percentage of children with hearing loss, this dual diagnosis poses specific interventions and support requirements in terms of these children's developmental and educational needs (Vernon and Rhodes, 2009).

When considering the communication abilities and literacy, cognitive and auditory skills of children with hearing loss the diversity of this group becomes apparent (Duncan *et.al*., 2012). If a spoken language gap exist in early childhood and persists, children with hearing loss may

encounter barriers to developing fluent literacy skills (Duncan *et. al.,* 2012) which poses significant implications for learning.

Children with hearing loss who have an additional disability have needs that are distinct from children with hearing loss as a single disability. Historically, children who have hearing loss and other disabilities have had limited access to educational opportunities when compared to their hard of hearing peers (Ewing & Jones, 2003). The reason for this could be ascribed to the complex developmental needs resulting from the secondary disability or a combination of the two (hearing loss and ASD) and has a significant impact on the education of these children as well as the intervention services offered to their caregivers. Therefore when this occurs, specialist practitioners with expertise other than hearing impairment are required. This highlights the need for collaboration among interdisciplinary team members (Sattler, 2014).

Complexities relating to specific disabilities in children with hearing loss have hindered curriculum planning and appropriate placement. Placing emphasis on categorical disabilities has become a stumbling block that results in the child's needs being overlooked and an emphasis is being placed on teaching children according to their disability labels (Ewing & Jones, 2003). Ewing and Jones (2003) argue that such a categorical view of disabilities emphasises characteristics of the group rather than the needs of individuals. A categorical emphasis alone is not an adequate basis for educating children with multiple disabilities. However, teachers of children with multiple disabilities report that category-specific resources do provide some helpful information. This is in direct contrast to Jones and Jones' (2003) belief of paying specific attention to individual needs, which according to their argument, provides a more valid rationale for curriculum and placement than a focus on categorical disabilities. Unfortunately there exist a significant gap in the South African literature due to a shortage of resources and funds for research.

2.3.5   Available intervention for children with hearing loss

Children with hearing loss are by no means homogenous and therefore there can be no single educational method, system or approach suitable for all children with hearing loss (Northern & Downs, 1991, p. 323). The most important aspect of intervention all professionals agree on, is that intervention should be implemented as soon as possible (Ross & Deverall, 2014). The effects of hearing loss will, however, vary according to the age of onset, the degree thereof, its configuration and the stability of the impairment (Northern & Downs, 1991).

Therefore the intervention will vary according to these factors. Caregivers are faced with making three important decisions regarding intervention for their child with hearing loss. The first relates to the issue of assistive hearing technology and the suitability thereof for their child. The second is around the specific communication modality to be used, and finally caregivers are faced with making a decision regarding the educational placement of their child (Störbeck, 2016). These decisions can cause caregivers "… immense frustration and stress due to the impact that the decisions will have on the lives of the caregivers and their children (Störbeck, 2016, p. 436)."

Intervention should ideally be focussed on the child within his or her context and address the specific needs of the family. Therefore caregivers should be supported to make informed decisions regarding all interventions for their child and family (Buethe, *et al.*, 2013). Decisions regarding intervention will include language learning options which involve auditory approaches, visual methods or a combination of both. Flexor (2008) notes the following language-learning options: auditory-oral, auditory-verbal, cued speech, sign-supported speech and language, simultaneous communication, American Sign Language, total communication, and bilingual-bicultural approach. Intervention is further customised according to whether the communication modality is manual, oral or according to a bilingual approach. For the purpose of this study the researcher has chosen to look at interventions most commonly referred to in South Africa. These include assistive hearing technology, communication modalities and educational placement.

2.3.5.1 *Assistive hearing technology*

Assistive hearing technology is also referred to as *amplification* (Buethe *et al.*, 2013; Störbeck, 2016) and consists of digital programmable hearing aids, bone-anchored hearing aids, cochlear implants, hybrid cochlear implants, and personal frequency modulation (FM) systems (Duncun *et al.,* 2012, p. 212). Hearing technology is designed and purposed to make spoken language accessible to children with hearing loss (Seewald et. al., 2005; Duncan *et al.*, 2012). Hearing aids specifically are used for all types of hearing loss and can be fitted within weeks after birth (Störbeck, 2016, p. 436). Hearing technology is chosen based on the severity of hearing loss (Duncan, 2012) and the accessibility of resources by the family of the child with hearing loss. Assistive hearing devices hold significant financial implications for the family and this plays a role in deciding on the most appropriate intervention (Van der Spuy & Pottas, 2008). Assistive hearing technology devices are fitted by audiologists (Buethe

et al., 2013) and this fitting process as well as the management of the device, requires close co-operation by the caregivers (Ross & Deverell, 2014). The earlier and more consistent the hearing aids and/or cochlear implants are used by the child, the better the outcome or impact on the child's development (Duncan, 2012). Caregivers are taught how to care for and maintain hearing technology by the specialist practitioner through explicit instruction and practical experience. Eventually the child becomes responsible for this process (Duncan, 2012; Ross & Deverell, 2014).

2.3.5.2   Communication modality

Children with hearing loss may use signed language, spoken language or a combination of sign and spoken language. This is referred to as the communication modality of the child. The communication modality of a child with hearing loss can be manual, auditory-oral, total communication or bilingual (Störbeck, 2016). As with the degree to which the child with autism is affected by ASD, so the communication ability and therefore the use of the language modality of children with hearing loss fall along a continuum. At the one end of the continuum is the exclusive use of visual language (sign language) and, at the other end, is the exclusive use of an auditory-based spoken language (Duncan, 2012). This decision is by no means an easy one to make (Ross & Deverell, 2014). When hearing loss has conclusively been diagnosed and unbiased information has been provided to the caregivers, they choose the communication modality that best suits the culture and needs of the family. The four communication modalities briefly mentioned are based on the work of Störbek (2016) and Ros and Deverell (2014).

The auditory-oral approach to communication entails auditory training, speech and lip-reading. This approach makes use of, or develops, any residual hearing (with the use of hearing aids) and prohibits signing or gesturing of any kind. Oralist methods are divided into a unimodal approach which places emphasis on auditory and the use of residual hearing, whereas the multimodal method combines audition with lip-reading and visual cuing. The multimodal auditory approach is further distinguished as it makes use of systems such as cued speech. The goal of the auditory-oral approach is for deaf children to fit into the hearing world which includes the majority culture of their family and community. Within this approach caregivers are not expected to learn a new language such as sign language.

Sign language, also referred to as the manual approach, regards sign language as the first language of the child with hearing loss. The language of the hearing is the second language.

This approach encourages the use of, and exposure to, sign language as early as possible and this is primarily due to the consideration of the critical language acquisition period (Brazelton and Greenspan, 2000 in Störbeck (2016). The main goal of the manual approach is a well-developed deaf child who achieves typical language development, cognitive skills with a strong sense of their cultural identity, social and emotional stability and second language literacy.

The total communication approach represents a method of instruction as well as a philosophy of instruction (Ross & Deverell, 2014, p. 285). This approach makes use of whatever is available to help the child with hearing loss acquire language. It also recognises varying degrees of hearing loss and its aim is to reach the child through any means necessary whether it is oral or manual modes. This could include the use of signs, gestures, listening, speech, amplification, speech reading, mime, pictures and print (Störbeck, 2016).

The bilingual-bicultural approach upholds the belief that the development of first language competency is a prerequisite for the development of typical cognitive processes (Cummins, 1984 in Störbeck, 2016). It entails the use of two languages and competency in both. This approach emphasises the equality of the deaf and hearing cultures as it acknowledges the first language of the child with hearing loss as sign language and the second language as that of their hearing family (Störbeck, 2016).

It is strongly recommended that the child with hearing loss and their caregivers are fluent in the same communication modality – whether it is sign language or an auditory-based spoken language (Duncan *et al.,* 2012). Unfortunately this is not always realised specifically when the child with hearing loss is at a signing school away from their caregivers and the fact remains that caregivers of children with hearing loss are not always able to sign (Du Toit, 2017). Duncan *et al*. (2012) emphasise the importance of caregiver-child interaction to be abundant and consistent throughout the child's life and that this ensures the maximisation of communication development.

2.3.5.3   *Educational placement*
The last two decades has seen the adoption of inclusion within the South African education system (Swart & Pettipher, 2013). The philosophy of inclusion allows for teaching methods to be adapted in order to facilitate optimal learning for all children based on their particular needs, whilst considering their barriers to learning. Based on the premises of the White Paper

6 (National Department of Education, 2001) all children are able to achieve learning with the right support and this recognises the need for a change of attitudes, behaviour, teaching methodologies, curricula and the environment in order to meet the needs of all learners. According to this policy the aim of special needs schools is to support and develop learners with barriers to learning to such an extent in order for them to be reintegrated into main stream education. However due to the nature of the communicative needs of children with hearing loss, the Deaf community regards this goal of full integration of learners with hearing loss into hearing schools as being restrictive to deaf learners (Office Deputy President, 1997).

As was discussed, important decisions to be made regarding a child with hearing loss are the decided upon communication modality, as well as the educational placement. These two factors often go hand in hand because most educational curricula are language based (Buethe *et al*., 2013, p. 163). Duncan (2012) considers understanding the educational needs of children with hearing loss a complicated endeavour because there is rarely one explanation that justifies a particular approach to the child's education. Educational placement will vary according to the child's age, degree of hearing loss and the extent of their functional hearing, communicative needs and also by the family's financial resources and commitment to learning a new communication system (Buethe *et al*., 2013).

Historically, children with hearing loss generally fall behind their hearing peers in academic subjects, including literacy and mathematics (Marschark, 2003). Factors that contribute to this include the age of diagnosis, aetiology, language and instructional practices. When referring to children who use sign language, Marschark (2003) suggest that it is reasonable to state that children with hearing loss have different knowledge bases, cognitive strategies and experiences that influence literacy and academic skills. This reiterates the importance of early identification, and consequent early intervention, for children with hearing loss (Van der Spuy & Pottas, 2008). Interestingly (Antia, Jones, Reed & Kreimeyer, 2009) say that language development and educational opportunities are the two most predictive influences on educational achievement of children with hearing loss.

As with children on the autism spectrum, children with hearing loss experience increased difficulty with tasks dependent on executive functioning (Buethe *et al*., 2013; Ming, 2014; Sattler, 2014). Executive function is higher-order cognitive processing responsible for metacognition and behaviour regulation. These skills include the ability to inhibit response to stimuli, one's working memory, emotional control, sustained attention, task initiation,

planning and prioritising, organisation, and flexibility (Sattler, 2014). Academic achievement is strongly related to a child's level of executive functioning and for this reason the development thereof, through intervention and support, is crucial (Duncan 2012). Executive functioning skills are essential skills for school-based activities and should therefore be taught explicitly by teachers and therapists working with children who have hearing loss (Duncan *et.al*., 2012). Executive functioning is influenced by a multitude of factors and the development thereof is closely related to the family and school environments. Leigh (2008) highlights the role of practitioner and therapist instruction in the development of executive functioning.

Generally speaking children of school-going age with hearing loss either attend a mainstream school where certain adaptations are made in order to accommodate the learner with hearing loss or the child is placed in a special needs school for the deaf, also referred to as a sign language environment (Störbeck, 2016).

Störbeck (2016) identifies specific adaptations which are made within the mainstream school setting by the teacher to learning and teaching approaches and materials. These include a focus on vocabulary development, providing an overview of lesson plans in advance, focus on the development of reading comprehension, providing clear instructions, adapting teaching strategies to include sufficient visual support, and the inclusion of the support strategies in group work is critical to the success of a learner with hearing loss. It is recommended that teachers within the mainstream environment draw on support from resource centres, relevant district-based support teams, as well as other specialists as they "… develop and implement unique learning support strategies …" for learners with hearing loss (Störbeck, 2016, p. 442).

The second educational placement option for the child with hearing loss is the sign language environment. It is important that sing language is made accessible to the child with hearing loss in this environment through the skilled use of South African sign language (SASL) by trained teachers of the Deaf who skillfully make the curriculum accessible to the learners through the necessary theoretical and practical educational knowledge (Störbeck, 2016).

Although the role of interventionists will vary depending on the educational environment, it is recommended that a multi-disciplinary team approach is followed which entails the involvement of speech and language therapists, educational audiologists, teachers and other

therapists such as occupational therapists within the educational environment (Buethe *et al*., 2013). Collaborative interventions are considered to be most supportive for children with hearing loss and their families (Flexir, 2008).

2.3.6   Hearing loss in the South African context

Despite the universally accepted truth of the value of early intervention, proven benefits of early identification and intervention for children and infants with hearing loss, more than 90% of the estimated 718 000 infants born annually with congenital or early onset hearing loss, live in developing countries where environmental risks are more prevalent and early identification programs are uncommon. Based on these alarming statistics Swanepoel *et al*. (2009) consider infant hearing loss in developing countries as a salient health priority.

In the South African context early identification through infant hearing screening protocols have been advanced through the Health Profession Council of South Africa (HPCSA, 2007) which has formulated specific guidelines in their Hearing Screening Position Statement disseminated in 2002 along with the revised Early Hearing Detection and Intervention (EHDI) body which was launched to support and promote the practice of screening, diagnosis and intervention nationally (Swanepoel & Störbeck, 2008). The unfortunate reality is that despite a reasonably developed health care system with appropriate guiding documents and protocols, the vast majority of children in South Africa will not have their hearing screened at birth (Swanepoel *et al*., 2009).

Access to services depends on the availability of intervention resources in the area of residence of the caregivers. This in particular becomes a relevant concern as the availability of early intervention centres in South Africa is limited whilst approximately seventeen babies are born with hearing loss every day (http://www.ehdi.co.za/). Although early identification should be followed by access to services which include personal amplification and family-centred early communication intervention, this is not the reality for many families in South Africa due to a lack of resources and available services (Van der Spuy & Pottas, 2008).

Some progress has been made through the initiation of early hearing detection and intervention programs but unfortunately these have reached a very limited number of people. According to Swanepoel and Störbeck (2008) 25% of infants born with permanent bilateral hearing loss annually are born in Sub-Saharan Africa. South Africa, that falls in this region, although considered as demographic to some of the least developed nations in the world, has

a comparatively well-developed infrastructure. In terms of its health care infrastructure SA is characterised by a high degree of inequality based on racial group and socioeconomic status. 85% of the SA population relies on the public health sector while the minority (15%) makes use of the private health care sector.

Through the inclusion of Early Childhood Development planning in South African policy documents within the Departments of Health, Education and Social Development respectively, the importance of the young child has been recognised. However, progressive and comprehensive policies do not translate into actual services rendered. With no specific budget for children and families with disabilities the departments of Health, Education and Social Development are not able to address the needs of all families and children with special needs (Störbeck & Moodley, 2011). Unfortunately, South African reports are indicating that few screening programmes are being conducted in both public and private health care settings which results in late identification of children with hearing loss (Swanepoel, Hugo & Louw 2006; Swanepoel & Störbeck, 2008).

Regardless of the fact that priority is given to groups considered as vulnerable – this includes mothers and children as well as people classified as disabled – within the South African context with its National Health system service, it does not translate into services for all. The main objective for the existence of the National Health system according to the proposal of the ANC (1994(a):19-20) is to ensure access for everyone to good-quality health care. However, these services are under significant strain and many South Africans are forced to seek medical intervention from independent health care providers who are paid for privately (Dennill, King, & Swanepoel, 1999, p. 43).

Swanepoel *et al*. (2005) argue that even though support services are an essential part of a complete hearing detection programme the need for early intervention services will only truly become apparent once screening programmes are identifying infants with hearing loss. Therefore the lack of early intervention programmes in South Africa cannot be regarded as a reason to not run early hearing screening services.

The results of a research study done by Van der Spuy and Pottas (2008) conclude that the mean age of diagnosis of hearing loss in urban South Africa is estimated at 23 months of age, the fitting of hearing aids is estimated at 28 months of age and enrolment into early intervention programmes is 31 months of age.

When it comes to the implementation of early intervention for children with hearing loss and their families in the South African context significant barriers to rendering these services exist. These include socio-economic barriers such as inaccessibility of services, negative attitutes towards caregiver involvement and insufficient caregiver psycho-education which prevents caregivers from adequately participating in intervention programmes (Van der Spuy & Pottas, 2008). Unfortunately there are many factors which impact the development of young South African children negatively such as violence, crime, malnutrition, unemployment and poor education. Such factors contribute to the higher age of diagnosis of hearing loss and subsequent intervention for children with hearing loss.

Internationally, the importance of cooperation with families throughout the process of intervention and support for children with hearing loss has brought about a shift towards family-centred approaches where caregivers are directly involved in the decision-making process. Swanepoel *et al*. (2005) state that in a developing country, such as South Africa, early intervention programmes should be family-centred within a community-based model of service delivery that is culturally congruent.

2.4 DUAL DIAGNOSIS OF AUTISM SPECTRUM DISORDER AND HEARING LOSS

According to Roper, Arnold and Monteiro (2003) symptoms of hearing loss mimic those of ASD and vice versa. Children with a dual diagnosis of ASD and hearing loss constitute a population presenting unique challenges and considerations for service providers all around the world, including South Africa. Limited information related to the characteristics of children with a dual diagnosis significantly increases the difficulty of making accurate early diagnoses and subsequently providing appropriate early interventions (Myck-Wayne, Robinson & Henson, 2011).

2.4.1 Prevalence and aetiology of dual diagnosis of autism spectrum disorder and hearing loss

The presence of ASD in children with hearing loss is estimated by Hitoglou, Ververi, Antoniadis and Zafeiriou (2010) to be at 5.3%. Within the population of profoundly deaf children approximately 34% also have ASD and in 2009–2010 the Annual Survey of Deaf and Hard of Hearing Children and Youth indicated that one in 59 children with hearing loss also received autism-specific services (Birath, Le Beau & McConkey Robbins, 2014).

According to statistics generated by the National Deaf Children's Society (NDCS) in 2012 the prevalence of hearing loss in children with ASD is estimated at between 2 – 4.2% (NDCS, 2012). These studies therefore indicate that the incidence of ASD in the population of children with hearing loss is higher than within the hearing population.

In reality professionals are therefore faced with the particular challenge of providing intervention services and support to caregivers of children with this dual diagnosis (Szymanski *et al*., 2012). This increased prevalence of ASD among children with hearing loss poses significant concern as a co-occurance of ASD and hearing loss could result in delayed or missed diagnoses (Roper *et al*., 2003). Caregivers have reported significant time lapses between the first diagnoses and receiving the second diagnoses, specifically when the diagnosis first made was hearing loss (Birath, Le Beau & McConkey Robbins, 2014).

Specific conditions which have been linked to severe hearing loss and characteristics consistent with ASD are Rubella Syndrome, cytomegalovirus (CMV), herpes, prematurity, toxoplasmosis, CHARGE, meningitis and measles (McCay & Rhodes, 2009). Although genetics have been implicated in the cause of ASD (Muhle, Tretacoste & Rapin, 2004) and has been found to be the case in 80% of children with hearing loss (Arnos & Pandya, 2003) it is not possible to say that these are related due to the fact that both of these conditions have their own documented genetic influences (Szymanski *et al*., 2012).

2.4.2   Diagnosis of autism spectrum disorder and hearing loss

Due to the difficulty of diagnosing ASD in very young children, identification and diagnosis of co-occuring hearing loss is made all the more challenging (Vernon & Rhodes, 2009). A possible reason for this is the overlapping characteristic symptoms or *diagnostic overshadowing* of these distinct disorders (Birath, Le Beau & McConkey Robbins, 2014). For example, behaviours resulting from hearing loss could be considered part of the symptoms of ASD and vice versa. Examples of such behaviours include a lack of attention, speech impairments, avoidance of eye-contact and clumsiness. The disruption of the language and communication functioning associated with ASD may present in a similar fashion in children who experience severe hearing loss and therefore distinguishing between these two populations is challenging (Szymanski *et al*., 2012). Communication-related issues are therefore central to both of these conditions. Therefore, when such a dual diagnosis is suspected, referral to a clinician who is specialised and is regarded as having experience to be

able to distinguish the unique communication difficulties and thus make such a diagnosis should be consulted (Birath, Le Beau & McConkey Robbins, 2014).

Making a dual diagnosis is a comprehensive process and multiple sources of data are referred to, including diagnostic criteria as stipulated by the DSM-5 and the ICD-10 codes. The reliability of such a dual diagnosis is determined by the use of these multiple sources of data. Sources consulted include case records, observations, client interviews, as well as family interviews (Reiss, 2010). Reiss (2010) proposes three guidelines when attempting to make a dual diagnosis. The first guideline is to consider patterns of behaviour and not isolated symptoms. The second guideline is to diagnose deteriorations of functioning known as regression. As the third guideline Reis (2010) cautions professionals that disorders should not be over diagnosed and that the limitations of current knowledge should be admitted.

In the 1970s the construct dual diagnosis was introduced by Frank Menolascino, an American psychiatrist, as an alternative to primary versus secondary diagnosis. Menolascino diagnosed both disabilities and identified all important service needs (Reiss, 2010). This shift in paradigm brought about holistic intervention that focused on the child's global development.

Orelove *et al*. (2010) refers to receiving a dual diagnosis as being "thrust into a strange, complex, and confusing world of medical, therapeutic, and educational services". These authors refer to the process whereby a family receives a dual diagnosis as: "… a lifelong experience that will require Herculean endurance and resources". Caregivers often need to go in search of support within their community which can be confusing and anxiety provoking as the availability of resources, services and caregivers' knowledge base impact with receiving services and support. It is a time-consuming and exhausting process and with commencement of this process caregivers do not know or understand the scope of the child's special needs (Shah, Wadoo & Latoo, 2010; Markoulakis, Letcher & Bryden, 2012; Hsieh & Lo, 2013).

The experience of diagnosis and caregiver reactions to diagnosis are affected by multiple and complex factors such as the family's culture, family structure, religious beliefs and socio-economic status, experience with disability, availability of support structures, the reactions of family and friends to the diagnosis of the disability as well as the severity of the diagnosis and prognosis thereof (Turnbull & Turnbull, 2001). It may be years before caregivers know the true scope of their child's special needs (Orelove, Sobsey, & Silberman, 2010).

Dishion and Kavanagh (2003) explain that in a positive caregiver-child relationship there exists a good balance between the needs of the child and the overall needs of the family. However, it is difficult to attain this equilibrium when a child has a disability that requires significant levels of intervention and support. Caregivers may inadvertently allocate a disproportionate amount of time and resources to support the child with a dual diagnosis of ASD and hearing loss.

Caregivers of children with special needs experience significant emotions after receiving a diagnosis. Caregivers report that dealing with a diagnosis and coming to terms with their child's diagnosis was an ongoing process which prevented them from acknowledging the possibility of a secondary diagnosis (Myck-Wayne *et al*., 2012).

2.4.3   Intervention and support for children with autism spectrum disorder and hearing loss

Historically, doctors and specialists in the field of special needs have had to distinguish between primary and secondary disabilities (Reiss, 2010) in order to determine service eligibility and consequently to allocate and direct caregivers towards appropriate special services or interventions based on their primary disability. Due to the difficulty of diagnosing ASD and hearing loss in young children determining which is considered the primary diagnosis is difficult and inadvertently determines which services are rendered when.

The dual diagnosis of ASD and hearing loss has significant educational implications specifically related to communication (Ewing & Jones, 2003). When ASD and hearing loss both occurs communication and language difficulties are more severe (Rosenhall *et al*., 1999). Sattler (2014) states that children who experience multiple disabilities, such as hearing loss and ASD, will experience increased academic difficulties compared to children with a single diagnosis of hearing loss. With this being said it is concerning that intervention services for children with hearing loss and ASD is only beginning to emerge whilst "… documented behavioural interventions and educational strategies, and social skills courses for children with hearing loss and ASD do not yet exist" (Szymanski *et al*., 2012, p. 2028). Although specialised intervention approaches exist and are being used for ASD and hearing loss respectively, whilst delivering different degrees of success, no research is available on effective therapy methods for children with ASD and hearing loss (Malandraki & Okalidou, 2007).

2.5   CONCLUSION

In Chapter 2 the author presented the reader with literature related to ASD, hearing loss and a dual diagnosis of ASD and hearing loss in order to create a theoretical canvas for the study. This investigation into available and most current and relevant literature created a context for the exploration of caregivers' lived experiences of receiving a diagnosis and subsequent intervention services for the child with ASD and hearing loss. Chapter 3 follows with a detailed description of the research process that was followed in order to answer the research question. The rationale behind specific choices of methodology within the boundaries of the research paradigm will be explained.

CHAPTER 3:
RESEARCH DESIGN AND METHODOLOGY

3.1   INTRODUCTION

Following the discussion in Chapter 1, the purpose of this study was to gain insight into, and an understanding of the lived experiences of caregivers of children with a dual diagnosis of ASD and hearing loss as they receive a diagnosis for their child and seek appropriate intervention services in the Cape Town Metropole.

The researcher will use this chapter to provide the reader with a clearly formulated and logical explanation of the research process that was followed in order to address the research question. Therefore the researcher's steps and rationale for making specific choices in methodology will be motivated. The researcher will reflect on the choice of the research paradigm and position the study in epistemological and ontological terms. Advantages relating to this research design will be presented and serve as motivation for the choices made in this regard. The research methodology and design along with the chosen methods and procedures utilised to collect and analyse the data will function as an illustrative roadmap for navigating the research study. Issues pertaining to the quality and trustworthiness of data as well as considerations and issues of data verification will be reflected on critically in order to uphold a high standard of research practice.

The research for the study was guided by a single primary research question, defined as empirical in nature as it addresses a real life occurrence, as well as three secondary questions. Before the discussion on the research design and methodology commences, the research questions are briefly revisited.

The primary research question is:

> *What are the lived experiences of primary caregivers of children with a dual diagnosis of hearing loss and Autism Spectrum Disorder?*

Three secondary questions were employed to explore the primary research question. They are:

> 1. *What were caregivers' experiences of identifying signs and behaviours presented by their children that were unusual and alerted them to the fact that their children could*

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possibly require special intervention? (When did caregivers first notice that something was different about their children?)

2. *What influences caregivers' experiences of intervention and support services after diagnosis?*

3. *What process did this experience take on in relation to caregivers' needs at the time?*

3.2   RESEARCH PARADIGM

The research paradigm derives from assumptions that reflect the particular philosophical stance held by the researcher (Creswell, 2007, p. 19). Paradigms of qualitative researchers vary according to the set of beliefs they bring to the research process. However, their quest for understanding and in-depth inquiry underlies the entire research process (Henning, 2013, p. 3). For Bertram and Christiansen (2014, p. 22) a paradigm represents a worldview that helps the researcher to define what they regard as acceptable to research and how it should be done.

Introspection into the researcher's personal philosophical worldview consequently formed part of the process of deciding on the interpretive paradigm. This process of introspection related to the discovery of a basic set of beliefs that would guide her actions throughout the research process and lead to new personal discoveries as a novice researcher. The researcher was inspired by the academic work of Carl Dunst and Yurie Bronfenbrenner who work from a family-centered orientation. These newly discovered beliefs sat comfortably with the considerations of the interpretive worldview (Neuman, 2000; Lincoln & Guba, 2000; Schwandt, 2007; Crotty, 1998).

The interpretive paradigm is sometimes referred to as social constructivism, depending on the author writing about it (De Vos, Strydom, Schulze & Patel, 2011, p. 3). Babbie and Mouton (2001, p. 28) refer to human beings as all being engaged in the process of making sense of their worlds and continuously interpreting, and creating, giving meaning, defining, justifying and rationalising their daily actions. According to Creswell (2007) people seek to understand the world in which they live and work. The researcher could relate to this notion as the goal of the study was to explore and understand experiences of caregivers who had children that were experiencing similar challenges as those faced by the child in her work environment. This understanding further meant that the researcher would investigate the subjective meanings of the experiences of caregivers (Creswell, 2009, p. 19). The interpretive paradigm

entailed the most suitable set of beliefs to navigate the researcher's actions to complete this study.

The research paradigm guided the researcher in deciding what questions could be asked, what could be observed and investigated, as well as how data would be collected and the findings be interpreted. Consequently, the answers that the researcher derived from the research reflected a particular belief about the nature of the social world, what could be known about it and how to approach the search for the answers. Bertram and Christiansen (2014 p.22) puts it as follows: "It makes sense that the way in which we see the world influences the way in which we research the world". The choice of research paradigm therefore shaped the inquiry as it accentuated the worldview held by the researcher. Lincoln and Guba (2000, p.17) refers to the concept of a paradigm or worldview as "a basic set of beliefs that guide actions". These actions refer to the step-by-step approach taken by the researcher in undertaking the inquiry and this process is guided by the philosophical stance of the researcher with regards to ontology, epistemology and methodology. The research paradigm will thus shape the practice of the researcher.

The researcher was mindful of the belief that meanings are varied and multiple and therefore the goal was not to narrow the meanings into a few categories or ideas, but rather to look at and explain the complexity of the views held by the caregivers of children with both ASD and hearing loss. The caregivers' views and understanding of their experiences were regarded as of utmost importance in exploring the process of diagnosis and intervention. The researcher also considered how the subjective meanings held by caregivers were negotiated socially and historically as the meanings caregivers ascribe to their experiences are formed through interactions with others such as therapists, doctors, teachers and family, and through historical and cultural norms such as how the conceptualisation and understanding of disability, specifically ASD and hearing loss, has developed and been understood.

The researcher held to the belief that the way in which people respond in a given situation is determined by and dependent on their past experiences, as well as their circumstances or contextual factors. Caregivers' responses to receiving a primary diagnosis and the complex nature of the situation where caregivers receive a second diagnosis, with the subsequent process of intervention and support, is therefore viewed bearing in mind the context and past experiences of the family system.

According to the interpretive paradigm the researcher strived to describe and understand the experiences of the people: how people make sense of their world, and how they make meaning of their actions instead of aiming to predict what caregivers would have done. It is not expected of the researcher who works within the interpretive paradigm to remain objective (Bertram & Christiansen, 2014, p. 26). The researcher conducted research to derive data from which meaning was extracted through an interactive process whereby the researcher was subjectively involved. Meaning could only be found through an in-depth study of the caregivers' experiences by absorbing the viewpoints of the caregivers as a whole and then considering how the parts thereof relate to the whole (Neuman, 2003, p. 76)

When considering the theory of knowledge (epistemology) according to the qualitative approach, the researcher considered knowledge as constructed by observable phenomena, such as people's intentions, beliefs, values and reasons, meaning-making, and self-understanding (Henning, 2013). The experiences of caregivers of children with a dual diagnosis of hearing loss and ASD were understood through interpretation that was influenced by, and interaction with, the social context caregivers exist in. Therefore, the researcher remained sensitive to the role of the context (*in sino*). The researcher acknowledged the subjective nature of reality and therefore considered that it can only be known (epistemology) through asking questions about reality and the meaning attributed to specific events such as receiving a diagnosis, and intervention services could be discovered through asking these questions.

The researcher's ontological position was that people socially construct their view of reality, and therefore the implication for the epistemological dimension of interpretive paradigm was that the process needs to take place where these multiple realities can become accessible. Knowledge becomes available through interaction between the researcher and the caregivers in their context.

The researcher was guided by the interpretive framework as parts or aspects of the lives of caregivers of children with a dual diagnosis of hearing loss and autism were captured and described in order to attempt to understand the personal meaning of their experiences (Henning, 2013). The researcher intended to present the reality of each of the caregivers from his and her subjective perspective by delving into personal meaning for the caregivers.

In terms of rhetoric the data collected by the researcher largely reflects the voices of the caregivers. The role of the researcher was thoroughly described and the context was considered. The type of research informed the researcher's practices and the strategy of inquiry put the paradigm into action (Merriam, 2009).
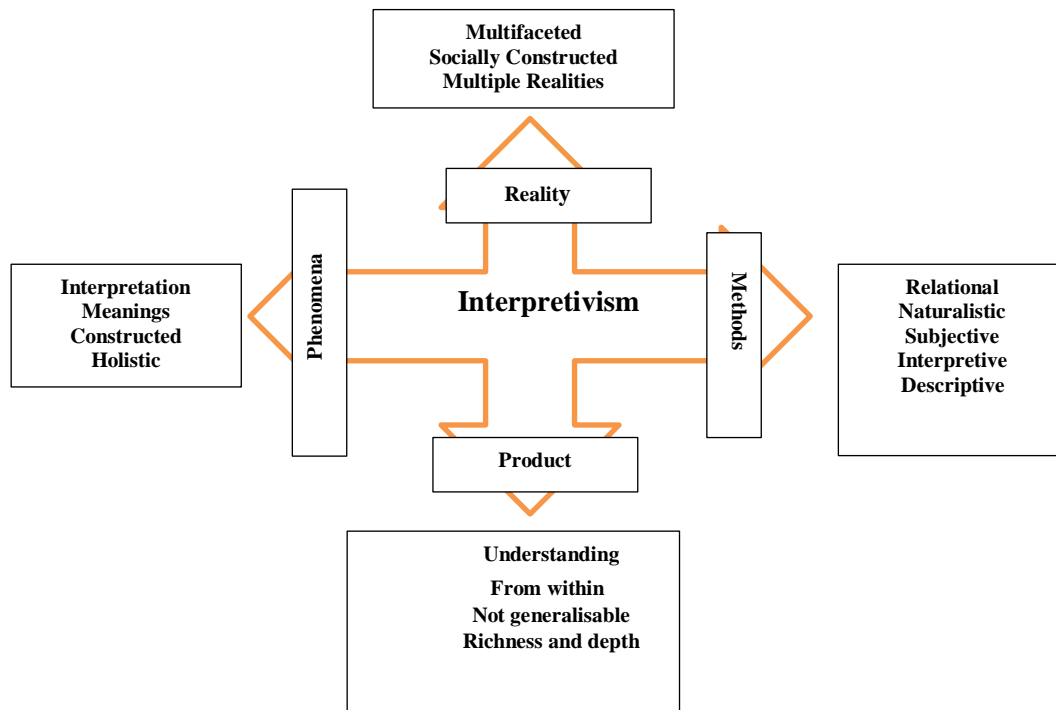
Figure 3.1: Representation of interpretivism

(Maree, 2010, p. 61.)

3.3   RESEARCH METHODOLOGY

To give a description of the research methodology the researcher will focus on providing an explanation of the research process that was followed (Babbie & Mouton, 2001). This includes a discussion of the choice of "tools and procedures" used. A step-by-step account of the tasks at hand related to measurement, sampling procedures, data collection and data analysis. The research study was qualitative.

First, the researcher provides a look at the rationale for qualitative research and how it defines this study. Qualitative research is holistic in nature and its main aim is to understand social life and the meaning people attach to everyday life experiences (McRoy, 1995). In order to achieve this aim with qualitative research the researcher attempted to provoke "accounts of meaning, experience or perceptions" (Fouche & Delport, 2011, p. 65). A qualitative research

design was most suitable because its underlying assumptions encapsulate the essence of what the researcher aimed to explore and attempted to understand: *What meaning do caregivers ascribe to their experiences of receiving a dual diagnosis of hearing loss and ASD and how did they consequently seek appropriate intervention for their children?*

The purpose of the research was to gain an in-depth understanding of the caregivers' experience of this specific phenomenon, and therefore the study was positioned within the qualitative, interpretive paradigm. Based on the definition given to qualitative research by Denzin and Lincoln in 2011 (Creswell, 2013) it has the capacity to change the world.

This topic has not previously been investigated in the Western Cape, South Africa. Therefore the research was explorative and descriptive in nature and the researcher gained insight into the lived experiences of caregivers of children with a dual diagnosis of ASD and hearing loss (Fouché & De Vos, 2011; Hays & Singh, 2012).

Characteristics of qualitative research highlighted by the authors Creswell (2007) and Hays and Singh (2012) respectively, which are of particular relevance to this study, are as follow:

Qualitative researchers are considered to be key instruments in the research process. In accordance with this characteristic of qualitative research the researcher spent extensive time interviewing each caregiver individually or as a couple, and carefully examined documents to compile a time line of caregivers' experiences of diagnosis and intervention. This alludes to the second and third characteristics of qualitative research being that qualitative researchers gather multiple sources of data rather than relying on a single data source, and that qualitative research involves fieldwork. The researcher gained access to caregivers' natural settings, in and around their children's special needs school. The researcher attempted a subjective exploration of reality from the perspective of the insider. Data produced from the interviews were descriptive and presented in the caregivers' own words which is also typical of qualitative research.

Throughout the research process the researcher was focused on learning about the meaning caregivers ascribed to their experiences. Although the researcher investigated available literature on the topic in-depth, caregivers' perspectives were the focus of the investigation and therefore the research was regarded as being inductive in nature. The researcher did not attempt to predict findings or disprove hypotheses, but rather to formulate new understandings based on the experiences shared by the caregivers.

Based on the inquiry the researcher would make an interpretation of what was heard, seen and understood. This interpretation, however, was influenced by the researcher's own background, history, context and prior understanding. The researcher worked towards developing a complex and holistic view of the phenomenon of caregivers' experiences of the diagnosis and intervention services for their children with a dual diagnosis of hearing loss and ASD.

3.4   RESEARCH DESIGN

The conceptualisation of the research design was based primarily on the proposed end product of the research study and therefore describes the kind of study executed in order to achieve the researcher's objectives (Babbie, 2007). The research design can further be viewed as a reflection on the logic of the study and provides guidance on the kind of evidence that was required in order to address the research question adequately.

Case study design is characterised by a focus on a phenomenon that has identifiable boundaries. What takes place is intensive description and analysis of a single unit or bounded system (Henning, 2013). Yin (2009) provides a two-fold technical definition that describes a case study design as an empirical inquiry that investigates a contemporary phenomenon in-depth and within its real-life context, especially when the boundaries between the phenomenon and the context are not clearly evident. The case study method therefore presented the researcher with what was necessary to attempt to understand this real-life phenomenon in depth (Yin, 2009), all the while considering the environment and context in which it took place.

Within this design the content becomes the main indicator of meaning (Henning, 2013). Therefore the case study design could be employed to gain in-depth understanding of a specific social issue, that being caregivers' experiences and the meaning they ascribed to the experiences of receiving a dual diagnosis and intervention services for their child with HL and ASD. This important hallmark of good qualitative case study design is identified by Cresswell (2013, p. 98). The researcher was interested in the context rather than a specific variable and discovery rather than confirmation (Merriam, 1999) and therefore this qualitative research design was considered as contextual. The case study design relied on multiple sources of information or evidence which also allowed for data to link up in a triangulating fashion (Yin, 2009).

The types of qualitative case studies are distinguished in terms of their composition and size, as well as the intent of the case analysis (Yin, 2009, p. 99). The researcher employed a collective case study design as the research focused on a specific, real-life issue i.e. the experiences of caregivers, but the researcher identified and selected multiple case studies to illustrate the social issue. As the contexts of the cases differed the researcher was reluctant to generalise from one case to another. Three cases were selected best to understand this phenomenon and therefore this case study research is known as an instrumental case (Stake, 1995).

When Merriam eludes to the process as being more important than the product, Henning (2013) supposes that what is being referred to here is a description of how, where, when and why things happen. Caregivers' lived experience of seeking intervention, receiving a diagnosis of ASD, hearing loss or both are noted and form an essential part of the study (Henning, 2013). In this sense then, the process becomes part of the researcher's outcome. Context is more than part of the case; it is the interaction between context and action. In other words, the experiences of caregivers were identified as the unit of analysis.

Within this qualitative research approach of the case study design, theory development is inductive as it precedes data collection as well as the process of explaining the dataset (Hayes & Singh, 2012). Yin (2009) argues that a case study, when utilised as a research design, offers the rigorous researcher the possibility to generalise findings derived from the data into theoretical propositions and not to generalise findings to populations. In other words the researcher does not strive through the use of a case study design to represent a sample but rather to expand and generalise theories. It is important to be understood that this generalisation is not statistical, just as the cases are not sampling units (Yin, 2009). The multiple cases should be regarded more as multiple experiments would be in a quantitative research paradigm. The mode of generalisation is analytic in nature as previously developed theory is used as a template with which to compare the empirical results of the case study. Yin (2009) states that if two or more cases are shown to support the same theory, replication may be claimed. If two or more cases support the same theory, the empirical results are considered to be more potent than if this is not the case.

Therefore this small-scale study hopes to contribute to the existing body of knowledge in the field of special needs, particularly dual diagnosis of HL and ASD by refining existing theory. Regardless, however, of whether or not this particular research project will generate theory,

personal theory plays a role in all research (Mabry, 2009). The researcher hoped to formulate a conceptualisation of the phenomenon being studied.

3.5   RESEARCH METHODS

The research methods applied to this study were chosen based on whether they could assist the researcher to address the research questions in a manner that aligned with the research design. The methods chosen were: purposive sampling techniques; two data collection techniques, namely individual interviewing guided by a semi-structured interview guide, as well as a narrative text; and thematic analysis. These methods will now be discussed in terms of their application to the research study.

3.5.1   Selection of participants

Sampling in this study entailed selecting caregivers who would be able to shed optimal light on the social issue being investigated (Henning, 2013, p. 71). Cases were selected because studying them served the real purpose and objectives of the researcher of discovering, gaining insight into and understanding of the phenomenon of caregivers' experiences of diagnosis and intervention for their children with a dual diagnosis.

The cases were considered unique due to the rare nature of a dual diagnosis of ASD and hearing loss. Criteria for inclusion into the study was having a child with a dual diagnosis of ASD and hearing loss. The researcher thus made use of the non-probability sampling method of purposive sampling with specific criterion-based selection to identify participants as information-rich cases that best address the research question (Hays & Singh, 2012). The population from which the sample was drawn was all primary caregivers of children with a dual diagnosis of ASD and hearing loss within the Cape Town Metropole.

In order for the researcher to determine whether there were in fact children with such a complex diagnosis, contact was made with therapists who worked in schools for children with hearing loss, which would be considered the primary diagnosis, to enquire whether the school had a class for children with multiple disabilities. The researcher thus made use of her professional network to be guided towards information-rich potential participants. Given the rarity of the occurrence of a dual diagnosis of hearing loss and ASD, only three potential participants were identified. All agreed to participate in the study. The study therefore included primary caregivers of three children, who have been diagnosed with hearing loss and ASD.

The primary unit of analysis were the lived experiences of caregivers. As it would be impossible to collect information that covers the totality of the experience of being caregivers of a child with a dual diagnosis of ASD and hearing loss, the researcher directed her focus to exploring caregivers' experiences of receiving such a diagnosis and the consequent intervention services. Information related to the experiences of caregivers of the diagnostic process and intervention services were collected.

Table 3.1: Biographical details of the caregivers

Caregivers of child	Age of caregiver	Gender	Occupation father; mother	Child's age	Number of other children	Disability in the family	Class and years in school
Ellen's caregivers	28	M	mechanic	18	1	hearing impairment	Class for multiple disability; 15 years
	27	F	general worker				
James' caregiver	29	M	fire-fighter	14	2	specific learning disability	Class for multiple disability; 11 years
	24	F	housewife				
Anton's caregivers	40	M	technical consultant	14	2	none	Grade 5; 11 years
	38	F	counsellor				

3.5.1.1   *Context of research*

The research took place at a school for the deaf within the Western Cape. The school accommodates children from the ages three to twenty years and consists of a pre-school phase up to senior phase as well as a vocational training department. It is considered to be an inclusive school as it makes provision for children with multiple disabilities with a primary diagnosis of hearing loss. Intervention and support is offered through a multi-disciplinary team approach and the team consist of a psychologist, audiologist, social worker and a school nurse.

3.5.2   Procedures

The researcher obtained written consent from the Western Cape Education Department to conduct research with caregivers whose children are enrolled as learners in a public school.

The researcher was granted ethical clearance and permission to conduct the research project by the ethics committee of Stellenbosch University.

Permission was obtained from the principal of the school involved in order to be granted access to the school and proceed with the research process.

Possible participants who fulfilled the criteria were approached by the school psychologist to request participation.

Individual interviews were scheduled school hours at a time convenient to the caregivers in a natural setting of either their home or at the school involved. The interviews did not interfere with school activities.

On meeting the caregivers the researcher explained the details of the interview process and addressed any queries and concerns. The consent forms were signed and finalised.

The caregivers were requested to agree to the interviews being audio recorded.

In addition to participating in the interviews, permission was obtained from caregivers to obtain relevant documents from the school for review.

Pseudonyms were used for all participants.

The duration of the interviews ranged from sixty to ninety minutes.

3.5.3   Methods of data collection

Methodological implications of the interpretivist approach entail unstructured observations, open interviewing, idiographic descriptions and qualitative data analysis directed towards the capturing of insider knowledge. Therefore inquiry was undertaken in a natural setting to collect substantial situational information (2013). In their natural settings the participants' behaviour is placed in context and therefore becomes meaningful and understandable. The researcher spent extensive and intensive time collecting and analysing data (Hays & Singh, 2012). The researcher hoped to gain an understanding of the context of research participants by conducting the interviews in their homes or at the school.

Interviews and document collection were the primary means of data collection. Permission was obtained from caregivers to obtain documents from the school for review in order to compile a time line of caregivers' experiences. The researcher remained cognisant of the fallibility of observation as there is no absolute truth, but multiple realities (Henning, 2013). This served as a motivation for the use of multiple sources of information.

The literature review in combination with the methods of data collection (written documents, interviews, observation and document study) were therefore employed by the researcher to "...understand and embrace families' perspectives (Hammer, 1998)".

3.5.4   Development of data collection instrument

In order to ensure reliability, the interview questions were compiled and tested by a professional person in the field of educational psychology. Before commencing the full data collection process, a pilot study was conducted with a selected caregiver of a child with multiple disabilities who consented to participate. The researcher interviewed a caregiver of a child with a dual diagnosis of Down syndrome and ASD due to the limited availability of known children who have a dual diagnosis of hearing loss and ASD. By conducting the pilot study the dependability and credibility of the study was improved (Brink, 1993). Through this process the researcher was focused on developing relevant questions and probing sentences whilst remaining present and engaged with the caregiver. This exercise proved valuable because it helped the researcher to identify the main concerns and issues important to caregivers. Adjustments were made to the interview guide based on the information derived from the pilot study. The data collection process followed. The interview guide is attached as Addendum F.

3.5.4.1   Semi structured interviews

Semi structured interviews allowed the researcher to have a set of predetermined questions on an interview guide. The interviews were guided by these questions but not dictated by them (Greeff, 2011). Issues introduced by the caregivers during the interviews could be further probed and explored. Within this design, the researcher is the primary instrument of investigation and in the search for meaning, the researcher hoped to gain understanding of the experiences of the caregivers (Merriam, 2009). Through direct contact and interaction with the caregivers the researcher gained insight into the caregivers' unique experiences as well as the meanings they ascribed to these experiences (Merriam, 1998). The individual meaning renders the complexity of what was being studied (Creswell, 2009).

Data were collected by means of semi-structured interviews with the participants. Themes informed by the research questions, as well as information reviewed during the literature review and the pilot study, provided a foundation for the formulation of the interview guide. Thus the interview guide focused the researcher on a broad range of themes (Greeff, 2011).

Open-ended interview questions that focused on the diagnostic process for hearing loss and ASD, interventions and service delivery offered to the participants related to hearing loss, ASD, and hearing loss and ASD combined, allowed caregivers to construct the meaning of their experiences (Creswell, 2009). The researcher understood that these subjective meanings formed by caregivers occurred through interaction with the role players in their environment such as family members, school support teams, doctors and therapists. Creswell (2009) explains that this meaning-making process is socially and historically negotiated and constructed, and thus the researcher understood that the background of the participants influenced their interpretation thereof. The researcher supposed that the participants engage with their world and made sense of it based on their historical and social perspectives

As such, caregivers were encouraged to share their perspectives on the process of obtaining services and the types of services made available to them. The purpose of the individual interview was therefore for caregivers to describe their experiences in their own words. This constitutes the first step of data collection.

3.5.4.2   *Document study and timeline creation*

True to the interpretivist belief that observation is fallible (Henning, 2013, p. 19) the researcher made use of multiple sources of data in order to strive for validity. The interpretivist view of reality is that it does exist, but cannot be captured by a single observation or by a single researcher, but rather through multiple observations and through different processes of observation (Hays & Singh, 2012). Throughout the undertaking of this process the researcher was concerned with witnessing in order to describe, identify and understand caregivers' experiences. Reality is therefore imperfectly grasped because of basically flawed humans and their biases and theoretical beliefs that underpin their work (Henning, Van Rensburg & Smit, 2004)

Documents were studied as secondary data sources in order to supplement data derived from the interviews (Hays & Singh, 2012, p. 313). These documents included current or past individual educational programs (IEDPs), audiograms, medical reports, developmental assessments, psychological reports, and behaviour management plans. The time line offered the researcher the opportunity to illustrate caregivers' personal journeys from their children's births to where they were at the time of the study. Through the application of the described methods the researcher can provide a carefully formulated approximation of the experiences of caregivers in the form of the constructed timelines.

3.5.5   Method of data analysis

Patton (2002, p. 432) states that "...qualitative analysis transforms data into findings". When it comes to approaching data analysis in case study research, methods differ according to the unit of analysis. As mentioned before, the researcher had selected three cases to analyse and compare. Through this process of in-depth description of the three cases the researcher uncovered themes, issues and specific situations in each case. These themes were then organised into a chronology and analysed across cases to discover similarities and differences.

Data analysis occurred inductively as the researcher generated general themes from particulars shared by the caregivers (Creswell, 2009). This method proposes thorough planning which assists in analysis. The interviews with participants were voice recorded and transcribed verbatim. Texts derived from data collection was analysed and interpreted in a cyclical and recursive manner. The researcher did so in accordance to the six steps proposed by Braun and Clarke (2006). She familiarised herself with the data by transcribing and re-reading data, noting initial ideas. The second step entailed generating initial codes in a systematic manner across the data set. The researcher then searched for themes by collating codes into potential themes. These themes where then reviewed by reflecting on initial coded extracts to generate a thematic map of the analysed data. The researcher then generated clear definitions and names for each theme through an on-going process and finally selected vivid, compelling extracts relating back to the research question and literature to produce a report of the analysis. This process can be perused in Addenda G and H.
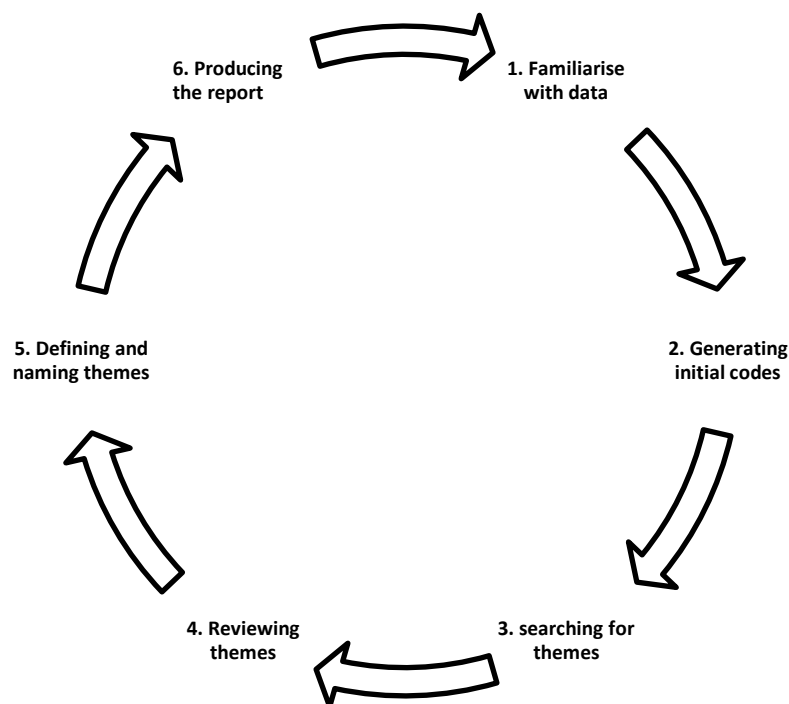
Figure 3.2: The process of thematic analysis as proposed by Braun and Clarke (2006)

3.6   TRUSTWORTHINESS AND QUALITY OF DATA

Lincoln and Guba (1985) pioneered the key criterion of good qualitative research through the conceptualisation of trustworthiness. In essence the trustworthiness of the research study relates to the truthfulness of the findings and conclusions. Hays and Signh (2012, p. 192) describe this as the researchers' ability to allow the research participants' maximum opportunity to be heard. In order to confirm the trustworthiness of the research project, translation of the qualitative methods such as components of credibility, transferability, dependability, and confirmability, as was developed by Lincoln & Guba (1985) were evaluated and reported. According to these authors the four constructs mentioned reflect the assumptions of the qualitative paradigm (Schurink, Fouché & De Vos, 2011, p. 419).

3.6.1   Credibility

The researcher here provides proof that what is reported rings true and reflects the participant's reality (Bertram & Christiansen, 2014, p. 188). Credibility, alternatively known as authenticity, as Schurink, Fouché and De Vos propose, was first ensured through the means by which the interviews were conducted. The interpretivist researcher was concerned with the meaning making and the experiences of the participants and therefore the researcher spent time engaging fully with the caregivers as they retold their lived experiences during the interview process. The researcher describes the caregivers' experiences by using their own

words and the depth to which it was done reflects the validity thereof. The researcher's representation of the participants' experiences directly reflected the participants' views. Therefore it was considered credible. The participants' retelling of their experiences where audio-recorded and transcribed verbatim. This process can be confirmed through the transcripts of the interviews. The researcher worked towards understanding the caregivers' experiences from their perspectives and therefore entered into a prolonged engagement with the data which entailed "persistent rereading" of the data as Bertram and Christiansen (2014, p. 189) describe it. This process contributed to the credibility of the study.

3.6.2   Transferability

Transferability refers to the extent to which the research findings would apply to other situations with similar characteristics (Bertrman & Christiansen, 2014, p. 191). The researcher did however not aim to generalise findings, but rather to gain a deeper understanding of the experiences of caregivers within the bounded system of the case study, as is traditional for the interpretive paradigm. The case study therefore was an intensive description and analysis of a bounded system and strengthens the usefulness of the study for other settings (Schurink, Fouché & De Vos, 2011, p. 420). Merriam (1998) argues that the process is more important than the outcome and that the description of how, where, when and why things happen in the parameters of a case is what the researcher focuses on and attempts to capture.

3.6.3   Dependability

The nature of the social world according to the views of interpretivist researchers however, is that it is always changing and therefore the concept of replication as Schrunick *et al.* reiterate, is fundamentally problematic (2011, p. 421). The researcher remained mindful throughout the process that no qualitative study can be completely replicated. The researcher continuously reflected on whether the research process that was conducted followed a logical process. This required that the researcher's process was well documented and audited. The process followed in conducting this study was outlined in Section 3.5 Research Methods and provides proof of its dependability. A supervisor guided the researcher throughout the process with academic experience and in-depth knowledge of the research process.

3.6.4   Confirmability

Confirmability is explained by Schurink *et al.* (2011, p. 397) as a construct which captures the concept of objectivity. Lincoln and Guba (2000) explain that this is the degree to which

findings are a product of the focus of the inquiry and not of the biases of the researcher. In other words, the emphasis is on whether the research findings reflect the meaning intended by the research participants (Shenton, 2004, p. 72). The question these authors ask relates to whether or not the findings of the study could be confirmed by another. Bertram and Christiansen (2014, p. 190) state that confirmability is a data verification strategy which relates to making the research process transparent. The researcher kept the theoretical understanding of the construct of confirmability in mind and through the application of the practical strategies ensured that the research would be confirmable. The researcher made use of the services of a professional scribe who transcribed the audio-recordings. This meant that the audio-recordings were reviewed by more than one person and that things that one person missed could be picked up by the other, thereby increasing the confirmability of the data. The researcher provided sufficient evidence that upholds the confirmability of the data set.

3.7   DATA VERIFICATION STRATEGIES

Data verification strategies are an integral part of the research process, specifically in ensuring that quality research findings are produced. There are different strategies which the researcher could apply to substantiate data in order to ensure the quality of the study. One way of achieving this was through focusing on the research process. This is known as the process of trustworthiness which emphasises rigour and authenticity (Schurink *et al.*, 2011, p. 421). The strategies applied to ensure verification of data in this study, namely triangulation, audit trial, peer examination, and reflexivity, will be discussed in the following paragraphs.

3.7.1   Triangulation

The process of triangulation included the researcher's process of document study. A document study of learner IEPs, doctors' and therapist reports, academic progress reports, etc. was made in order to obtain substantiating information regarding the caregivers' experiences. These documents allowed the researcher the opportunity to triangulate the data derived from the individual interviews. The researcher was then able to compile a timeline of caregivers' experiences based on the data derived from the interviews and the document study which functioned as a visual representation to the reader of the process caregivers went through before receiving a dual diagnosis of ASD and hearing loss, and the subsequent intervention services. Burn (2000, p. 467) highlights the importance of document study as a means of corroborating evidence derived from other sources, as such a study can specify events addressed by interviewees in greater detail. The researcher kept in mind that these

documents were not 100% accurate and that the authors of the documents were likely to be somewhat biased as the documents were written with a specific audience and purpose in mind (Burns, 2000, p. 467).

The researcher tried to cut out the possibility of being blindsided by unanticipated factors within the design of the research instrument. She attempted to ensure that the interview guide would capture the essence of caregivers' experiences. Construct validity was achieved through conducting a pilot study, which entailed testing the interview guide with a caregiver of a child with multiple disabilities. The researcher also acknowledged that any account is only one among other possible representations of the social reality of caregivers of children with multiple disabilities, but to increase the trustworthiness of the description, triangulation was used (Bertram & Christiansen, 2014, p. 188).

An audit trail is common practice in interpretivist research. It entails that the data collection and analysis process is made transparent (Bertram & Christiansen, 2014, p. 190). Schurink *et al*. (2011, p. 422) also refer to it as the "… research story". The researcher therefore elaborated on the process of the research in such a way as to make it possible for readers to follow the process step-by-step starting from data collection all the way to analysis. These steps were reported on in depth in section 3.4 Research Design. However, in Chapter 3 and Chapter 4 of the study the researcher provides the complete audit trail of the research process. The role of the researcher in this process was to be alert to possible bias or distortion within the processes followed and this formed part of reflexivity.

The interaction that took place between the researcher, the caregivers and the process represents an audit trail and elaborates on what was discovered and also how it was discovered. The researcher was explicit regarding involvement in this process (Etherington, 2006). In terms of the definition of the audit trail in Schrunick *et al*. (2011, p. 422) it is a systematically maintained documentation process of the researcher's continuous critical analysis of all decisions and actions taken during the entire research process. Here are some particulars of the audit trail.

Before the data collection started the researcher conducted a pilot study. This was undertaken in order to develop a research instrument that would address the research question optimally. As explained earlier the pilot study entailed an interview with a caregiver of a child with Down syndrome and ASD. The researcher made use of this opportunity, along with the

consequent observation notes, to develop the interview guide. An audio recording of each of the three interviews were made. The audio recordings were transcribed, read and reread numerous times in order to engage fully with the data. As the researcher engaged with and began analysing the data, data analysis products were generated. These include reflection notes on the theory as well as written summaries of the researcher's thought process in terms of how the data was understood through knowledge gained from the theory. These notes naturally took shape and were influenced by the researcher's reading resulting from the completion of Chapter 2, the literature review. The notes evolved through a combination of cyclical engagement with the data and theory as well as regular discussions with the supervisor. Data synthesis products further included tables and diagrams of the derived themes, findings and conclusions. The researcher made reflective notes to document her experiences and thought processes throughout this process. The researcher's personal interest and intellectual curiosity related to caregivers' experiences of diagnoses and intervention for their children with ASD and hearing loss was a driving force behind the process (Flick, 2006).

3.7.2   Peer examination

The study formed part of the thesis component of the Master's degree in Educational Psychology. Regular supervision and review formed part of the research process and thus also the data verification process. The involvement of the research supervisor entailed critical discussions around the data analysis and synthesis process. Supervision further entailed discussion of the researcher's experience in the context of the participants, the experience of conducting the interviews, as well as interaction with the participants and the content of the interviews. The discussions with the supervisor offered the researcher valuable insight into another perspective on the experiences which meant that possible alternatives, as well as areas of concern, could be reflected on and addressed. The researcher was also encouraged by areas of strength that were identified and was reminded of the significance of particular experiences as a novice researcher. On completion of the study the final product of the thesis will be reviewed by an external examiner appointed by Stellenbosch University (Merriam, 2009, p. 220; Shenton, 2004, p. 67). These processes are viewed as the data verification strategies.

3.7.3   Researcher reflexivity

Hammersley and Atkinson (2007) in Hays and Singh (2011, p. 137) define reflexivity as the self-reflection of the researcher on the research process. Early on in the research process the researcher acknowledged her own role as a research instrument as well as her role to maintain an appropriate research relationship to the research goal and the according responsibility to check on and be aware of personal biases. This will be discussed in greater detail in the following section on ethical considerations.

According to Stake (1995) the researcher's thoughts and feelings, as well as her reactions and interpretations of the data, are part of the research process. Reflexivity therefore becomes a "benchmark" for how credible and trustworthy the qualitative design is for the audience (Hays & Singh, 2011, p. 137). Through elaborating on the theoretical perspective and the researcher's personal worldview in Sections 1.2 and 2.1.1 the researcher explicated personal biases and values related to the research study. As the readers familiarise themselves with these aspects it allows them to formulate an understanding of and a possible insight into the rationale of the researcher in deriving the particular research results.

3.8   ETHICAL CONSIDERATIONS

Strydom (2011, p.113) explains the concept of ethics with which the researcher agrees.

Ethics is a set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students.

Ethical considerations remain central to all aspects of research. Burns (2000, p. 18) clearly states that ethical issues relate to both the subject matter of the research as well as to its methods and procedure. When research involves people and their experiences, such as it was in this case, ethical issues have the potential to be pervasive and complex (Strydom, 2011, p. 113).

Within the field of Educational Psychology there are ethical guidelines and protective measures presented and upheld by the Professional Board for Psychology, as well as the Health Professions Counsel of South Africa, in the form of a code of conduct which protect the well-being and human rights of users of these services. The ethical considerations of a researcher ultimately relate to the morals and professional responsibility towards the research

participants and the profession of Educational Psychology. Professionals within the field of Educational Psychology need to keep ethical considerations in mind in order to achieve success in practice and in research (Strydom, 2011).

The discussion of the ethical considerations for this study which lead to the success of the study was included under the discussion of the Procedures (3.5.2) and included obtaining ethical clearance, voluntary participation, being granted informed consent, maintaining participant confidentiality, respect for participants, safeguarding and management of the data, as well as the ethical role of the researcher and the importance of a reflective process in the profession of Educational Psychology.

Before the empirical investigation was started ethical clearance was sought from the Research Ethics Committee of Stellenbosch University. Clearance was granted with National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.

3.8.1   Voluntary participation

The procedures followed by the researcher honoured the caregivers' right to voluntary participation. These procedures were outlined in Section 3.5.3. This included approaching the school via the principal, providing the caregivers with information regarding the nature and extent of the research, as well as what their participation would entail; and waiting for their permission to contact them.

3.8.2   Informed consent

Informed consent is considered by Burns (2000, p. 19) as the "… most fundamental ethical principle …" involved in research. Obtaining informed consent entails that the researcher be open and honest in communicating to participants the aims and purpose of the research study, the extent of participation, the limits of confidentiality and how anonymity would be ensured, any possible risks and benefits due to participation, as well as how data will be presented in the findings (Mouton, 2005, p. 244). The researcher compiled an Informed Consent form containing these aspects. Prior to the interview the participants were given the invitation letter containing details regarding the purpose of the study and their expected involvement. On meeting with the caregivers the Informed Consent form was discussed and explained in the caregivers' mother tongue. A copy of the form was given to the caregivers to keep. The signed informed consent forms provide proof that the researcher had consent from the participants. The key for the consent to be informed, however, was to communicate, as

explained above, clearly to all caregivers what exactly participation in the study would entail. It was also stated clearly that participants had the right to refuse any questions or to opt out at any stage without there being any consequences. Caregivers' decision yo opt out would be accepted without questioning. The researcher included particulars of whom to contact should the caregivers have any questions pertaining to the research study or should there be an adverse event (Devlin, 2006, p. 163).

3.8.3   Anonymity and confidentiality

Anonymity relates to caregivers remaining unidentifiable throughout the study, as well as in the presentation of the results. Anonymity therefore strongly applies to the process of collecting data. The researcher was granted permission by the caregivers to make audio recordings of the interview (Mouton, 2005, p. 243). The recordings were stored securely on a password-protected laptop and accessed only by the researcher. Confidentiality refers to the information gathered from the caregivers and the steps taken to remove identifying details (Mouton, 2005). The researcher therefore made use of pseudonyms in reporting on the findings and the school was referred to only as a special needs school with a class for children with multiple disabilities. Confidentiality reiterates the participants' right to privacy which protects their worth and dignity. The researcher undertook to ensure that private information pertaining to the participants was protected and that access to this information was limited to the researcher and the supervisor for the purpose of achieving the research goal.

Hays and Singh (2011, p. 91) identify two key ethical issues related to the researcher's role which were experienced by the researcher in conducting this study. The first was related to the role of the researcher as an instrument, which required her to collect quality data whilst displaying an understanding in the context of the study. The second issue related to the researcher's role to develop and maintain an appropriate research relationship relevant to the research purpose (Hays & Singh, 2012). Corbin and Strauss (2008) allude to the fact that it is not possible to separate who you are as a person from what you are doing in qualitative research. Therefore the researcher was ethically obliged to keep in mind the fact that the central research instrument was imperfect and human, bringing with her a unique set of imperfections, fears, sensitivities and anxieties (Soobayan, 2003, p. 118). With this in mind the researcher was guided by Haverkamp's (2005) suggestion to reflect constantly on how the researcher was influencing the research process and outcomes. The researcher observed and

interpreted the data from her own frame of reference (Halbrook & Ginsberg, 1997). The researcher continuously reflected on how she influenced the research process and the outcomes of the qualitative inquiry. Reflections entailed reviewing why particular participants, topics and methods were selected. The researcher clearly stated and motivated how these decisions related to personal interests.

3.9   CONCLUSION

The researcher used this in-depth discussion in Chapter 3 to describe the step-by-step approach followed in order to address the research question. The researcher positioned the study in ontological and epistemological terms and reflected on the choice of the research paradigm. The rationale for specific methodological choices such as the research design, data collection and verification process was provided. Before concluding this chapter the researcher focused on strategies that were employed to ensure quality and trustworthiness of data and an ethical approach that was followed throughout the project. In Chapter 4 the author will focus on the product of the investigation. The derived themes and a detailed discussion of the findings will follow.

CHAPTER 4:
RESEARCH FINDINGS, DISCUSSION AND RECOMMENDATIONS

4.1   INTRODUCTION

In Chapter 3 the author provided an in-depth discussion of the research process that was followed in order to answer the research question. Chapter 4 is dedicated to presenting the research findings as derived at through this particular research process. A brief discussion of the context in which the study was conducted is provided due to the importance of its role within the bio-ecological perspective, and reference is made to the process that was followed to create participant narratives. The findings of the data are then presented in a discussion of the derived categories and themes through the process of qualitative content analysis and the existing literature review. Strenghts and limitations of the study are identified and finally the chapter is concluded with the presentation of recommendations to professionals working with caregivers of children with a dual diagnosis of ASD and hearing loss in South Africa.

4.2   PRESENTATION AND DISCUSSION OF RESEARCH FINDINGS

While theory development is not usually expected in small-scale studies the use of theory to guide the analysis and synthesis process may nevertheless be a highly productive part of the interpretive process (Mabry, 2009). The bio-ecological perspective served as the theoretical underpinning for the discussion of the research findings as caregiver experiences were investigated at the different levels of the perspective, namely the micro-system, meso-system, exo-system, macro-system and chrono-system. The experiences of the caregivers which were shared through the individual interviews and studied through the document study were explored, data derived and processed which lead to the development of three themes. The derived themes answer the primary research question: What are the lived experiences of caregivers of children with a dual diagnosis of hearing loss and ASD.

Finally the case studies were ended with conclusions formed by the researcher about the overall meaning derived from the experiences of caregivers. Stake (1995) refers to these conclusions as "assertions" and Yin (2009) as building "patterns" or "explanations". The researcher hoped that the findings of the study would be considered as general lessons learned through the in-depth study of the cases. The research resulted in the formulation of

guidelines that will support the development of future support structures for caregivers of children with a dual diagnosis of hearing loss and ASD (Schurink *et al.,* 2011).
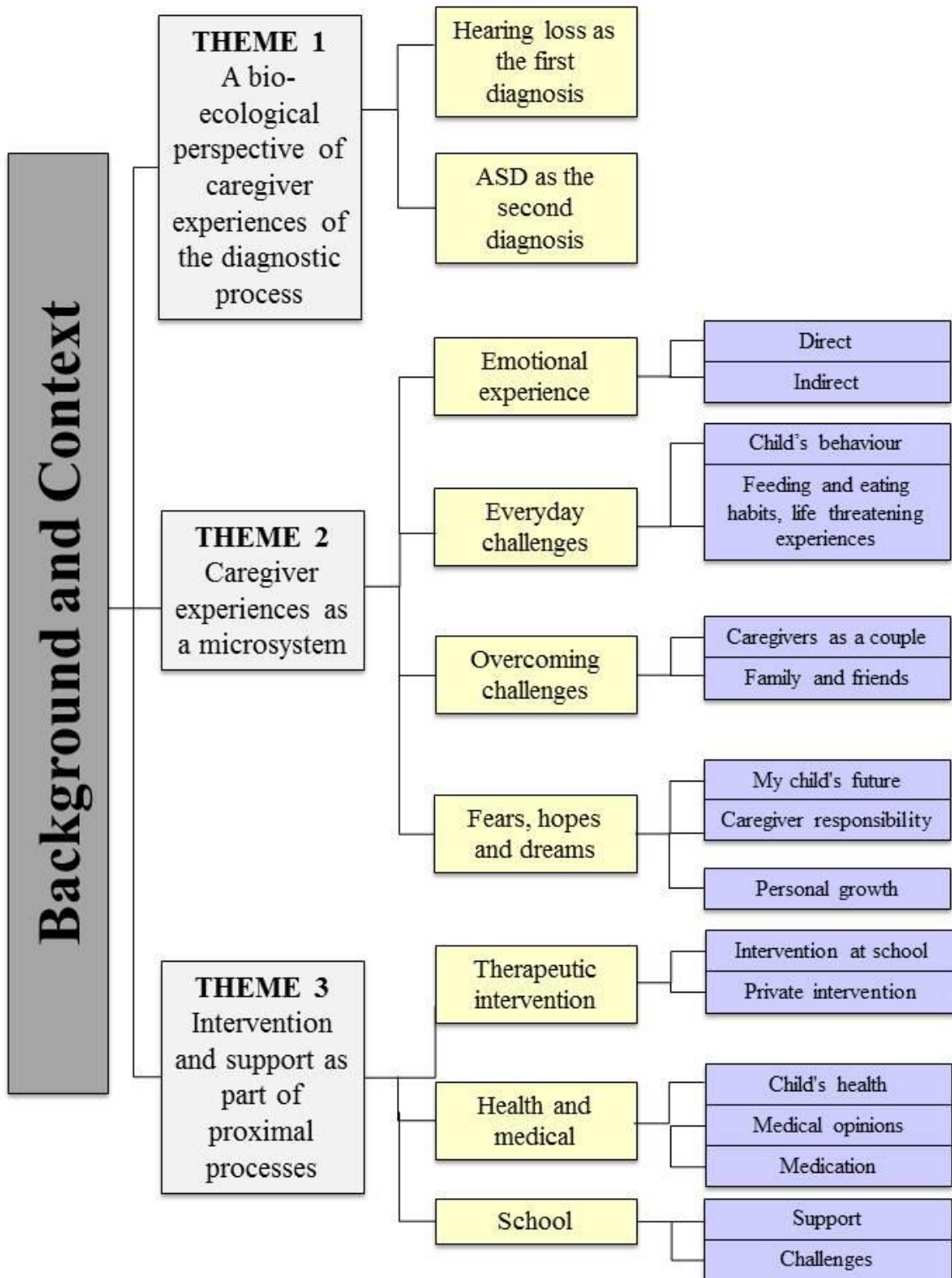
Figure 4.1: Thematic content of the research findings

In Figure 4.1 the author illustrated the derived themes, categories and subcategories as they emerged through the process of data analysis. The author illustrates the constant consideration of the background and context of the caregivers along with the integration of the bio-ecological perspective as a framework.

Three main themes were identified, namely: *a bio-ecological perspective of caregiver experiences of the diagnostic process*, *caregiver experiences as a microsystem* and *intervention and support as part of proximal processes*. The constant consideration of the bio-ecological perspective was fundamental to the discussion of the research findings. Through a focussed discussion of the research findings the researcher will answer the research question and sub-questions.

Theoretical triangulation facilitated the interpretation process by offering views of the data through different explanatory lenses (Mabry, 2009). The researcher clearly indicated how data triangulation occurred and referred to the sources of data. The interpretavist researcher was guided by the literature review and potential interpretations as suggested by the bio-ecological perspective to think deeply about meaning of the findings as they emerged through the data analysis process.

4.3   CONTEXT OF PARTICIPANTS

4.3.1   Background and context

This research study was conducted within a framework of the bio-ecological perspective to gain an understanding of the context and the details surrounding each caregiver. This played a significant role in answering the research question. As was mentioned in Chapter Two, the family structure is dynamic and each family has a unique composition (Turnbull & Turnbull, 2001). The researcher strived to understand the complex, yet unique structure of each family system, how it functions and the impact of the context on caregiver experiences. Caregivers' experiences were listened to and narratives were constructed through the data analysis process (Orelove, Sobsey, & Silberman, 2010).

The narratives included information on the caregivers' age, education level, work life, marital status as well as details regarding the child's birth, the particulars around the first signs observed that raised concerns regarding their child, experiences and details around the first diagnosis, the second diagnosis, the experience thereof, the presence of a family history of hearing loss, as well as the first experience of school placement along with their child's

scholastic and academic ability. The narratives allowed the researcher to engage meaningfully with the data by exploring the composition of each family, the socio-economic status and available resources, personal attributes, and special challenges faced by the caregivers. The exploration of the family system and context of each case is presented in the discussion. Samples of these narratives are presented in Addendum J.

The following table serves as a summary of the biographical information extracted from the interviews and document study of each family.

Table 4.1: Biographical information of the caregivers

Caregivers of Child	Age of caregivers at the birth of child	Relationship	Occupation father; mother	Child's age	Number of other children	Disability in the family	Class and years in school
Ellen's caregivers	28 and 27	husband and wife	mechanic; general worker	18	15 year old daughter, pupil	hearing impairment	Class for multi-disability; 15 years
James' caregivers	29 and 24	husband and wife	fire-fighter; housewife	14	11 year old twin daughters, pupils	specific learning disability	Class for multi-disability; 11 years
Anton's caregivers	40 and 38	husband and wife	technical consultant; part-time counsellor	14	23 year old, working son; 21 year old student son	none	Grade 5; 11 years

4.3.2   Theme one: A bio-ecological perspective of caregiver experiences of the diagnostic process

Theme One, *A bio-ecological perspective of caregiver experiences of the diagnostic process*, is divided into two categories namely *Hearing loss as the first diagnosis* and *ASD as the second diagnosis*. In these categories the author answered the research question of caregivers' experiences of the diagnostic process, as well as the sub-question relating to the signs and behaviours that lead caregivers to seek further support. In this first theme the author depicted the complexity of caregivers' experiences of receiving this dual diagnosis of hearing loss and ASD. This process was illustrated in detail through the construction of the individual

timelines which were compiled using data from the individual interviews and the document study. The timelines appear in Addendum I.

4.3.2.1   Hearing loss as the first diagnosis

Timeline 1 (T1), Timeline 2 (T2) and Timeline 3 (T3) indicate that the first diagnosis made in all three cases was that of hearing loss. Hearing loss was considered the primary diagnosis which was defined as the most serious and resource intensive condition (Prescott, 2015). The conversations held with the caregivers during the individual interviews confirmed this and was in line with research done by Roper *et al*. (2003, p. 249) who found that hearing loss was diagnosed first in children with a dual diagnosis of hearing loss and ASD.

Anton was diagnosed with hearing loss by a paediatric audiologist at six months of age. His caregivers were prepared for the fact that Anton could be born with hearing loss due to the fact that his mother contracted Rubella early during her pregnancy. Despite suspecting that Anton would be born with hearing loss his hearing was first tested at six months of age (T3 and interview).

> *"... they told me that they expect that he would most likely be born deaf and blind and be mentally impaired because I was so severely sick ..." (Anton's mother, interview, 83-84) [... hulle het vir my gesê hulle verwag hy gaan hoogs waarskynlik doof en blind en verstandelik gestremd wees omdat ek so erg siek ook was ...]*

> *"... we also did not have him tested immediately [only discovered that he was deaf at six months]..." (Anton's mother, interview, 303) [... ons het hom ook nie dadelik laat toets nie ... (op ses maande eers gevind hy is doof) ...]*

The individual interview revealed that James' caregivers only became concerned about his hearing at the age of three years when he would not respond to being called. This was what led them to seek professional advice from their docter. James' hearing was tested at the age of three years (T2) which is significantly delayed compared to the mean age of diagnosis of infants in South Africa at 23 months (Van der Spuy & Pottas, 2008). James' father shared that initially he was not concerned about James' behaviour as he himself also experienced delays in the development of language as a child and this experience at a micro-system level

contributed to the delayed diagnosis of James' hearing loss. James' caregivers' perception of language development was influenced by their own experiences at a micro-level.

> *"... one speaks to him ... he doesn't look at you ..." (James' mother, interview, 175-176) [... mens praat met hom ... hy kyk nie vir jou nie ...]*

> *"... I was never concerned that he was like that. I thought that he was exactly like I was because I have dyslexia ..." (James' father, interview, 325-326) [... ek het nooit geworry oor hy so is nie. Ek het gedog hy is presies soos ek want ek het disleksie ...] 325-326*

Ellen's caregivers' response to the initial diagnosis of hearing loss further illustrates how caregivers' experiences were significantly influenced by their background and context. At a micro-system level Ellen's caregivers had personal experience of hearing loss and their first language and means of communication is sign language. Ellen's caregivers are both deaf and come from families with a history of hearing loss. The first diagnosis of hearing loss was not unexpected. When asked about how they experienced the first diagnosis they explained that receiving the first diagnosis of hearing loss did not come as a shock or fall outside the realm of their experience.

> *"I am also deaf ... I can communicate with her, so it was not a problem for me." (Ellen's father, interview, 214-215) [Ek is ook doof ... ek kan met haar kommunikeer, so dit was nie vir my 'n probleem nie.]*

James' caregivers, however, were shocked and considered the adjustments they had to make as a family, which included having to learn sign language in order to communicate with James. The effects of the diagnosis of hearing loss on the family remain pervasive. Challenges and needs associated with interpersonal relationships such as communication as expressed by James' caregivers will arise (Ross & Deverell, 2014). The impact of the diagnosis of hearing loss was felt to a greater degree within this family system compared to Ellen's caregivers as Ellen's family had personal experiences of living with hearing loss. Information gathered through the document study confirmed the reported experiences of James' caregivers and is indicated on T2. Having the diagnosis of hearing loss confirmed can be a shattering experience for caregivers and precipitates a crisis for many caregivers.

Reactions of shock and despair, amongst other emotions, are considered normal and to be expected (Ross & Deverall, 2014).

> *"... we were shocked, we didn't expect it." (James' caregiver, interview, 204-205) [... ons was geskok gewees, ons het dit nie verwag nie.]*

> *"... okay now he is deaf, but it is an adjustment for us. Now we have to learn all those gestures ... and [The School for the Deaf] is far from here ..." (James' mother, interview, 210-212) [... ok nou is hy doof maar nou is dit 'n aanpassing vir ons. Nou moet ons al daai gebare ... leer en [Die Skool vir die Dowes] is ver hiervandaan ...]*

Soon after James was diagnosed with hearing loss his caregivers were sent to Carel du Toit School for early intervention services that are focused on the auditory-oral approach. After careful consideration of the intervention options available to the family James' caregivers decided that this was not the route for the family and that placement at The School for the Deaf, and therefore the manual approach, would be a better fit. Störbeck (2016, p. 22) explains that when caregivers decide on the manual approach to communication with the child with hearing loss it is expected that caregivers sign to their children from as early as possible and therefore it is required that caregivers learn sign language to achieve optimal language development for their child. Due to the benefits of intervention taking place as early as possible children with hearing loss start to attend The School for The Deaf from as early as three years of age (Olusanyo, 2005; Yoshinaga-Itano & Gravel, 2001). James started at The School for the Deaf promptly after his caregivers decided on the manual approach. This transition was a difficult one for the whole family.

Anton's caregivers were told before birth that he would most likely have hearing loss as a result of having Rubella Syndrome. Along with concerns of possible hearing loss doctors predicted that he would have an array of related challenges and birth defects (T3 and interview 3). His birth and what was found at his birth was much less damning than was expected. It is unclear to what extent being prepared for possible challenges contributed to Anton's caregivers' experiences after his birth. Their experiences were different to what the doctors had predicted.

"Yes, it was wonderful. It was different ... he was extremely small and timid and we were very protective of him ... [except that] he was feeding regularly ... he was actually an easy baby, he was healthy and he was very cheerful." (Anton's mother, interview, 294-301) *[Ja, dit was wonderlik. Dit was anders ... hy was geweldig klein en fyntjies en ons was maar baie beskermend teenoor hom ... [behalwe dat] hy nou redelik gereeld gevoed het ... was hy eintlik 'n maklike ou babetjie gewees, hy was gesond en hy was baie vrolik gewees.]*

4.3.2.2   *Autism spectrum disorder as the second diagnosis*

ASD was the second diagnosis made in all three cases as illustrated by T1, T2 and T3 and reported during the individual interviews. This category falls under the *Personal experiences of the diagnostic process*. As caregivers shared their experiences of receiving the ASD diagnosis several issues of interest emerged. These were the specific behaviours observed that were related to ASD, and the fact that caregivers did not know what ASD was. Once they received the diagnosis caregivers experienced that the diagnostic features matched their child's behaviour. They sought advice from professionals, formulated or had their own understanding and conceptualisation of what caused ASD, and identified familiar behaviours in their child that they themselves exhibited as children.

Caregivers' experiences of ASD as the second and later diagnosis (T1, T2 and T3) are echoed by the findings of Steinberg (2008) and Menzer-Der *et al.* (2014) who observe that deaf children usually get a diagnosis of autism later than hearing children due to the fact that it is challenging to identify whether the child's communication and social delays are a result of the hearing loss or possible ASD. This is particularly unfortunate because the period between the ages of 1 and 4 years is a period when brain plasticity is at its maximum and it is easiest to establish or alter neural pathways (Sacks, 1989). Ellen, James and Anton's caregivers all noticed some of the distinguishing features of ASD, but were unsure what to attribute them to as the caregivers were too busy dealing with their child's behavioural challenges and managing their educational needs to focus on these concerns. Ellen and James' caregivers noticed the lack of eye-contact and a preference for playing on their own.

"... communicating [and eye contact] was difficult ..." (Ellen's caregiver, interview,236) [... kommunikeer [en oogkontak] was moeilik ...]

> *"... when I was a child I was also like him, alone ..." (James' father,interview, 319) [... toe ek 'n kind was was ek ook soos hy gewees, alleen ...]*

Investigations into the concerns related to the children's behaviour and the possibility of co-morbid ASD were initiated by their teachers in all three cases. Anton's teacher who had special needs training became aware of features of ASD that presented in Anton and expressed her concern to his mother.

> *"... (his teacher) had special training and she started telling me that hey this child has ... there are things, he's got ... autistic type ... trends there are many similarities in terms of ASD and his behaviour." (Anton's mother, interview, 445-450) [... (sy juffrou) het spesiale opleiding gehad en sy het vir my begin sê jong die kind het ... daars goeters, hy't ... outistiese tipe ... neigings, daar is baie ooreenkomste met outisme by hom.]*

All three children experienced high levels of frustration and displayed behaviour their caregivers referred to as tantrums across different settings. This undesired behaviour posed particular challenges to caregivers on a micro-level and consequently the family system. Anton's mother spoke about the particular challenges that their family faced when going out in public or away for a holiday. She mentioned that Anton did not travel well as a child and due to his uncontrollable behaviour they do not go out much as a family. A sense of isolation is often reported by caregivers of children with special needs, due to the children's behaviour (Orelove, Sobsey & Silberman, 2004).

Trips to the shopping mall were described as particularly distressing because Anton would not stop at anything to get his way and he would go as far as to physically assault his mother in public. Although Anton did not display an indication of experiencing shame, these situations caused embarrassment on her behalf and she felt that people were judging her parenting skills.

Holidays remain particularly challenging for Anton's caregivers as they are not able to rest and recuperate because even at the age of 12, Anton required constant supervision. The reason for this is that although Anton is desperate to socialise with other children he is not accepted by his peer group. Due to his social awkwardness he requires the support of an adult to facilitate interactions with peers. Thus the impact of his disability on the family was

experienced on a macro-level or through the culture of the society in which the family exists. This culture does not accept or allow integration of Anton into their social sphere. This exclusion of Anton affects his caregivers on a micro-level

> *"... I try to limit going out with him because I find it very difficult to handle him when he throws a tantrum in the mall ... he does not mind who sees him and sees it as the perfect opportunity to set all his demands for what he wants. He does not take "no" for an answer and will physically attack me in the mall and throw himself on his back... people would stare at me ... mrs what is wrong with you ... why don't you help this child?" (Anton's mother,interview, 909-913) [... ek probeer ook maar beperk om met hom iewers te gaan want dit is vir my baie moeilik om hom te hanteer as hy 'n tantrum gooi in die mall ... hy ontsien niks en niemand nie dan is dit nou sy ideale geleentheid om al sy eise te stel. Hy aanvaar nie nee nie, so hy sal in die mall vir my te lyf gaan en skree en homself op sy rug gooi ... mense my sal aankyk ... mevrou wat is fout met jou ... hoekom help jy nie hierdie kind nie?]*

Disruptive behaviour is an important consideration for caregivers of children with ASD as the challenges associated with disruptive behaviour, such as physical or verbal aggression, pose significant stress on the family system. Furthermore, disruptive behaviours are known to contribute to poor health and well-being of individuals with ASD as well as their caregivers. Behavioural challenges have been associated with increased parental stress (Lecavalier, 2006).

> *"... he wants to be alone ... the dinosaur or the doll and the girls may not touch it then he becomes hysterical especially when he was younger ..." (James' mother, interview, 308-310) [... wil hy alleen wees ... die dinosaur of 'n poppie en die meisiekinders mag nie daaraan raak nie dan raak hy histeries, veral toe hy jonger was ...]*

Caregivers were able to reflect on their experiences and identified specific behaviours that were troubling for them, but at the time it was difficult to ascribe the signs to something other than developmental delay on account of their child's hearing loss. This is because signs and symptoms of hearing loss and ASD overlap and making a diagnosis of ASD in children who have hearing loss is a difficult task. ASD is often overlooked in young children with hearing

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loss due to the fact that communication disorders are inherent in both ASD and hearing loss (Hanley & Michelle, 2005). Another contributing factor is the fact that all children with ASD are unique and present uniquely in terms of symptoms (Doyle & Doyle, 2004; Ming, 2014). Anton's mother was painfully aware of associated features of ASD such as the regular melt-downs, but his social nature and ability to make eye-contact deterred her from considering ASD as a possible cause for his challenging behaviour.

> *"I noticed it, but it was difficult as he was very sociable and he makes eye contact and it is so not autistic, but ... much of the other [behaviour] ... the terrible tantrums, frustrations ..." (Anton's mother, interview, 449-451) [Ek het dit gesien, maar dit was moeilik want hy is baie sosiaal en hy maak oogkontak en dit is so nie outisties nie, maar ... baie van die ander [gedrag] ...die verskriklike tantrums, frustrasies ...]*

a)   Not knowing what ASD is

At the time of receiving the ASD diagnosis Ellen's caregivers were not familiar with what ASD was and had never heard of it. The diagnosis was made by an English-speaking psychiatrist visiting The School for the Deaf. As Ellen's caregivers received the diagnoses of ASD they communicated a particular need for someone to explain to them what ASD was. They wanted someone to explain to them how Ellen was affected by ASD. The fact that Ellen's caregivers were both deaf, with their first language being sign language and that they were unable to understand spoken English, meant that receiving the diagnosis of ASD was a challenging experience. This issue was specifically complicated by their knowledge base and communication needs. This experience illustrated that caregivers did not have equal access to knowledge, information and support services within their immediate environments. Ellen's caregivers sought advice from their general practitioner, but he was unable to provide them with answers to their questions and concerns.

> *"I knew nothing about autism ..." (Ellen's mother, interview, 254) [Ek het niks geweet van outisme af nie ...]*

> *"It feels as if you ask the doctor ... and he doesn't have answers." (Ellen's mother, interview, 384) [Dit voel jy vra vir die dokter ... en hy het nie antwoorde nie.]*

b)   *Knowing that the ASD diagnosis and description fits my child*

Interestingly the mothers of Ellen, James and Anton all reported that there were specific descriptions of ASD they could identify in their children prior to the diagnosis and as they did their own research and read information provided to them by the school the symptoms became recognisable in their child.

> *"I read about what autism is ... everything is exactly the same as her." (Ellen's mother, interview,361) [Ek het gelees wat is outisme ... alles is presies dieselfde as haar.]*

> *"... that which I am telling her now about the symptoms ... James has these ..." (James' mother, interview, 385) [... dit wat ek nou vir haar vertel het van die simptone ... dit het James ...]*

c)   *Own conceptualisation of what caused ASD*

Part of Ellen's caregivers' process of trying to make sense of the ASD diagnosis was trying to pinpoint what could have caused it. Ellen's mother attributed it to what she recalls as x-rays that were done before Ellen's birth. Ellen's father also felt that something must have gone wrong during his wife's pregnancy. If Ellen's caregivers had support during the process of diagnosis these concerns and experiences of guilt could have been addressed and the misinformation discredited.

> *"... only later did I realise that they took X-rays when I was pregnant with Ester because I later read on their door that they must not take X-rays when a person is pregnant." (Ellen's mother, interview, 405) [... eers later het ek besef hulle het X-strale geneem toe ek vir Ester verwag het, want later toe lees ek op die deur dat hulle moenie X-strale neem as mens swanger is nie.]*

> *"Something must have gone wrong in the womb while Susan (pseunonym) was expecting her ..." (Ellen's father, interview,386) [Daar moes fout gegaan het terwyl Susan (skuilnaam) vir haar verwag het nog in die baarmoeder ...]*

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d)   *Familiar behaviours observed in the child – this is similar to what I was like as a child.*

Interestingly, James' father identified with symptoms presented by his son which are associated with ASD, yet unequivocally stated that he has not accepted the diagnosis of ASD. Responses associated with denial to the diagnosis of ASD is not unusual as caregivers have up until the point of diagnosis had expectations of "normality", and the experience of denial is often a defence mechanism to the immense hurt and shock of receiving a diagnosis (Ross & Deverell, 2014). Another possibility for the reaction of James' father could be the manner in which his beliefs influence how much he trusts the professionals making the diagnosis (Zajicek-Faber, 2013). Caregiver beliefs have the potential to influence the manner in which the family adapts to their child's disability.

> *"I thought that they were talking a load of rubbish." (James' father, interview, 379). [Ek het gedink hulle praat 'n klomp bollie.]*

> *"… when I was a child I was also like him. I was alone. I did not worry about my brothers or sisters …" (James' father, interview, 319-320) [… toe ek 'n kind was, was ek ook soos hy gewees. Ek was alleen. Ek het nie geworry oor my broers en susters nie …]*

> *"So I was exactly the same as him … I do not have autism, I have never bothered with it." (James' father, interview, 386-387) [Ek was dan presies soos hy gewees … ek het nie outisme nie, ek het my nog nooit daaraan gesteur nie.]*

Although Ellen's caregivers did not identify with her symptoms they also expressed having difficulty in accepting die ASD diagnosis. Denial forms part of the natural grieving process as caregivers mourn the loss of their previous expectations of their child (Ross & Deverell, 2014).

> *"... will never accept it." (Ellen's mother, interview,241) [... sal dit nooit aanvaar nie.]*

4.3.3   Theme two: Caregiver experiences as a microsystem

Theme Two with its categories and sub-categories emerged during the data analysis process and was coded and constructed accordingly. In this theme the author focuses on caregivers'

experiences on a micro-level. This relates to *emotional experiences*, *everyday challenges*, *overcoming challenges*, and *fears, hopes and dreams* as categories which were further divided into sub-categories.

4.3.3.1   *Emotional experiences*

Caregivers shared an array of different emotions which they experienced either as a direct result of their child's diagnosis and the associated behaviours, or indirectly as they responded to the treatment of their child by other individuals. Caregivers reported a sense of heartache when their child was treated poorly by others, but also shared their experience of excitement at progress made by their child.

A significant emotion shared by James' and Anton's caregivers was that of guilt. James' caregivers shared how they wondered what impact private education would have had on James' development if they were able to provide financially for James to receive a private education. This relates to the inherent desire of caregivers to provide their children with the best possible care (Durand, 2011; Orelove, Sobsey & Silberman, 2004) and the consequent experience of guilt when they realise that their financial constraints are holding them back from providing their child with interventions that could help the child progress well.

> *"... I don't have the money, so I could not do it ..." (James' father, interview, 511) [... ek het nie die geld nie, so ek kon dit nie gedoen het nie ...]*

> *"... but you do want the best for your child ... if we had that kind of money ... we would have done it for him ..." (James' mother, interview, 538-540) [... maar mens wil ook die beste vir jou kind hê nê ... as ons daardie geld gehad het ... sou ons dit gedoen het vir hom ...]*

Caregivers thus gave expression to guilt they experienced for not providing what they regard as sufficient input into their child's development, whether it be having the financial means to do so or providing individual time and energy to teach and instruct their child themselves. Anton's mother shares how she often experiences a sense of guilt for not taking Anton to more therapies and not spending more time teaching him directly herself. Kuhn and Carter (2006) find that caregivers' experience of guilt and the extent to which they feel they lack agency has a negative impact on caregivers' experience and sense of parental self-efficacy, which was clearly reflected on by these caregivers.

> *"… some days I feel rather guilty because I think I could have done much more for Anton than I have done in the sense of sitting with him and helping him and taking him to all kinds of things, I don't know …" (Anton's mother, interview, 715-717) [... ek voel nogals skuldig party dae want ek dink ek kan seker baie meer vir Anton gedoen het as wat ek gedoen het in die sin van rerig sit met hom en hom help en vir hom vat na allerhande goeters toe, ek weet nie ...]*

The individual interview with Anton's mother revealed that caregivers compared their level of input to other caregivers of children with special needs. Her perception of what other caregivers were providing for their children in terms of therapies and interventions was making her wonder whether she could have gotten better results.

> *"… I think maybe I'm missing something … there are many parents who have great input into their disabled children's lives and they achieve a lot with the children. I don't know if I could have done more …" (Anton's mother, interview, 765-768) [... ek dink miskien mis ek iets ... daar is baie ouers wat verskriklik input lewer in hulle gestremde kinders se lewens en baie regkry met kinders. Ek weet nie of ek meer kon doen nie ...]*

Anton's mother shared her experiences of sacrifices made in order for their child with special needs to receive the necessary intervention. These sacrifices included the relocation of the entire family to be in close proximity to The School for The Deaf. This meant that the family left behind their dream home and country lifestyle. Isolation is another experience on the micro-level that was felt by caregivers of children with a dual diagnosis. This mother described the social and emotional cost for the family and the impact it had on the family as a whole in the following way.

> *"… he didn't want to come here [family relocated] and he tried everything, but when he saw that it is not working out … we relocated …" (Anton's mother, interview, 418-419) [...hy wou nie hiernatoe kom nie [family relocated] en hy het alles probeer, maar toe hy sien dit werk nie uit nie … het ons getrek ...]*

> *"… we don't have a normal life, we are relatively isolated, our social pattern has changed completely and we hardly ever, to never, go out."(Anton's mother,*

interview, 870-871) [... ons het nie 'n normale lewe nie, ons is redelik geïsoleer, ons sosiale patroon het totaal verander ons gaan baie min uit, tot nooit.]

4.3.3.2   *Everyday challenges*

Everyday challenges primarily reflected the challenges associated with activities and tasks which took place as part of the caregivers' daily routines in caring for their child with special needs. However, this category and the related sub-categories of the child's behaviour, feeding and eating habits as well as life-threatening experiences, do not address experiences of diagnosis or intervention. They relate to caregivers' experiences of everyday challenges which speak to the sub-question of signs and concerns that raised concern and which led caregivers to either seek further intervention or ask important questions about their child's specific behaviour associated with ASD.

a)   *Child's behaviour*

Child's behaviour refers to challenges resulting from specific behaviours demonstrated by the child within different settings and situations. These are behaviours caregivers found difficult to deal with and which caused significant stress on a daily basis.This finding is echoed by research done by Hsien and Lo (2012) who found that getting through tasks of daily living with children with ASD is a source of significant stress for caregivers. All three groups of caregivers reported having experiences of challenging behaviour such as anger, aggression and, what they referred to, as *tantrums*. Anton's mother shared her experience of her son's explosive behaviour.

> *"... you know the terrible tantrums, frustrations ..." (Anton's mother, interview,451) [... jy weet die verskriklike tantrums, frustrasies ...]*

> *"He is a small bomb that goes off, that expolodes. He is a strong personality ..." (Anton's mother, interview,649) [Hy is 'n bommetjie wat afgaan, wat ontplof. Hy is 'n stérk persoonlikheid ...]*

> *"... he stops for nothing or no one. He roars like a lion. If he gets cross he knocks the window out or smashes the TV." (Anton's mother, interview,654-655) [... hy stuit voor niks of niemand nie. Hy brul soos 'n leeu. As hy kwaad is, slaat hy die venster uit of hy slaan die TV stukkend.]*

Ellen's caregivers shared the challenges they faced as a result of her behaviour.

> *"Difficult, yes No one is allowed to upset her. Then she becomes aggressive, screams and then she gets so angry that she hits." (Ellen's mother, interview, 496-497) [Moeilik, ja. Niemand mag haar kwaad maak nie. Dan raak sy agressief, gil, dan raak sy so kwaad sy slaan.]*

The child's behaviour further caused significant challenges within the home environment in the fulfilling of tasks of daily living. These related to daily clashes in getting ready for school and the process of toilet training their child. This challenge relates to the fact that their child remains dependent on them for the fulfilling of these tasks which regularly resulted in power struggles which were exhausting their emotional resources on a micro-level. It is a known fact that children with ASD present with cognitive and adaptive limitations that limit their independency. The reality is that these children will require care and assistance from their caregivers for the duration of their lives (Volkman & Pauls, 2003).

> *"... yes, but struggled a lot at home [nappi]" Ellen's mother, interview, 137) [... ja, maar by die huis baie geskukkel (nappi)]*

b)   Feeding and eating habits

Interestingly, caregivers all reported that their children experienced, and continue to experience, difficulty with eating. Anton's mother raised valid questions around the possible sensory nature of this difficulty, but at the time of the interview it was not formally diagnosed or treated by an occupational therapist in any of the three cases. This was rather concerning, as it is a well-known challenge amongst children with ASD. Considering the far reaching impact of eating and feeding difficulties on the health of a child, and consequently the family, (Eicher, 2013) there is an urgency for it to be addressed. Feeding and eating habits of the children further caused strain on caregivers' emotional resources.

> *"Yes, I have to fight very hard (for her) to eat other vegetables, but then she vomits." (Ellen's mother, interview, 150) [Ja, ek moet hard baklei (dat sy) ander groente eet, maar dan gooi sy op]*

"Yes ... eats it very, very slowly. It can take two hours or longer." Ellen's mother, interview, 606) [Ja ... eet dit baie, baie stadig. Dit kan 'n uur of twee ure lank vat.]

"I get very despondent with her slow eating ..." (Ellen's mother, interview, 607) [Ek raak moedeloos met haar stadige etery ...]

"It is the same. He refuses to eat. I don't know if you saw how thin he is ..." (James' father, interview, 904) [Dit is dieselfde. Hy weier om te eet. Ek weet nie of jy gesien het hoe maer hy is nie ...]

"Anton [pseudonym] has a problem with food. He doesn't eat any food. His eating habits are a nightmare at this stage. I now have a name of a specialist in desensitising ... uhm ... so I want to take him there ..." (Anton's mother, interview,528-530) [Anton (skuilnaam) het 'n probleem met kos. Hy eet nie enige kos nie. Sy eetgewoontes is vir my 'n nagmerrie op die stadium. Ek het nou 'n naam wat gespesialiseer het in desensitasie ... uhm ... so ek wil nou vir hom soontoe vat ...]

c)   *Life threatening experience*

Ellen's caregivers shared their experience of two separate incidents that were particularly traumatic to them as caregivers. The first experience was as a result of Ellen almost suffocating as a baby. Although this experience is seemingly unrelated to the child's diagnosis of hearing loss and ASD, there is no way of knowing to what extent Ellen's developmental delay and "floppy neck" or possible low muscle tone could have contributed to this incident. It was further complicated by the fact that her father, who was looking after her at the time of the incident, is deaf and does not communicate verbally and therefore experienced difficulty in calling for help.

"Ellen's mouth is blue ... he needs help ... he runs ... he sees Emmie [neighbour] ... she knows he doesn't speak a word. Emmie grabs the baby and smacks her twice on the back, all the winds are out ..." (Ellen's mother, interview, 175) [Ellen se mond is potblou ... hy het hulp nodig ... hy hardloop ... hy sien vir

> *Emmie [neighbour] ... sy weet hy praat nie 'n woord nie. Emmie gryp die baba en slaan haar twee maal op haar rug, al die winde is uit ...]*

Children with ASD often demonstrate an unawareness of danger (Reid & Lannen, 2012). This poses a significant responsibility and even a burden on caregivers as they need to anticipate possible dangerous situations in order to prevent their child from being harmed. The second incident further speaks to the complexity of having a child with multiple disabilities and being a deaf caregiver. Particularly stressful incidences such as when a child goes missing are escalated due to the complexity of not being able to hear or communicate with the hearing world. When Ellen's caregivers could not find her while they were on an outing to the aquarium the routine procedure of making an announcement to call Ellen's attention was futile. Her caregivers also found it difficult to express themselves to those trying to help them find Ellen.

> *"... when Ellen disappears, I go mad." (Ellen's mother, interview, 625) [... as Ellen wegraak, dan raak ek mal.]*

> *"We were scared somebody had abducted her." (Ellen's mother, interview, 642) [Ons was bang iemand het haar dalk ontvoer.]*

Anton's caregivers' experience of knowing from the start that their child would be born with Rubella Syndrome is unique. Although undeniably traumatic, caregiver expectations will have been defined by their awareness of the congenital disorder of Rubella Syndrome (Ross & Deverell, 2014). Regardless of being prepared for what was to come, being faced with the numerous issues related to his birth, and particularly to his health, held additional challenging experiences for his caregivers. The impact of Anton's biological attributes on his caregivers' experience was significant and was illustrated by the experience of his caregivers being faced with the advice from doctors and specialists to abort the pregnancy after the foetal scan. All the arrangements for the termination were made by the specialist conducting the foetal scan, regardless of the parents' decision to continue with the pregnancy, which was communicated to the doctors. When Anton's mother did not turn up on the Monday morning the response from the doctors was one of disbelief. She describes how having to make such a decision was particularly challenging.

"...(She said) I can go to the hospital of my choice, here is the form for permission and authorisation from her that I must take along, I just need to call her and please complete the form because she would like to obtain the foetus for an autopsy My husband responded to her by asking 'But what if there is nothing wrong with him?' but she responded as if to say but what is wrong with you do you want to argue with all that has been found and they did call me that Monday to ask me at which hospital I was at but we replied that we were not at a hospital and that we were continuing with the pregnancy ... that weekend was especially difficult for me." (Anton's mother, interview, 187-198) [(Sy sê) ek kan na die hospitaal van my keuse toe gaan, hier is die vorm wat ek moet saamneem vir toestemming van haar af, ek moet net vir haar bel en ek moet hierdie vorm invul want sy wil asseblief die fetus hê vir na doodse ondersoek. Toe sê my man vir haar 'En sê maar daar is niks fout met hom nie?' Toe maak sy net so asof jy weet wat is fout met jou wil jy nou teen alles stry en hulle het toe die Maandag gebel om te hoor in watter hospitaal is ons en toe sê ons maar ons is ... nie by 'n hospitaal nie ons gaan aan ... daardie naweek was besonders moeilik vir my.]

4.3.3.3   *Overcoming challenges*

This category clearly depicts the manner in which caregivers were able to deal with the challenges they faced as a result of having a child with this particular dual diagnosis, dealing with the process of diagnosis, and also intervention services. The researcher came to realise that these experiences could not be separated or clinically isolated, but where considered as an ongoing evolving process within the caregiver system. Caregivers found support within their relationship as a couple, from friends and family, through their faith and to a lesser degree, self-nurturing.

a)   *Caregivers as a couple*

Caregivers had divergent experiences of dealing with the challenges related to their child's diagnosis and the intervention. Therefore their specific needs for support were different. Anton's caregivers referred to their experiences as a couple during the period of first being told that their unborn child would be born affected by Rubella Syndrome and the fact that, although caregivers have different ways of dealing with stressors and might be stronger at different times, they remained supportive of each other. Caregivers thus complemented each other in dealing with particular challenges and their relationships served as a buffer against

difficulties faced, such as learning that their child would have Rubella Syndrome (Bronfenbrenner, 1994).

> *"It is strange how you support each another ... there were always times when the one was stronger than the other one and then the stronger one would support the other ..." (Anton's mother, interview, 210-212) [Dit is eienaardig hoe mens eintlik mekaar ondersteun ... daar was altyd 'n tyd gewees wanneer een sterker was as die ander een, wanneer die een die ander een ondersteun het ...]*

Couples also experienced conflicting perceptions of specific situations and had to deal with these as they arose and needed to negotiate in certain situations to find a midway that could suit both individuals. Although caregivers did not elaborate on the differences they experienced in terms of their perceptions, references made to this experience were seen as significant.

> *"I think it is absolutely normal. People are just individuals and each one has his own idea." (Anton's mother, interview, 410) [Ek dink dit is dood normal. Mense is mos maar individue en elkeen het sy eie idee.]*

The impact on a marriage of having a child with hearing loss will depend significantly on the history of the couple as depicted across the chronosystem of the bio-ecological perspective. Other important factors in this regard are the availability of their emotional and material resources (Ross & Deverell, 2014). Anton's mother experienced a degree of resentment as roles were ascribed to each parent that entailed specific responsibilities towards the child's care for example. The role she found most challenging was that of addressing his behaviour on her own without the support of her husband. Ross and Deverell (2014, p.274) refer to parental stress often experiences by mothers of children with hearing loss "... as the father retreats into a secondary role because he feels less competent than his wife". The father might also take on the role of provider which could take him out of the home for extended periods of time, such as in the case of James' and Anton's families. This leaves the mother to address the needs of the child on her own.

> *"Well, I handled most of it on my own because my husband wasn't here. It was difficult, I was often very angry with him because ... he doesn't want to face it ... he made sure that he didn't need to be here. That's how it felt to me." (Anton's*

mother, interview, 461-463) "Wel, ek het meeste van dit alleen hanteer, want my man was nie hier nie. Dit was moeilik, ek was baie keer baie kwaad vir hom want ek het gedink ... hy wil dit nie 'face' nie. Hy het gesorg dat hy nie hier hoef te wees nie. Dis hoe dit vir my gevoel het.]

(... I work 24 hour shifts, ten days a month...) James' father, interview, 73) [... ek werk 24 uur skofte, tien dae 'n maand...]

As described by Shah *et al.* (2010) the lifeworld of caregivers was also significantly impacted by their child's disability in that they reported being isolated from their social world. This impact is experienced on the micro-level and could extend to the meso-system as the dependency of the child with hearing loss on the mother increases restriction of her daily activities and negatively affects the development of relationships within the family system (Ross & Deverell, 2014).

"We don't have a normal life, we are relatively isolated, our social interaction has changed completely and we hardly ever go out." (Anton's mother, interview, 870-871) [Ons het nie 'n normale lewe nie, ons is redelik geïsoleer, ons sosiale patroon het totaal verander. Ons gaan baie min uit, tot nooit.]

Couples had different ways of dealing with the challenges associated with their child's diagnosis. Anton's mother shared how she gave expression to her emotional experience and moves on from feeling sorry for herself, whilst her husbands works to escape from the reality of their child's disability. These experiences as reported on by Anton's caregivers are an indication of how daily experiences of productivity, pleasure and restoration within caregiver occupations have been known to assist with caregivers' adaptation to the caregiving task (Hsieh & Lo, 2012).

I lose the plot every now and then and I feel sorry for myself and oooooo and then I get over it again." (Anton's mother, interview, 875-876) [...ek hak so nou en dan bietjie uit en dan voel ek jammer vir myself en oooooo en dan kom ek weer daaroor.]

b)   Family and friends

As caregivers reflected on their experiences, the significant role that family and friends played in their lives became evident. Families of children with special needs "*... are affected by the condition of their near ones (Shah et al., 2010, p. 327)*". The family system comprises of different members who not only provide practical help but also emotional support. This finding is perfectly in line with the findings of Divan *et al*. (2012) who describes the family as a network of support. Receiving support is an example of how caregivers are positively influenced by their surrounding family. Caregivers shared how their family system has shown support by providing simple encouragement, practical help and advice.

> *"My brother, he encourages her a lot ..."(Ellen's mother, interview,589-591) [My broer, hy moedig vir haar baie aan ...]*

> *"... my mother helped me a lot and my friend Emmie also helped me." (Ellen's mother, interview, 161) [... my ma het mos baie vir my gehelp en my vriendin Emmie het ook vir my gehelp.]*

Friends also contributed to less supportive experiences as in the case of Anton's caregiver where friends recommended that they terminate the pregnancy. This contribution at a meso-level was experienced, as friends were being judgemental of their decision to have the baby regardless of his disability.

> *"... supporters [were] our close friends (and) medical friends ... we were obedient, we listened, to carry on with the pregnancy, but it is now time to put an end to it, basically again implying that we are irresponsible." (Anton's mother, interview, 175-177) [... ondersteuners [was] ons naby vriende (en) mediese vriende (volgens hulle) was ons gehoorsaam, ons het geluister om aan te gaan met die swangerskap, maar dit is nou tyd om 'n einde daaraan te maak, basies weer gesinspeel dat ons onverantwoordelik is.]*

c)   Faith

As caregivers process and deal with their child's disability, they also come face to face with their own beliefs regarding who and what they consider as possible influences on their own future, as well as the future of their child (Faber & Maharaj, 2005). This process often entails reflection on their personal beliefs or faith considerations. Caregivers shared how they drew

on their faith and relied on God for strength. Spiritual support is considered a coping resource (Shah *et al.*, 2010). Caregivers received support from their faith-based communities and experienced encouragement to carry on when their situations got tough. This point of interaction between caregivers and their faith community contributed to the development of resilience in caregivers, and therefore these interactions are considered as effective (Swart, 2012).

> *"… I have spiritual support from a small group of women who together do inner healing and guidance of people in difficult situations … we support each other, we talk, we pray together …" (Anton's mother, interview, 893-896) [... ek het geestelike ondersteuning van …'n klein groepie vrouens wat saam innerlike genesing en begeleiding van mense in baie moeilike situasies doen … ons ondersteun mekaar, ons praat, ons bid saam ...]*

> *"God helped us and gave us strength. I prayed a lot for her …" (Ellen's father, interview, 580) [God het vir ons gehelp en krag gegee. Ek het maar baie gebid vir haar ...]*

> *"Persevere, persevere." (Ellen's mother, interview, 577) [Aanhou, aanhou.]*

Anton's mother explains how her journey as the mother of a child with special needs has shaped her perception and consequently her approach to dealing with the challenges associated with having a child who requires such high levels of support. This explanation by Anton's mother illustrates how experiences at different levels of the family system work together to shape an individual (Bronfenbrenner, 1994). Caregivers' interaction with their environment and their relationships with each other played a significant role.

> *"From the beginning I was immune. I just had to develop a rhino skin, but it's just who I am … my belief, that is my anchor and not people and so I have … uhm … my husband …"(Anton's mother, interview, 494-495) [Ek was van die begin af immuun ek moes net 'n renostervel ontwikkel, dis maar net wie ek is ... my geloof wat my anker is en nie mense nie en so ek het … uhm … my man ...]*

Xu (2007) explains that caregivers' views influence their interpretation of events related to their child's disability. Caregivers sought deeper meaning from their experiences as they held

on to promises received through their faith which gave them a sense of hope for what was to come. Caregiver views and perspectives thus have a significant influence on their ability to make sense of their situation and therefore their ability to adapt, negotiate differences, manage stress, and make decisions (Zajicek-Farber, 2013).

> *"… The Lord promised us that we will be astounded by what He is going to do for Anton." (Anton's mother, interview, 831) [… die Here het ons belowe dat ons gaan verstom wees oor wat hy vir Anton gaan doen.]*

d)   Self-nurturing

Caregivers played an active role in their own well-being as they made efforts to self-nurture. Self-nurturing was an important factor in the management of personal resources which is fundamental to managing stress within the micro-system. Caregivers could identify their methods of self-nurturing and displayed personal insight as they admitted to the value and role self-nurturing plays in their lives and how it contributed to their ability to cope as caregivers of a child with special needs.

> *"Uhm … for me, I have adapted to it and I filled my life with things that feed me during the times that he is at school, so that I am okay..." (Anton's mother, interview, 874-875) [Uhm … vir my het ek aangepas daarby en ek vul my lewe met goed wat my voed in die tyd wat hy by die skool is, sodat ek ok is, ek haak so nou en dan bietjie uit en ek voel jammer vir myself en dan kom ek weer daaroor.]*

> *"What helps me so much, I play computer games. If I could not play computer games then I would probably have been a serial killer in order to cope …" (James' father. Interview 254-256) [Wat help my so, ek speel computer games. As ek nie computer games kan speel nie dan sou ek seker 'n reeks moordenaar gewees het om te kan cope ...]*

4.3.3.4   Fears, hopes and dreams

This category delved into a deeper level of caregiver experiences of their child's disability as it looked at concerns of the caregivers, their fears and the personal dreams they cherish for their child. Caregivers communicate their experience with a deep concern and sense of responsibility with which only caregivers of children with special needs could identify. There was an identifiable difference in concern based on caregivers' economic status when it came

to their child's future and provision for their child, however there was a common concern amongst all of the caregivers on an emotional level. Sub-categories to emerge are *my child's future*, *caregiver responsibility* and *personal growth*.

a) My child's future

Caregivers all communicated specific needs and hopes for their child's future, but also immediate concerns which have the potential to impact their child's future. Immediate needs were to be included in a "normal" class with higher levels of support and more individual attention. This need in particular is one that should ideally be addressed within the multi-disciplinary team, but due to the breakdown that has occurred in the relationship between James' caregivers and the school, unfortunately has not taken place.

> *"… we would like it if he could go to the normal class where he would get more attention. [We] believe that he needs a little bit of extra attention so that he can … focus …" (James's father, interview, 810) [...ons sal daarvan hou as hy na 'n normale klas toe gaan waar hy bietjie meer aandag kry. [Ons] glo hy het net daardie bietjie ekstra aandag nodig sodat hy kan … focus ...]*

Caregivers were able to identify specific educational needs of their child which could be addressed through concessions, but which were not being attended to in their current placement. An example of this was expressed by Anton's mother who had the need for her child to be able to complete his exams orally as he experiences difficulty with writing. This educational need is one that is supported by the Screening Identification Assessment and Support Policy of the Department of Education and therefore remains a future possibility.

> *"… I would like Anton to do his exams orally … they do not allow it." (Anton's mother, interview, 788) [... ek wil hê Anton moet mondelings eksamens skryf ... hulle laat dit nie toe nie.]*

In contrast to the academic needs which caregivers expressed, which were attainable, their desires for their child to be happy, accepted and to enjoy life were based on dreams onto which they held. Caregivers' expectations at this point were heartfelt and not based on their child's personal level of functioning. Caregivers could not put into words how these dreams were practically possible.

"… he must be outside and play and he must be happy. It is very important for me." (Anton's mother, interview, 754) *[… hy moet buite wees en speel en hy moet gelukkig wees. Dis vir my belangrik."*

"I dream that she must have a normal life and can communicate normally and … can be free to talk."(Ellen's mother, interview, 564) *[Ek droom dat sy moet normaal lewe en kan normaal kommunikeer en … kan vry wees om te kan gesels.]*

The caregivers however all spoke about their concerns related to their child's dependency on them as caregivers which is echoed by the findings of Markoulakis et al. (2012). Caregivers shared how their children were dependent on them for tasks of daily living and could not be left to be on their own.

"Can't do own things … drink coffee or tea or eat something, she can't make it for herself, I must make it first or give water." (Ellen's mother, interview, 525-526) *[Kan nie eie goeters doen nie … koffie drink of tee of iets eet, sy kan nie self maak nie, ek moet eers maak of water gee."*

"I feel responsible, I must do everything … help with everything. She cannot do anything without me." (Ellen's mother, interview,620) *[Ek voel verantwoordelik, ek moet als doen … alles help. Sy kan nie sonder my klaarkom nie.]*

"… we do not want him to walk to the shop alone, we will not allow him to ride down the road alone on his bike." (James' mother, interview, 927) *[… ons wil hom nie alleen laat winkel toe loop nie, ons sal nie vir hom laat fietsry in die pad af alleen nie]*

Anton's mother communicated her understanding of how he needed her in the following way:

"I am an involved mother, I have to fight for him, I must help him because if I do not do it, no one else will do it." (Anton's mother, interview, 607) *[Ek is die betrokke ma, ek moet veg vir hom, ek moet hom help want as ek dit nie doen nie, gaan niemand anders dit doen nie.]*

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Caregivers all held onto expectations and dreams for the future and believed that their child would achieve something. Ellen's caregivers had made provision for her to attend a care facility after she finishes with school, whilst Anton's caregivers were hoping that he would be able to become actively involved on their family farm. James' caregivers shared that they were not going to force him to do anything, and that it all depended on what he would want to do.

> *"... we are not going to stand in his way ... if he wants to do it." (James' father, interview, 596) [... ons gaan nie in sy pad staan ... as hy dit wil doen nie.]*

> *"I would just like to see him, say, going into computers." (James' father, interview, 689) [Ek sal net laaik om te sien dat hy sê in rekenaars in gaan."*

> *"You do not need to be able to hear to go into programming, you must just be able to type and to see on the screen, so he can also do it from home." (James' father, interview, 714-716) [Jy het nie nodig om te kan hoor om te kan programeer nie, jy moet net kan tik en kan sien op die skerm, so hy kan dit van die huis af ook doen.]*

b)   Caregiver responsibility

Caregivers communicated an understanding of the tremendous responsibility they had in caring for their child. This sense of responsibility relates to the degree to which children with special needs are dependent on their caregivers for tasks of daily living (Orelove, Sobsey, & Silberman, 2010).

> *"I feel responsible, I must do everything ... help with everything. She cannot do anything without me." (Ellen's mother, interview,620) [Ek voel verantwoordelik, ek moet als doen ... alles help. Sy kan nie sonder my klaarkom nie.]*

Caregivers' responsibility further entailed making provision for their child's adult life and this in particular contributed to caregiver concern amongst the caregivers of Ellen and James. Zajicek-Farber (2013) refers to instrumental stressors with which caregivers are faced, and one of these is the concern for the financial provision and the financial impact that the child's special needs has on the family system.

"I was worried about finances and costs." (Ellen's father, interview, 631) [Ek was bekommerd oor finansies en oor kostes.]

"And the school also does not give subsidies because my salary is too high, but my deductions are more than my salary. I bring very little home in a month ..." (James' father, interview, 544-546) [En die skool gee ook nie vir my subsidie nie want my salaris is te hoog, maar my aftrekkings is meer as wat my salaris is. Ek bring bitter min huis toe in 'n maand ..."]

Caregivers expressed concern for their child's happiness and a desire to ensure that their child would have the opportunity to live a normal life. This statement by Anton's mother expresses this desire but also illustrates the responsibility she feels in making this a reality.

"... but to me it feels Anton [pseudonym] must also be happy and have a normal childhood, I do not want to push him into a box the whole day, it makes him aggressive and unhappy." (Anton's mother, interview, 758) [... maar dit voel vir my Anton (skuilnaam) moet ook gelukkig wees en 'n normale kinderlewe hê, ek wil hom nie heeldag in 'n blik druk nie, dit maak hom agressief en ongelukkig.]

c)   Personal growth

Caregivers of children report on their personal growth as individuals as a result of having a child with special needs (Karst & Van Hecke, 2012; Zajicek-Farber, 2013). The third sub-category, that of *Personal growth* was most strongly communicated by Anton's mother and demonstrates a personal journey of reflection throughout the experiences resulting from her child receiving this dual diagnosis.

"And my life is also not the same. I have changed completely as a person because of Anton [pseudonym]. (Anton's mother, interview, 807-808) [En my lewe is ook nie dieselfde nie. Ek het heeltemal verander as mens as gevolg van Anton.]

Personal growth was primarily experienced on a micro-level and includes her relationship with God. Her experiences and hardships as a caregiver of a child with ASD and hearing loss have equipped her to make a contribution to the lives of other people through proximal processes. This therefore illustrates the impact caregivers have on their broader community as a result of their experiences and thus the reciprocal nature of system influences (Swart, 2012).

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"I have a relationship with the Lord which I did not ... know how to have such an intimacy because you are forced ... you can't turn to anybody else but to Him and He began teaching me things from his Word because I often sat with the Word to ... make sense of life and from what He says and what He teaches us and from that has come a ministry where I help many people." (Anton's mother, interview, 811-815) [Ek het 'n verhouding met die Here wat ek nie ... geweet het hoe dit is om so 'n intimiteit te hê nie, want jy word geforseer ... jy kan na niemand anderste toe draai nie as na Hom toe en Hy het vir my goed begin leer uit die Woord want ek het baie met die Woord gesit om ... sin te maak uit die lewe en uit wat Hy sê en wat Hy vir ons leer en uit dit het eintlik 'n bediening gekom waar ek baie mense help.]

The difficulty associated with the experiences of having a child with special needs was seen as part of shaping something which had value, although not faultless, and making a contribution to the surrounding community.

"But this is how diamonds are formed: deep under the earth, not that I am saying I am a diamond, definitely not, I am definitely not under any illusion regarding my shortcomings, but I think I play a role and I contribute to the community ..." (Anton's mother, interview, 828-830) [Maar dit is hoe diamante gevorm word: diep onder die aarde, nie dat ek sê ek is 'n diament nie glad nie enigesins nie, ek is glad nie onder enige illusie wat my tekortkominge betref nie, maar ek dink ek speel 'n rol en ek maak 'n bydrae in die samelewing ..."]

4.3.4   Theme three: Intervention as part of proximal processes

4.3.4.1   *Therapeutic intervention*

The third and final theme answers the sub-questions of what influences caregivers' experiences of intervention and support services after they received a diagnosis, as well as what processes these experiences took on. From the data it became apparent that caregivers did not necessarily actively seek intervention for their child, but that the referral processes led them to a crossroads of having the choice of receiving specific services. Caregivers were therefore faced with decisions around whether or not to go along with these referral processes. Deciding on a specific intervention held certain responsibilities and expectations which entailed making contributions to the intervention process. Due to the early intake age

of The School for The Deaf, interventions in all three cases were primarily school based (T1, T2 and T3) with the exception of some additional private services sought by caregivers who had the financial means to do so. It further emerged from the data that intervention and support was focused on either hearing loss or ASD respectively and not on the dual diagnosis of hearing loss and ASD.

A detailed depiction of the services and interventions received proceeding the first diagnosis of hearing loss can be seen in the timelines. Caregivers shared the following regarding their experiences of intervention services during the interviews.

a)   Intervention at school

All three children were initially referred to Carel du Toit School (a school for children with hearing loss, which takes an oral approach to intervention) by the audiologist who then confirmed that they did, in fact, have hearing loss (T1, T2 and T3). Two of the three children were identified as possible candidates for cochlear implants but none of the caregivers went with this process as they decided that it was not the best option for their families. After the possibility of the aural route and cochlear implants were investigated and found not to be the most appropriate route for the families the caregivers of Ellen, James and Anton were referred to The School for The Deaf where sign language is taught as the primary means of communication and instruction. Consequently all three children were referred to The School for The Deaf from Carel du Toit School. Ellen, James and Anton have hearing aids and in all three cases the caregivers expressed in the interviews that they had difficulty getting the children to wear the hearing aids on a regular basis. This was confirmed by information gathered during the document study and T1, T2, and T3.

At The School for The Deaf intervention started with a focus on language development. For Anton's caregivers the first opportunity presented itself through a master's student who was conducting research at the school. This meant that Anton was included in a study group that taught his caregivers techniques to teach language to infants with hearing loss. Anton's mother described their involvement as a family in this research project as helpful and meaningful.

> *"And so they naturally recommended that we follow the cochlear route and we started with the program, but we tried to find out and researched and ... once again asked for guidance again and we very strongly experienced that that was*

not the route for us to follow ... we then came to [The School for The Deaf] and there was coincidentally a girl who was doing her master's degree ... it was language development in deaf children." 329-335 *[En toe het hulle nou natuurlik ja aanbeveel dat ons die koglêre ... pad stap en ons het met die program begin, maar ons het redelik probeer uitvind en oplees en ... weer leiding gevra en ons het ervaar baie baie sterk dat dit nie die roete vir ons is om te stap nie ... ons het toe [na Die Skool vir Die Dowes] toe gekom en daar was toevallig 'n meisietjie wat besig was met haar meestersgraad ... dit was taalontwikkeling by dowe kinders.]*

Children first start school at The School for The Deaf at the age of three years. In the preschool years there is a focus on language development which happens to be beneficial for children with ASD as well (Myck-Wayne *et al*., 2011).

Other therapies offered at The School for The Deaf included occupational therapy as well as speech therapy and although reference was made to these therapies caregivers could not give details around the focus of intervention or give an indication of when or at what stage these therapies were received. Therefore, although therapies were received caregivers did not form part of the intervention process, and for whatever reason, did not have input in this process. Therapies form an important part of the intervention process and have significant benefits for the child's development (Orelove *et al*., 2010) and therefore the caregiver and family system. This lack of involvement of caregivers in the child's therapy could be evidence of a break-down in the relationship between the caregiver and the school at a meso-system. Taking into consideration the importance of caregiver involvement in the intervention process in order to achieve optimal outcomes for the child and family makes this an area of concern (Easterbrookes & Handley, 2006).

"There at the school he received speech I am not sure if he received occupational therapy, I think he did, but I am not sure, I can't remember." (James' mother, interview, 567-568) [Hy het daar by die skool het hy spraak ek is nie seker of hy arbeidsterapie gekry het nie, ek dink hy het, maar ek is nie seker daarvan nie, ek kan nie onthou nie.]

> *"I did not always receive feedback in the report of therapy that they wrote about ..." (Ellen's mother, interview 520) [Ek het nie altyd in die rapport terugvoer gesien van terapeut wat hulle daar geskryf het ...]*

Bronfenbrenner (1994) refers to the family system as the most effective system for fostering and sustaining the development of a child. The involvement of the caregivers as active participants in intervention is critical for the success of the intervention which makes their participation an area of concern.

b)   Private intervention

Anton received private therapy from an occupational therapist as well as a physiotherapist. These services where paid for by his caregivers. Anton's mother explains that because Anton is primarily deaf, communication posed challenges to the therapeutic work by these therapists. It appeared from the interview with Anton's mother and T3 that therapies did not deliver the desired outcomes. This was also true for James's caregivers as he could not be fully assessed due to communication and behavioural difficulties (document study and T2). Therapists who were focussed on assessment and intervention within their domains required further training and skills to address these children's communication needs.

> *"... and because he is deaf it is so restricted because he is so completely deaf he cannot hear anything, I think he would ... be able to do well at a school for children with learning disabilities like Alta du Toit ... there are schools, special schools but because he is deaf, he is primarily deaf." (Anton's mother, interview 723-726) [... en omdat hy doof is, is dit so beperk want hy's ingrypend doof hy kan niks hoor nie, ek dink hy sal ... goed kon doen in 'n skool vir kinders met leergestremdheid soos Alta du Toit ... daar is skole, spesiale skole maar omdat hy doof is, hy is primêr doof.]*

Anton also received private swimming lessons of which the benefits could be seen at school. These swimming exercises took place once a week and the effects thereof were evident in different settings, including school. Teachers reported that it increased his participation in Life Orientation at school and improved his self-confidence and body consciousness.

> *"... it is now also only once a week ... it has helped a lot with his self-confidence ..." (Anton's mother, interview 536-537) [... dit is ook nou maar net een maal 'n week ... dit het baie gehelp met sy selfvertroue...]*

> *"... and they say at school they can see that he has changed a lot regarding his ... body consciousness, he participates more in Life Orientation and he has more self assurance ..." (Anton's mother, interview 539-541) [...en hulle sê hulle kan sien by die skool hy het baie verander rondom sy ... body consciousness, hy neem baie meer deel aan die Lewensorientering en hy het baie meer selfversekering ...]*

Anton's caregivers' sought interventions that would address the ASD-specific challenges he was experiencing. This led them to a principal of a private school who trains tutors to facilitate children with ASD. They started with the programme offered by the private institution, but realised that it was not a good fit for their family and that they could not keep up with the demands of the programme. This was an important realisation as caregivers' emotional resources were taxed to the point where participation in this programme was no longer sustainable in the family system and therefore it was discontinued. This proximal process therefore could not sustain development (Swart, 2012).

> *"... it's nearly as if she doesn't see the child as an individual, she has this determination ... It felt to him as if everything was about money for her ... the child must get into this program and he must eat these foods ... your whole life is taken over by this program that you have to follow and this food that you must eat and we really gave it a go ..."(Anton's mother, interview, 499) [... dis amper asof sy nie die kind as 'n individu sien nie, sy het hierdie dryf ... Dit het vir hom gevoel dit gaan als oor geld by haar ... die kind moet in hierdie program kom en hy moet hierdie kosse eet ... jou hele lewe word oorgeneem deur hierdie program wat jy moet volg en hierdie kos wat jy moet eet en ons het dit regtig 'n go gegee ...*

Anton's caregivers came to realise that part of the reason for this particular programme not being successful was that he had multiple disabilities of which the ASD traits were only one aspect. Being happy and fulfilled was part of the desired outcome for the caregivers and achieving this outcome was not prioritised in the programme. Consequently, this programme

did not address the needs of the family system as a whole and adherence to it was unattainable (Ross & Deverell, 2014).

> *"... he is also not purely autistic ... so what works for autistic children also does not precisely work for him ..." (Anton's mother, interview, 747-748) [... hy is ook nie suiwer outisties nie ... so wat werk vir outistiese kinders werk ook nie presies vir hom nie ...]*

Although this process was disrupted and the intervention was short lived, it led to the realisation that Anton required a facilitator in order to learn optimally. The outcome of the interaction of this particular proximal process was positive and helpful regardless of the fact that it took an alternative turn.

> *"I nearly want to say that this is our intervention: it's Rebecca [pseudonym, facilitator]. Rebecca is this constant stability in his life which has now accompanied him for a few years ..." (Anton's mother, interview, 773-778) [Ek wil amper sê dis ons intervensie: dis Rebecca [skuilnaam, fasiliteerder]. Rebecca is hierdie konstante stabiliteit in sy lewe wat nou al 'n paar jaar saam met hom kom ...]*

4.3.4.2   *Health and medical*

The category of *health and medical* emerged early on during the individual interviews with the caregivers. These caregivers' first experiences of challenges were related to the health of their children (T1, T2 and T3) and alerted them to the possibility that their children could require special intervention in the future. From this category of *health and medical* three sub-categories, namely *child's health*, *medical opinions* and *medication,* were derived.

a)   *Child's health*

Ellen and Anton's caregivers reported that they were faced with issues and concerns due to the health of their children. These concerns appeared soon after their births and were a source of significant distress within the caregiver system. As Ellen's caregivers reflected on her birth they now realise that they noticed a delay in her development, but unfortunately they remained unaware of the extent or nature of what they observed.

> *"... the baby very heavy because her neck was very floppy ..." (Ellen's mother, interview, 122) [... die baba baie swaar want haar nek was baie pap ...]*

As was discussed in Theme 1 Anton's caregivers were alerted to the fact that he would be born with Rubella Syndrome and although their doctors advised them to abort their child, they decided to continue with the pregnancy. After expecting the worst, Anton's caregivers were surprised at how the situation had turned out. Although Anton was born prematurely and therefore was a small baby he did not require immediate surgery or invasive medical procedures. He did, however, experience difficulty feeding due to the suck reflex being absent and therefore he needed to be tube fed. Anton's health needs had a significant impact on his mother as she worked hard to see to his needs. She experienced this as stressful and as a result her milk production was negatively affected. This example illustrated the impact of the child's health on the well-being of caregivers (Ross & Develell, 2014).

> *"... sat and literally dripped the milk for a half hour to an hour every two ours ... I basically fed and expressed (milk) for the first two months of his life, yes, then he started suckling later, but he struggled, and I did not have much milk I think I was stressed and probably tired ..." (Anton's mother, interview,249-252) [... sit letterlik en daardie melktjies indrup vir 'n halfuur na 'n uur toe elke twee uur ... ek het basies gevoed en (melk) gepomp vir die eerste twee maande van sy lewe, ja, toe het hy begin suig later maar hy het gesukkel, ek het ook nie baie melk gehad nie dink ek was gespanne seker en moeg ...]*

Ellen and James were both the first children of their caregivers. The caregivers described how they did not know what to expect and often did not know that what they were experiencing was problematic. This experience would be different had the caregivers been offered support as first-time parents and given the opportunity to discuss their concerns with someone from outside the family.

> *"It was our first baby ... how should you know?" (Ellen's mother, interview, 178-179) [Dit was ons eerste baba ... hoe moet jy weet?]*

> *"Biggest mistake of all, because if we had known at that time that they do not do hearing tests, then we would rather have gone to Panorama, but what did we know at that time? We didn't know, we did not initially ask such questions."*

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(James' caregivers, interview,119) [Grootste mistake van alles, want as ons daardie tyd geweet het hulle doen nie gehoortoetse nie, dan het ek eerder Panorama toe gegaan, maar wat het ons nou geweet daardie tyd? Ons het nie geweet nie, ons het nie sulke vrae gevra vooraf nie.]

b)   Medical opinions

Typically after receiving a diagnosis caregivers experience an enthralling need for information (Hornby, 2000). This was also the case with Ellen's caregivers who sought advice from their GP who was not knowledgeable or trained to address their questions regarding possible causes or treatment for ASD. Caregivers turned to a professional whom they trusted, but experienced frustration at receiving no answers or having to wait for feedback. In contrast to Ellen and Anton's caregivers who sought information after the ASD diagnosis of their child, James' caregivers did not ask for information.

"I talked to my GP. [He said] Ellen is autistic, but he knows nothing. He said he doesn't know autism and doesn't know how to help us." (Ellen's mother, interview, 375,376) [Ek het met my huisdokter gepraat. [Hy het gesê] Ellen is outisties, maar hy weet niks. Hy sê hy ken nie outisme nie, hy weet nie hoe om vir ons te help nie.]

It feels as if you ask … ask the doctor and he doesn't have answers." (Ellen's mother, interview, 384) [Dit voel jy vra vra vra vir die dokter gevra en hy het nie antwoorde nie.]

c)   Medication

James' caregivers had a long battle with the school regarding the use of medication for the treatment of symptoms associated with Attention Deficit Hyperactive Disorder in James (T2). They felt pressured to give consent for him to take medication. His caregivers were concerned that the medication would change his personality. They however report never having seen James on the medication.

"Yes we were against Ritalin …" (James' caregivers, interview, 392) [Ja ons was teen die Ritalin ...]

"... we refused to give at home, they fought with us for two or three years about the Ritalin stuff." (James', interview, 418,419) [... ons weier om by die huis te gee, hulle twee of drie jaar met ons baklei oor die Ritalin-goed.]

"... a person reads a lot of scary stories about Ritalin so ..." (James' caregivers, interview, 426,427) [... 'n mens lees 'n klomp scary stories oor die Ritalin so ...]

"Man, they (the school) also threatened that they were going to keep him back in the small school if we did not give him Ritalin, he would not progress and such things." (James' caregivers, interview, 447,448) [Man, hulle (die skool) het ook gedreig hulle gaan hom agterhou in die klein skooltjie as ons nie vir hom die Ritalin gaan gee nie, hy gaan nie vorder en sulke goed nie.]

In the end his caregivers succumbed to the school's request hoping that he would be able to improve the quality of his school work. This report of James' caregivers' experience is concerning. Perceived pressure and threats that James would fail without the medication is a further indication of a breakdown in the caregiver-school relationship at the meso-level (T2).

Anton's caregivers also refer to their experience of the use of medication. However, they told of its benefits, despite their feelings of not wanting him to be on medication. Their report on their experience speaks of two-way communication and a shared decision-making process between themselves and the doctor who prescribed the medication.

Yes, he is on (medication), sadly ... it is a terrible thing for me. I do not like it, but I have him on Risperdal, because he can't use Ritalin at all. It makes him much worse." (Anton's mother, interview 689-690) [Ja, hy is op (medikasie), ongelukkig ... dit is vir my 'n vreeslike ding. Ek hou nie daarvan nie, maar ek het hom op Risperdal, want hy kan die Ritalin glad nie gebruik nie. Dit maak hom nog erger.]

"And so he said he had read about it and they have found that such children react very well to Risberdal and Risberdal is actually an antipsychotic substance and it has made him much more calm." (Anton's mother, interview 703-705) [En toe het hy gesê hy het baie opgelees daaroor en hulle vind dat sulke kindertjies

reageer goed op Risberdal en Risberdal is mos eintlik 'n anti-psigotiese middel en dit het hom baie rusteriger gemaak.]

4.3.4.3   School

The School for The Deaf played a significant role in providing support and intervention to the caregivers. The school support team consisted of a social worker, an occupational therapist, a psychometrist, a physiotherapist and a teacher. The principal was also considered as a major role player in the school support team. Caregivers shared their experiences of support and intervention received from the school's multidisciplinary team. Interventions discussed are confirmed by the timelines (T1, T2 and T3) as well as the individual interviews.

a)   School as support

All three children started school at a young age and whilst considering the benefits of starting intervention as soon as possible, at times caregivers found the demands of early intervention challenging. Ellen formally started school when she was three years old, whilst James and Anton started attending the pre-school full time when they were four years old. Anton's caregivers first contacted The School for the Deaf on the recommendation of Carel du Toit School. His caregivers were invited to take part in a research project done by a master's degree student. Anton's caregivers were included in the parent support group which focused on teaching caregivers skills to develop language in infants with hearing loss. Anton was six months old at that stage. This experience is indicative of the positive effects of interactions between The School for The Deaf and tertiary institutions, thus proximal processes within the exo-system. The willingness of The School for The Deaf to allow university students to conduct researchers at their school benefitted Anton's caregivers.

> *"Yes, she helped us a lot at that stage how to communicate with him ..." (Anton's mother, interview 370) [Ja, sy het ons baie gehelp op daardie stadium hoe om te kommunikeer met hom ...]*

i)   Principal

The principal of The School for The Deaf was considered a beacon of support by Anton's caregivers as the principal acted as administrator of the intervention process and ensured regular meetings to discuss Anton's progress at school. This was however not reported on by Ellen's or James' caregivers which alerted the researcher to the nature of interaction and the

relationship between The School for the Deaf and Anton's caregivers. Although the reason for this is unclear, the principal's reported interest in and passion for his learners was noted.

> *"… the principal accommodated us, I must say, he's a tremendous help and a pillar of strength for us and for many of the teachers at the school, so we are wonderfully accommodated." (Anton's mother, interview, 611-613) [… die hoof het my baie geakkommodeer, ek moet sê, hy's 'n geweldige hulp en 'n steunpilaar vir ons en baie van die onderwysers by die skool, so ons word wonderlik geakkommodeer by die skool.]*

> *"… he has a passion for each child, to him each child is unique and a challenge and he wants to develop each child at the school to his maximum potential." (Anton's mother, interview, 572-573) [… hy het 'n passie vir elke kind, elke kind is vir hom uniek en 'n uitdaging en hy wil elke kind tot op sy maksimale potensiaal ontwikkel.]*

Anton's caregivers had regular difficult conversations with the school regarding Anton's progress. Questions regarding whether Anton was indeed in the most appropriate setting where his needs would be addressed optimally were raised. The evaluation of the success of intervention and methods of support could be experienced as challenging. However, the benefits outweighed the effort and meant that Anton achieved growth within the school context. Evaluating the success of the intervention in the multi-disciplinary team is a continuous process.

> *"At one stage we told him we were going to place everything on the table and tell each other: is Anton in the right place? Can you accommodate him?" (Anton's mother, interview, 557-558) [Ons het vir hom op 'n stadium gesê ons gaan moet alles op die tafel sit en vir mekaar sê: is Anton op die regte plek? Kan julle hom akkommodeer?] …"*

> *"Yes, we had many such discussions. We still have these discussions. At least twice a year we sit around the table with the whole department, all those who are involved, all the role players of Anton, his assistant, the audiologist, the school psychologist, some of his teachers and the principal, they accommodate us …" (Anton's mother, interview, 559-562) [Ja, ons het baie sulke gesprekke gehad.*

> *Ons het nou nog hierdie gesprekke. Ten minste twee maal 'n jaar sit ons met die hele departement, al die betrokkenes, al die rolspelers van Anton, sy assistent, die oudioloog, die skoolsielkundige, van sy onderwysers en die hoof sit ons om die tafel, hulle akkommodeer ons ...]*

ii)   Class for children with multiple-disabilities

A significant contribution made by The School for The Deaf was the piloting of a class for children with multiple disabilities. When the principal noted that there were children who were experiencing similar challenges and were not getting the support and intervention that they required, he met with his staff to devise a plan. The boundaries of the school system were flexible enough to allow for change as required in order to provide support (Swart, 2012).

> *"... the school declared themselves prepared to start a band for autistic deaf children which was fantastic ... there were many children ... that actually has the same problem which has not been diagnosed and which is not accommodated by the school." (Anton's mother, interview 508-513) [... die skool het toe hulle self bereid verklaar om 'n baan in die skool te begin vir outistiese dowe kinders wat fantasies was ... daar was baie kinders ... wat dieselfde probleem eintlik het, wat net nooit diagnoseer is nie en wat nie akkommodeer word by die skool nie.]*

iii)   Teachers

The School for The Deaf could further provide support to caregivers of children with this dual diagnosis due to the level of special-needs training the teachers had. This impacted on their ability to identify signs related to ASD which led to caregivers receiving a diagnosis of ASD.

> *"... she did special education ... she was on top of it, she really helped us." (Anton's mother, interview, 477) [...sy het spesiale onderwys ... sy was baie oulik gewees, sy het ons regtig baie gehelp.]*

Accurate identification of symptoms and the subsequent diagnosis of ASD within the deaf environment meant that further intervention strategies to address ASD-specific behaviour could be put in place across the home and school environment.

> *"... she played a big role yes to help us realize, but we are not only going to walk this route." (Anton's mother, interview, 479) [... sy het 'n baie groot rol gespeel, ja, om vir ons te help besef, maar ons gaan nie net hierdie roete kan stap nie.]*

> *"... uhm begin accommodating around it, specifically you know [around autism] ..." (Anton's mother, interview 523) [... uhm begin akkommodeer rondom dit, spesifiek jy weet (rondom outisme) ...]*

Caregivers were indirectly supported by teachers' intervention and guidance in the classroom, of which the effects could also be felt in the home context. Routine and firm, but loving discipline offered the caregivers and children security within the classroom context. This serves as an example of support in the exo-system.

> *"Unyielding routine and discipline ... not like losing the plot like there is no way that you are going to tell me what to do, I am going to tell you what to do and you are going to slot in with that with love." (Anton's mother, interview, 361-363) [Onwrikbare roetine en discipline ... nie soos uithak nie soos aanhou soos daar is nie 'n manier wat jy vir my gaan sê wat om te doen nie, ek gaan vir jou sê wat om te doen en jy gaan inval daarby en met liefde.]*

Reference made to one teacher in particular explains the manner in which her approach to the classroom situation offered guidelines and support, were experienced as life changing.

> *"... I am telling you she saved those children's lives, everyone in the school talks about what happened with those children." (Anton's mother, interview, 737-738) [...ek sê jou sy het daardie kindertjies se lewe gered, almal in die skool praat van wat het met daardie kinders gebeur het]*

The psychometrist/ counsellor of the multi-disciplinary team provided support to caregivers on an individual basis and supported caregivers as they worked towards resolving problems related to their children's disability within the school context. This support stretched across the chrono-system as support was on-going and entailed intervention at different stages of caregiver experiences.

> *"I often asked for her advice about problems at the school, what I should do …"*
> *(Ellen's mother, interview 344) [Ek het baie keer vir haar vir raad gevra oor*
> *probleme by die skool, wat moet ek doen ...]*

Anton's mother was the only caregiver to express her appreciation for the manner in which the school and teachers supported Anton and their family. Interestingly, her level of involvement and participation in the intervention and support services correlates with her level of appreciation for the services received.

> *"It was quite unbelievable how they really went out of their way to accommodate*
> *us …" (Anton's mother, interview, 546) [Dit was ongelooflik hulle het regtig uit*
> *hulle pad gegaan het om ons te akkommodeer ...]*

b)   Challenges experienced within the school context

Along with the support caregivers received within the school context which positively influenced their experiences, they shared some challenging situations which presented within the school context.

i)   Young school starting age

In contrast to the benefit of early intervention were the sacrifices caregivers needed to make in order for their child to attend The School for The Deaf. For Anton's caregivers this entailed moving to a town where they did not want to live, in order for him to be able to attend school (T2). The diagnosis of Anton's hearing loss and subsequent intervention required, influenced the family system as a whole by the necessity to relocate.

> *"... he (Anton's father) did not want to come here and he tried everything, but*
> *when he saw it was not working out ... he gave in, then we relocated, yes."*
> *(Anton's mother, interview 418-419) [... hy (Anton se pa) wou nie hiernatoe kom*
> *nie en hy het alles probeer, maar toe hy sien dit werk nie uit nie ... toe het hy nou*
> *maar bes gegee, toe het ons getrek, ja.]*

For James' caregivers it meant sending their child to the school's residence from a young age which meant that they could only see him on weekends. Being separated from their son had an impact on the proximal process of the relationship between caregivers and child.

> *"He was in a hostel from the age of four … I don't know how it must've felt for him … for us it was quite bad." (James'mother, interview, 32-33) [Hy was van die ouderdom van vier jaar oud in 'n koshuis gewees … ek weet nie hoe dit vir hom moes gevoel het nie … vir ons was dit nogals erg gewees …]*

ii)   Communication

The working relationship between the caregivers of Ellen and James and their teachers were significantly influenced by poor communication. Ellen and James' caregivers experienced the feedback received from their children's teacher as unhelpful and they did not feel that the comments made about their children were fair and could not identify what the teacher was referring to. This created a sense of frustration and resentment amongst these caregivers, which had a negative influence on the proximal process between caregiver and the teacher.

> *"Yes, Mrs van Rooyen (pseudonym) was her class teacher … there is a message book that goes between home and school and she wrote things in the book which I could not accept." (Ellen's mother, interview, 265) [Ja, mev van Rooyen (skuilnaam) was haar klasonderwyseres … daar is 'n boodskapboek wat tussen die huis en die skool gaan en sy het daar goed geskrywe wat ek nie kon aanvaar nie.]*

> *"… from all the letters that have always been received at home about him say he is naughty, he is disobedient, he does not listen …" (James' mother, interview, 20-22) […van wat ek altyd die briewe so huis toe kry van hom wat hulle sê hy is stout, hy is ongehoorsaam, hy wil nie luister nie …]*

iii)   Teacher and classroom dynamics

James' caregivers tried to make sense of the classroom situation and the feedback they were receiving from the teacher through conceptualising what they thought the cause of the problem was. This was done without interaction with the teacher by making assumptions about what the classroom situation entailed. This attempt to make sense could be seen as an attempt to gain autonomy. Unfortunately, this situation further indicated a break in communication between the caregivers and the teacher, which prevented effective collaboration within the team approach. Although the initial communication referenced the child's problematic behaviour, intervention was not put in place.

>*"What I think is the problem in today's schools, normal schools also, there are too many children in one class and the teacher can't pay attention …"(James' mother, interview, 493-494) [Wat ek dink wat die probleem is vandag se skole, gewone skole ook, daar is te veel kinders in die een klas en die juffrou kan nie aandag gee …]*

>*"His attention is easily distracted in class and they don't have time for that." (James' mother, interview 492) [Sy aandag lei baie rond in die klas … en daarvoor het hulle mos nie tyd nie.]*

This breakdown in communication led to James' caregivers extracting themselves from communication with the school. It has been three or four years since they last contacted the school.

>*"It can be three, four years, yes …"(James' mother, interview, 753) [Kan wees dit is drie, vier jaar, ja …]*

Important decisions such as the transitioning from the academic stream to the class for multi-disabled were deliberated on by the multi-disciplinary team. When communication is disrupted and the working relationship is compromised, caregivers can experience being left out of this process. James' caregivers could not recall the reasons for him being placed within the classroom for children with multiple disabilities.

>*"They didnt really tell us, just said that the teacher could not help him in the normal class …" (James' mother, interview, 488) [Hulle het nie vir ons rerig gesê nie, hulle het net gesê in die gewone klas kan die juffrou nie vir hom help nie …]*

A team approach entails trial and error in seeking the most appropriate intervention and support and through deliberation. The multi-disciplinary team is able to evaluate the effectiveness of interventions and determine which changes are required in order to achieve the outcomes that the multi-disciplinary team had set. In contrast to James' caregivers who sought more individual attention for their child, Anton's caregivers found that individual attention could be a problematic experience.

"... they then appointed a special teacher and she mothered and smothered him for a year on her lap and he twisted her around his pinky and it was a terrible year because nothing happened during that year in Anton's life ... she loved him so much, but she was not good for him ..."(Anton's mother, interview, 729 – 732) [... hulle het toe 'n spesiale juffrou aangestel en sy het hom gemother en gesmother vir 'n jaar op haar skoot en hy het haar om sy pinkie gedraai en dit was 'n verskriklike jaar want daardie jaar het daar niks in Anton se lewe gebeur nie ... sy was so lief vir hom, maar sy was nie goed vir hom nie...]

Children with special needs present with unique challenges and abilities which influence the dynamics within the classroom, which in turn influences the learning environment of each child. These dynamics should be carefully considered when devising strategies to support the child with a dual diagnosis. Anger and behavioural issues were repeatedly identified as areas of concern for the caregivers of these three children and further presented within their classroom context.

"... the Grade 5 class [sigh] was actually one of those all of whom are together now who were identified as enormously difficult children, they are all boys who all have anger issues ..." (Anton's mother, interview, 617-619) [... die Graad-5 klassie [sug] was eintlik, almal van hulle wat nou saam is, was geïdentifiseer as geweldige moeilike kindertjies, hulle is almal seuntjies, hulle het almal anger issues ...]

Communication between school and caregivers is an important aspect. When communication breaks down it is problematic and affects the level of support and intervention which is able to take place. Communication can be influenced by different factors. For James' caregivers the relationship with James' teachers and carers in the residence was crucial for effective communication. A further break in communication was the result of the family living far from the school, and when problems arose at school or his caregivers became aware of problems the caregivers were not be able to get to the school for meetings with the teachers.

"We live too far. I mean they want to see us when we phone. How does that help? ..." (James' mother, interview, 789) [Ons bly te ver. Ek meen hulle wil ons sien as ons bel. Wat help dit nou?]

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4.4   CONCLUSION

The research findings indicated that a dual diagnosis of ASD and hearing loss is a complex diagnosis and caregivers are faced with many challenges as they seek the most appropriate interventions for their children. The complexity of the experiences and needs, not only of children with this dual diagnosis, but also of their caregivers who are considered as the project managers of their intervention programmes, was highlighted. Children remain unique and intervention directed towards developing the child with such a dual diagnosis should remain flexible and focus on the needs of the family. The intervention should therefore first and foremost be family centered.

The focus of the current study was to explore caregiver experiences. The bio-ecological perspective proved to be effective in illustrating how the situations which occurred at multiple levels as caregivers received a dual diagnosis of ASD and hearing loss, along with the appropriate intervention and support services, influenced their experiences.

The findings indicated that the relationship between the school and caregivers played a significant role in the effectiveness of intervention services, as well as the follow through of caregivers. Without communication as the foundation, effective collaboration between caregivers and the rest of the multi-disciplinary team could not be achieved.

4.5   STRENGTHS AND LIMITATIONS OF THE STUDY

The nature and the structure of the research design allowed the researcher a rare glimpse into the life world of caregivers of children with a dual diagnosis of ASD and hearing loss. The researcher gained insights into caregivers' experiences of diagnosis of and intervention for their children, which resulted in the formulation of recommendations to professionals in order to offer support that is more specific and relevant to the needs of such families. These recommendations are therefore important as they add value to the field of special needs and the lives of caregivers of children with a dual diagnosis of ASD and hearing loss.

Furthermore this study allowed caregivers the opportunity to share their experiences and to reflect on their own process and growth throughout this process. This study highlighted the important role caregivers play and recognised the short comings of interventions and support provided to caregivers in order to improve these services.

Limitations of the study which the researcher felt were necessary to mention relate to the fact that the children of the participating caregivers were all from the same school. Caregiver

experiences are unique. One can understand that these experiences cannot reflect the experiences of all caregivers of children with a dual diagnosis of ASD and hearing loss across the country.

Although qualitative research studies often have small sample sizes, the primary limitation of this research study relates to the narrow scope and small sample size. Although the research study focused on gaining an understanding of caregiver experiences, and therefore used data collection methods which aimed at gaining insight into their meaning-making, the use of additional methods may have enhanced the research findings. The use of a focus group may have created the environment and opportunity for caregivers to have shared perceptions and points of views around their experiences of receiving a diagnosis and intervention which they feel is helpful. Possible suggestions for professional service providers on how to improve services offered could be offered whereby caregivers could validate and confirm the research findings and recommendations.

4.6 RECOMMENDATIONS TO PROFESSIONALS BASED ON THE RESEARCH FINDINGS OF THIS STUDY

In order to provide effective intervention and support services to caregivers of children with a dual diagnosis, a positive relationship between the service provider or professional and the caregivers need to be established (Orelove *et al.,* 2010). It is important that the professionals who work with caregivers seek to gain an understanding of the family system and have knowledge of how the family system functions. This includes the consideration of the family within its context with its influencing systems. A further consideration professionals should keep in mind is that participation of the caregivers with service providers is influenced by the structure and characteristics of the family. The following recommendations were formulated through the consideration of caregivers' experiences of diagnosis and intervention for their child with a dual diagnosis, as derived from the research findings.

4.6.1 When sharing the diagnosis

- When the diagnosis is first made and information is shared with caregivers it is important that the child's caregivers receive the news simultaneously.
- Professionals should honour the scope of practice of their profession as set out by the Health Professions Counsel of South Africa (HPCSA) and only make a diagnosis if they are qualified to do so.

- All information shared with the caregivers during the diagnosis should be provided to them in written format and in their mother tongue, such as a booklet, to be taken home to read when they are ready to do so.

- Questions and concerns raised by caregivers during the diagnosis should be addressed clearly and at the level of the caregivers' understanding in terms of their communication modality. Professionals should make medical terms accessible to caregivers by defining medical terms in every-day language.

- Allow caregivers time to process the initial diagnosis and be respectful of responses such as shock and possible denial. Processing these emotions form an important part of the process of accepting the diagnosis.

- When encountering possible denial consider caregivers' level of readiness for more information and reflect on the possible hurt caregivers are experiencing due to the nature of the diagnosis and the impact on their lives.

- Caregivers' views, values and beliefs should be explored and respected as part of their inherent ability to process their experiences.

- Ensure that first-time caregivers have access to a contact caregiver (someone who has gone through a similar experience) who would be able to share their experiences with them.

- Investigate caregiver perceptions of causes of ASD in order to dispel misinformation through providing sound information and further to address self-blame by caregivers.

- Professionals should ensure that they are knowledgeable and informed on issues related to hearing loss and ASD.

- Caregivers should be invited and encouraged to make contact with the professional who made the diagnosis and to schedule an appointment to meet again to discuss concerns and questions that might have surfaced as they had time to consider and process all the information. Professionals should prioritise following up with caregivers, should the caregivers not initiate the contact within a reasonable time.

- Understand that parenting a child with special needs is accompanied by special demands which caregivers are not necessarily prepared to meet at the time of the initial diagnosis. As parents navigate their way through this unexpected and non-normative situation which was previously unknown to them, they are faced with the enormous challenges of having to adapt.

- Adapting to having a child with multiple special needs is an on-going process which is renegotiated as the needs of the family evolve and the child with special needs develop.

4.6.2 When initiating or advising on possible intervention and support services for the family with special needs

- Caregivers should be considered as the central role players in the intervention and support process. They should be supported and equipped to fulfil this role.

- Caregivers should be included in all intervention and support services and their involvement should be matched with their available resources and emotional capacity to fulfil their role.

- Professionals should consider how a child with special needs forms part of a family that consequently has special needs.

- Identify intervention programmes within the community that caregivers find themselves in, in order to enable caregivers to build informal support networks throughout the process of intervention.

- Therapeutic support for caregivers should acknowledge complex emotional experiences such as guilt and feelings of anxiety. These emotions should be normalised and the opportunity for emotional expression be allowed.

- Manage the expectations of caregivers in terms of input into their child's development according to their unique capacity and to the degree that their personal and material resources allow.

- Factors that influence the family system should continuously be acknowledged throughout the process of intervention. Support to caregivers should entail offering a sounding board for reflection regarding the impact of these factors in order to create awareness.

- Strengths within the family system should be identified and utilised to support the outcomes of intervention and support endeavours.

- Areas of challenges which impede the effectiveness of intervention and support should be identified and discussed with caregivers in order to identify the extent to which personal and material resources might be redirected in this area and the required support be identified that could assist caregivers in reaching their family goals.

- Provide practical resources to support caregivers as they manage behavioural challenges posed by their child. Recognise existing endeavours by caregivers to manage their child's behaviour.

- Acknowledge challenges associated with the tasks of daily living and provide time to discuss these concerns.

- The option of medication is a sensitive subject and should be considered by a medical doctor within the team approach in consultation with caregivers. The well-being of the child and family within their context should be considered the primary focus in this process and the desired outcomes and goals as set by the caregivers and the team should be the driving force in making this decision. It is important that all concerns and questions of caregivers related to medication be addressed, and information regarding all options should be provided to them. The final decision remains that of the caregivers, and regardless of what their decision is, the multidisciplinary team should remain respectful of this decision and should remain supportive of the child and his or her caregivers.

4.6.3 When considering school and classroom placement

- Caregiver participation in school activities enables caregivers to get a sense of their child's participation in the school community. This conveys the message to their child that school participation is important.

- The school community should be a source of support, and promoting this relationship in order for this to be a reality is important to the well-being of the whole family.

- The relationship between caregivers and teachers should be underlied by effective and supportive communication. Therefore regular contact should be promoted and it should preferably be in the form of a conversation or face to face meeting. The use of language which promotes a team approach for supporting the child is advised. Caregivers and teachers are team members on the same team, working towards a unified goal.

- Desired outcomes and goals should be negotiated and should promote the well-being of the family system.

- Outcomes should be evaluated regularly in order to adjust the intervention and support to meet the needs of the child and caregivers.

- The school system should strive towards being respectful of decisions made by the the caregivers to promote family well-being and support caregivers in their endeavours and decisions.

- Interventions within the school context for children with a dual diagnosis should be aimed at focusing on the specific individual needs of the child, rather than on specific disability labels.

- Intervention services for children with a dual diagnosis of ASD and hearing loss should be focussed on the child as a whole being and not be fragmented. ASD and hearing loss interventions should be combined.

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ADDENDA

ADDENDUM A: LETTER OF ETHICAL CLEARANCE BY THE RESEARCH ETHICS COMMITTEE

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

Approval Notice
Stipulated documents/requirements

16-Jan-2015
de Villiers, Ayesha A

Proposal #: DESC/DeVilliers/March2014/7
Title: **Dual diagnosis of autism and hearing loss: caregivers'experience of diagnosis and intervention.**

Dear Ms Ayesha de Villiers,

Your **Stipulated documents/requirements** received on **08-Jan-2015**, was reviewed by members of the **Research Ethics Committee: Human Research (Humanities)** via Expedited review procedures on **16-Jan-2015** and was approved.
Sincerely,

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

ADDENDUM B: WCED RESEARCH APPROVAL LETTER

Western Cape Government
Education

Directorate: Research

Audrey.wyngaard@westerncape.gov.za
tel: +27 021 467 9272
Fax: 0865902282
Private Bag x9114, Cape Town, 8000
wced.wcape.gov.za

REFERENCE: 20140214-24773
ENQUIRIES: Dr A T Wyngaard

Mrs Ayesha De Villiers
13 Amberfield Way
Amberfield Estate
Pinehurst
Durbanville
7550

Dear Mrs Ayesha De Villiers

RESEARCH PROPOSAL: DUAL DIAGNOSIS OF AUTISM AND HEARING LOSS IN A SOUTH AFRICAN CONTEXT: CAREGIVERS' EXPERIENCES OF DIAGNOSIS AND INTERVENTION

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:
1.   Principals, educators and learners are under no obligation to assist you in your investigation.
2.   Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3.   You make all the arrangements concerning your investigation.
4.   Educators' programmes are not to be interrupted.
5.   The Study is to be conducted from **22 January 2015 till 30 March 2015**
6.   No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
7.   Should you wish to extend the period of your survey, please contact Dr A.T Wyngaard at the contact numbers above quoting the reference number?
8.   A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
9.   Your research will be limited to the list of schools as forwarded to the Western Cape Education Department.
10.   A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
11.   The Department receives a copy of the completed report/dissertation/thesis addressed to:
           The Director: Research Services
           Western Cape Education Department
           Private Bag X9114
           CAPE TOWN
           8000

We wish you success in your research.

Kind regards.
Signed: Dr Audrey T Wyngaard
Directorate: Research
DATE: 08 January 2015

Lower Parliament Street, Cape Town, 8001
tel: +27 21 467 9272   fax: 0865902282
Safe Schools: 0800 45 46 47

Private Bag X9114, Cape Town, 8000
Employment and salary enquiries: 0861 92 33 22
www.westerncape.gov.za

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ADDENDUM C: LETTER TO PRINCIPAL

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

11 August 2014

Dear ———

I am currently undertaking a research project for my thesis in partial fulfilment of the requirements for the degree of Master of Educational Psychology at Stellenbosch University under supervision of my study leader, Mrs L. Collair.

The title of my study is: Dual diagnosis of autism and hearing loss: caregivers' experiences of diagnosis and intervention.

Caregivers of children with multiple disabilities are referred by medical practitioners and developmental clinics to schools that offer support and education to learners with unique educational needs. As your school specifically facilitates learning and education for learners with a dual diagnosis of Autism and hearing loss through your department for Deaf students with multiple disabilities, you have been identified as an appropriate school to consider research participants from.

The Western Cape Education Department has granted me permission to conduct the empirical investigation for this study. I would like to request your approval and assistance through identifying caregivers of children with a dual diagnosis of hearing loss and Autism Spectrum Disorder who attend your school to be approached as possible research participants. Participation in this study is voluntary. Therefore I request that you provide possible participants with information regarding my study along with my contact details. The participants then have the autonomy to decide whether they want to make contact with me to participate or not.

The identity of your school and all individuals who choose to participate in this study will be kept under strict confidentiality. I am hoping to gather information through scheduling interviews with three participants in their home environment and study medical documents, audiology reports and individual educational programmes in order to compile a timeline of their experiences. Caregivers however have the right to whether they want to share this information with me or not.

Your help in this regard would be greatly appreciated.

Best Regards

Ayesha de Villiers
University number: 14849607

Ayesha   Mrs Collair
0725300901   021 8082304

Departement Opvoedkundige Sielkunde • Department of Educational Psychology
GG Cilliégebou/Building • Ryneveldstraat/Street 7600• Stellenbosch
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ADDENDUM D: CONSENT TO PARTICIPATE IN RESEARCH

STELLENBOSCH UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

Dual diagnosis of autism spectrum disorder and hearing loss: caregivers' experiences of diagnosis and intervention.

You are asked to participate in a research study conducted by Ayesha de Villiers, from the Department of Educational Psychology at Stellenbosch University. This research project is conducted in partial fulfillment of the master's degree in educational psychology. You were selected as a possible participant in this study because you are a caregiver of a child with a dual diagnosis of hearing loss and Autism Spectrum Disorder.

PURPOSE OF THE STUDY

Through conducting this study I hope to gain insight into the lived experiences of caregivers of children with dual diagnosis of hearing loss and Autism Spectrum Disorder. This includes knowledge relating to caregivers' experience of receiving a diagnosis and intervention offered by service providers.

1. **PROCEDURES**

If you agree to volunteer to participate in this study, the following procedure will be followed:

1) The researcher will explain the purpose of the study and answer any questions and concerns you might have. She will then ask you to give consent (permission) to participation in the research study.

2) An appointment will then be scheduled for a time convenient to you to talk about your experiences. The researcher will come to your house, at a time convenient to you, to speak with you.

3) The conversation(interview) will be voice recorded in order for the researcher to listen to it again and not to miss any valuable information you might share with her. This interview will take more or less an hour and a half (90 minutes).

4) The researcher will request your consent to view medical reports, your child's individual educational programs and school reports that reflect the intervention process thus far. The purpose of viewing these documents is to be able to create a time line of your experiences in order to gain a deeper understanding of your experiences of the process of diagnosis and consequent intervention thus far. Making these documents available

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during the interview process remains your decision and you will in no way be forced to do so.

2. POTENTIAL RISKS AND DISCOMFORTS

Some of the questions in the interview may touch on sensitive areas. However, every effort will be made by the researcher to minimise your discomfort. If at any time you feel you would like to withdraw from the research study, you will be free to do so. If you do experience emotional discomfort and you feel the need for debriefing, you will be referred to a counsellor for support. Annemarie Loftus 023 342 2560.

3. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Information gathered through this study may produce findings which could lead to the initiative of future support structures and services for caregivers of children with a dual diagnosis of hearing loss and Autism.

4. PAYMENT FOR PARTICIPATION

You will not receive any compensation for participating in this study. There will be no financial gain for participating in this study.

5. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

Anonymity will be maintained by means of the use of pseudonyms. If the research results are to be published every effort shall be taken to protect the confidentiality of participants. Confidentiality and autonomy will be maintained by allowing participants to contact the researcher if willing to participate directly and not via the principal or psychologist of the school. The interview process will take place in the privacy of the participant's home.

The recorded interviews will be stored on a computer requiring a password for access. The researcher and study leader will have sole access to the data.

6. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The researcher may withdraw you from this research if circumstances arise which warrant doing so.

7. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Ayesha de Villiers (researcher) 0725300901 or Mrs L. Collair (study leader) 021 8082304.

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8.   RIGHTS OF RESEARCH SUBJECTS

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 subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development at Stellenbosch University.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to me _____(name) by Ayesha de Villiers in Afrikaans/English and I am in command of this language or it was satisfactorily translated to me. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

_____
Name of Subject/Participant

_____
Name of Legal Representative (if applicable)

_____   _____
Signature of Subject/Participant or Legal Representative   Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ (name of the participant and/or his/her representative _____ (name of the representative). He/she was encouraged and given ample time to ask me any questions. This conversation was conducted in Afrikaans/English and no translator was used.

_____   _____
Signature of Investigator   Date

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UNIVERSITEIT STELLENBOSCH

INWILLIGING OM DEEL TE NEEM AAN NAVORSING

Dual diagnosis of autism spectrum disorder and hearing loss: caregivers' experiences of diagnosis and intervention.

U word gevra om deel te neem aan 'n navorsingstudie uitgevoer te word deur Ayesha de Villiers, van die Opvoedkundige Sielkunde Departement aan die Universiteit Stellenbosch. Die navorsingsresultate sal in 'n nasvorsingstesis uiteengesit word as gedeeltelike vereiste vir die voltooing van die magister graad in Opvoedkundige Sielkunde. U is as moontlike deelnemer aan die studie gekies omdat u 'n versorger is van 'n kind met 'n diagnose van Autisme Spektrum Afwyking sowel as doofheid.

1. DOEL VAN DIE STUDIE

Deur die uitvoering van die navorsingsprojek beoog die student om insig te verkry aangaande die geleefde ervarings van versorgers van kinders met dubbele diagnose van Autisme Spektrum Afwyking en doofheid. Die geleefde ervarings hou verband met die verkryging van 'n diagnose sowel as intervensie opsies wat aan versorgers gebied is deur diensverskaffers.

2. PROSEDURES

Indien u inwillig om aan die studie deel te neem, sal die volgende prosedures gevolg word:

1)   Die navorser sal die doel van die studie aan u verduidelik en enige vrae of bekommernisse wat u mag hê aanspreek. Sy sal u dan versoek om inwilliging (toestemming) te gee om aan die studie deel te neem.

2)   'n Afspraak vir 'n individuele onderhoud sal met u geskeduleer word vir 'n tyd wat u gerieflik vind. Die onderhoud sal in u huis plaasvind.

3)   Daar sal 'n bandopname van die onderhoud gemaak word sodat die navorser herhaaldelik daarna kan luister om te verseker dat geen belangrike informasie, soos deur u verskaf is, uitgelaat word nie. Die onderhoud sal ongeveer 'n uur en 'n half (90 minute) duur.

4)   Die navorser sal u toestemming versoek om u kind se mediese verslae, individuele opvoedkundige programme en skool verslae, wat die intervensie tot dusver vertoon, te versamel en te bestudeer. Die doel daarvan om die bogenoemde dokumente te bestudeer is om 'n tydlyn te formuleer van u ervaringe wat beter verstaan van u ervarings van diagnose en gevolglike intervensies moontlik maak. U behou die reg om die bestudering van genoemde dokumente te weier.

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3. MOONTLIKE RISIKO EN ONGEMAKLIKHEID

Sommige van die vrae in die onderhoud mag dalk oor sensitiewe onderwerpe wees. Die navorser sal als moontlik doen om die ongemak tot n minimum te hou. Indien u so sou voel, is u geregtig om enige tyd gedurende die onderhoud te ontrek. Indien u enige emosionele ongerief ervaar en dit nodig vind, sal u vir die nodige ontlonting verwys word na 'n berader. Annemarie Loftus 023 342 2560.

4. MOONTLIKE VOORDELE VIR PROEFPERSONE EN/OF VIR DIE SAMELEWING

Informasie wat deur hierdie studie ingesamel word kan moontlik lei tot bevindinge wat toekomstige inisiatiewe wat handel oor ondersteunings raamwerke en dienste vir versorgers van kinders met 'n diagnosis van gehoor verlies en autisme kan staaf.

5. VERGOEDING VIR DEELNAME

U sal geen vergoeding ontvang vir u deelname aan die studie nie. Daar sal geen finansiele baat wees vir u deelname aan die studie nie.

6. VERTROULIKHEID

Enige informasie wat ingesamel word en verband hou met hierdie studie en wat dit met u verbind sal vertroulik hanteer word en sal slegs blootgestel word met u toestemming of volgens wetlike aanvraag.

Anonimiteit sal ten alle tye behou word deur die gebruik van skuilname. Indien die navorsing gepubliseer raak sal als moontlik gedoen word om te verseker dat u identiteit vertroulik bly. Vertroulikheid en outonomiteit sal behou word deurdat die deelnemer self besluit of hulle aan die navorsing wil deelneem deur direk kontak te maak met die navorser nadat die nodige inligting aan die deelnemer verskaf is deur die skoolhoof.

Die onderhoude wat elektronies opgeneem sal word sal op 'n rekenaar gestoor word wat n sleutelwoord verlang en sal slegs vir die navorser en studie leier toeganklik wees.

7. DEELNAME EN ONTTREKKING

Dit is u keuse om deel te neem aan hierdie studie. Indien u sou instem om deel te neem aan hierdie studie is u geregtig om engie tyd te onttrek van die studie sonder enige nagevolge. Dit is ook u reg om enige vraag wat aan u gevra word te weier en steeds voort te gaan met deelname aan die studie. Die navorser behou die reg om u van die studie te onttrek indien verwikkelinge dit verg.

8. IDENTIFIKASIE VAN ONDERSOEKERS

Indien u enige vrae of besware het oor die navorsing kan u gerus kontak maak met Ayesha de Villiers (Navorser) 0725300901 of Mrs. L. Collair (Studieleier) 021 8082304.

9. REGTE VAN PROEFPERSONE

U kan te eniger tyd u inwilliging terugtrek en u deelname beëindig sonder dat die besluit enige nadelige gevolge vir u mag inhou. Deur deel te neem aan die navorsing doen u geensins afstand van enige wetlike regte, eise of regsmiddel nie. Indien u vrae het oor u regte as proefpersoon by navorsing, skakel met Me Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] van die Afdeling Navorsingsontwikkeling van die Universiteit van Stellenbosch.

2

VERKLARING DEUR PROEFPERSOON OF SY/HAAR REGSVERTEENWOORDIGER

Die bostaande inligting is aan my, _____, gegee en verduidelik deur Ayesha de Villiers in [*Afrikaans/English*] en [*ek is/die proefpersoon is/die deelnemer is*] dié taal magtig of dit is bevredigend vir [*my/hom/haar*] vertaal. [*Ek/die deelnemer/die proefpersoon*] is die geleentheid gebied om vrae te stel en my/sy/haar vrae is tot my/sy/haar bevrediging beantwoord.

[*Ek willig hiermee vrywillig in om deel te neem aan die studie/Ek gee hiermee my toestemming dat die proefpersoon/deelnemer aan die studie mag deelneem.*] 'n Afskrif van hierdie vorm is aan my gegee.

_____
Naam van proefpersoon/deelnemer

_____
Naam van regsverteenwoordiger (indien van toepassing)

_____   _____
Handtekening van proefpersoon/deelnemer of regsverteenwoordiger   Datum

VERKLARING DEUR ONDERSOEKER

Ek   verklaar   dat   ek   die   inligting   in   hierdie   dokument   vervat   verduidelik   het   aan _____[*naam   van   die   proefpersoon/deelnemer*]   en/of   sy/haar regsverteenwoordiger   _____[*naam   van   die regsverteenwoordiger*]. Hy/sy is aangemoedig en oorgenoeg tyd gegee om vrae aan my te stel. Dié gesprek is in [*Afrikaans/*Engels*] gevoer en [*geen vertaler is gebruik nie/die gesprek is in _____ vertaal deur _____*].

_____   _____
Handtekening van ondersoeker   **Datum**

3

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ADDENDUM E: CONSENT TO RESEARCHER TO STUDY DOCUMENTS

UNIVERSITEIT STELLENBOSCH

INWILLIGING OM BESTUDERING VAN DOKUMENTE DEUR NAVORSER

Dual diagnosis of autism spectrum disorder and hearing loss: caregivers' experiences of diagnosis and intervention.

Hiermee gee ek toestemming dat die navorser, Ayesha de Villiers, my kind se mediese verslae, individuele opvoedkundige programme en skool verslae, wat die diagnostiese proses sowel as intervensie tot dusver vertoon, te bestudeer.

Die doel hiervan is aan my verduidelik, naamlik dat daar deur die bestudering van die bogenoemde dokumente 'n tydlyn geformuleer kan word van my ervaringe wat 'n beter verstaan van die diagnostieseprosesse en gevolglike intervensies aan die navorser bied. Ek behou die reg om die bestudering van genoemde dokumente te weier.

DOKUMENTE	JA	NEE
Mediese verslae		
Individuele Opvoedkundige Programme		
Skoolverslae		
Raporte		
Ander:		

_____
Naam van deelnemer

_____
Handtekening van deelnemer

_____
Datum

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STELLENBOSCH UNIVERSITY

CONSENT FOR RESEARCHER TO STUDY DOCUMENTS

Dual diagnosis of autism spectrum disorder and hearing loss: caregivers' experiences of diagnosis and intervention.

I hereby grant the researcher, Ayesha de Villiers, permission to view documents related to the diagnostic process and consequent interventions related to my child's dual diagnosis. These include medical reports, my child's individual educational programs and school reports that reflect the diagnostic and intervention process thus far.

The purpose of viewing these documents that was explained to me, is to be able to create a deep understanding of my experiences of the process of diagnosis and consequent intervention of my child's condition to date. Making these documents available during the interview process remains my decision and I will in no way be forced to do so.

Please indicate by ticking the appropriate box in the table below whether or not you grant permission for the documents to be made available to Ms De Villiers.

DOCUMENTS	YES	NO
Medical Reports – doctors reports -		
Therapists reports - physiotherapists, ocupational therapists, speech and language therapists		
Psychologists reports		
Learning support reports		
Individual Educational Programs		
School Reports		
Multi-disciplinary team reports		
Social Worker reports		

Name of Participant

_____

ADDENDUM F: INTERVIEW GUIDE

Interview Guide:

Dual diagnosis of autism and hearing loss: caregivers' experiences of diagnosis and intervention.

Time of interview:

Date:

Interviewer:

Interviewee Code (participant):

(Briefly describe the research project)

A. Demographic information

1. Tell me about your family: who forms part of your family?
2. Do you work outside the home?
3. When was your child born?
4. Where was your child born?

B. Developmental History

5. When did you first notice that something was different about your child?
6. Who did you approach, where did you seek help?

C. Diagnostic Process

7. Which diagnosis did you receive first?
8. Who made the diagnosis?
9. Tell me about how that was for you?
10. Tell me about how you received the second diagnosis.

D. Intervention Process

11. What interventions were recommended to you?
12. Who made this diagnosis?
13. Tell me what you experienced as you received the second diagnosis?
14. What was your experience of receiving intervention for your child with a dual diagnosis?

1

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E. Services and Support

15. What services were recommended to you as a result of the dual diagnosis?

16. When did your child start at this school?

17. How are things for you now?

18. Tell me about your support structure?

F. Conclusion

19. Is there anything that you would like to add to this conversation?

20. (Thank the individual for participating in this interview. Reassure the individual of confidentiality of responses and potential future interviews.)

2

ADDENDUM G: TRANSCRIPT WITH OPEN COLOUR CODING

			Line
42. Intervention proceeding ASD diagnoses	1		
	2	○ Hulle het niks vir ons gegee daaroor of gesê nie, hulle het net gesê hy gaan na die multi-gestremde klas toe en hy gaan na die koshuis toe waar die multi-gestremde kinders is.	484,485
		○ *Ayesha: En wat beteken dit? Watter intervensies is dit? Wat doen hulle met hom wat anders is as in die ander klasse?*	486,487
		○ Hulle het nie vir ons rerig gesê nie, hulle het net gesê in die gewone klas kan die juffrou nie vir hom help nie want jy weet	488,489
		○ Niks wat ons van weet nie	580
	3	○ ja en ons het by haar ingeskakel en ons het toe 'n tutor gekry, P*	472
		○ ons was heeltyd by Die Skool vir Dowes... hy was toe by D*en sy het 'n bietjie ekstra opleiding gehad, bo en behalwe sy het spesiale onderwys by gedoen dink ek nê, dis spesiale onderwys daardie ekstra jaar, sy was baie oulik gewees, sy het ons regtig baie gehelp	474-477
		○ my man, ek het probeer die pad met A* stap maar my man se rugraat het stokstyf getrek en al die hare op sy lyf het opgestaan as hy haar net gesien het hy kon dit nie hanteer nie.	496-497
		○ Ek dink net haar... dis amper asof sy nie die kind as 'n individu sien nie, sy het hierdie dryf en hierdie, dis snaaks my man is ook nogals so hy is ook 'n drywer en 'n complete finisher en maar sy moet seker so wees om resultate te kry met wat sy doen. Dit het vir hom gevoel dit gaan als oor geld by haar oor die kind moet in hierdie program kom en hy moet hierdie kosse eet, jy weet jou hele lewe word oorgeneem deur hierdie program wat jy moet volg en hierdie kos wat jy moet eet en ons het dit regtig 'n go gegee en D* het toe begin gaan vir opleiding...	499-505
		○ Kyk hy is ook nie suiwer outisties nie, glad nie, so wat werk vir outistiese kinders werk ook nie presies vir hom nie, hy is rerig net hierdie unieke kindjie wat daar nie 'n modelletjie voor is nie... ons doen wat ons kan, ons kan seker meer doen uhm ons doen wat ons kan en ek probeer, ek is 'n kampvegter daarvoor dat my kind ook moet gelukkig wees en hy moet speel, ek wil nie heeldag vir hom in roetines en programme en sy lewe organiseer nie dit is een van die groot redes hoekom ons nou plaas toe gaan	747-752
43. Not knowing what ASD is	1	○ Toe stuur sy vir my kliniek toe. Ek het niks geweet van outisme af nie tot u vir my presies gesê het wat dit is.	254-255
		○ Outisme in Afrikaans vertaal...	357
	2		
	3		
44. Knowing that the ASD	1	○ Ek het gelees wat is outisme want as jy lees alles is presies dieselfde as haar. (ma)	361

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Theme	#		Quote	Page
diagnosis/description this fits my child's behaviour		o	Uit die notas uit kon ek sien alles wat daar gestaan het is presies soos Ellen* is.	363
	2	o	Ma: want dit wat ek nou vir haar vertel het van die simptone en daai dit het James*	385
45. Calming, coping with, strategies	3			
	1			
	2			
	3	o	Ek was van die begin af immuun ek moes net 'n renostervel ontwikkel dis maar net wie ek is, ek weet nie uhm my geloof wat my anker is en nie mense nie en ek het my man.	494-495
46. Seek advice from doctor but no answers/ explanations	1	o	Nooit. Hoe kan die dokter weet hoe Ellen*… vir outisme. Ek het vir dokter H* gesê Ester het outisme maar hy weet niks, maar hy weet nie hoe om met outisme te hanteer nie.	372,373
		o	Ek het met my huisdokter gepraat dr. H* hom gesê Ester is outisties maar hy weet niks, hy sê hy ken nie outisme nie hy weet nie hoe om vir ons te help nie.	375,376
		o	Ja hoe lank gewag vir dokter om te antwoord oor outisme. Waar kom die outisme vandaan?	377,378
		o	Die dokter van Pretoria	380
		o	O die psigiater	381
		o	…lank gewag, ek wil graag weet, …outisme, hoekom is sy so	382
		o	Dit voel jy vra vra vra vir die dokter gevra en hy het nie antwoorde nie.	384
		o	Nooit antwoorde nie.	385
	2			
	3			
47. Own ideas/ conceptualisation of what caused ASD	1	o	Daar moes fout gegaan het terwyl L* vir haar verwag het nog in die baarmoeder dit is wat ek dink, hy het nie toe sy gebore is was daar papier….ekstrale geneem sonder 'n beskermende baadjie-daar was nie 'n waarskuwingskennisgewing op die muur nie).	386-388
		o	…gebreek, ja …swangerskap is verbode mag nie ekstrale neem nie.	389
		o	X-straal foto van buik dokter wil seker maar of ek kan kraam of keisersnit	382
		o	O hulle het X-strale geneem van haar, was dit X-strale of 'n scan? En toe het hulle besef dat ek kan nie normaal geboorte gee nie hulle moet 'n keiser doen.	393,394
		o	…die oggend X-straal foto geneem omdat ek die eerste kraam pyne gehad.	395
		o	Dokter vir my gesê X-straal foto laat afneem.	398
		o	Ayesha/ Talk Ok. Dink jy dit is die X-strale? Dink jy die X-strale het probleme gemaak dat sy outisties is?	399
		o	Ek het nie bewys nie.	402
		o	Ek kan nie onthou nie, voor sy ……later gelees op die hospitaal….ek sit in die badkamer toe sien ek teen die deur 'n swanger vrou is verbode.	403,404

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Theme	Code	Quote	Lines
		o Wat gebeur het is eers later het ek besef hulle het X-strale geneem toe ek vir Ellen* verwag het want later toe lees ek op die deur dat hulle moenie X-strale neem as mens swanger is nie.	405-407
		o *Ayesha: Is dit iets wat jou pla en wat by jou bly die heel tyd?*	413
		o Presies. Dit is wat ek dink. Nou in die moderne tyd weet hulle hulle mag nie X-strale neem nie, maar hulle het X-strale van haar geneem.	414-415
		o Ek het nie geweet nie, dokter vir my gesê het ek moet gaan.	417
		o Ek is nie 'n dokter nie sê N* ek weet nie of dit die X-strale is nie.	423
	2		
	3		
48. Parental guilt/ regret	1		
	2	o Dit is die ander ding wat ons 'n mens het nie geld om jou kind na 'n privaatskool, ek ek is seker daarvan as ek die geld gehad het om vir hom van die begin af in 'n privaatskool te gehad nê dan was dit baie beter af gewees het as hy die aandag kon gekry het wat hy nodig gehad van die begin af.	502-505
		o Ek kan nie, soos ek sê ek het nie rerig 'n gevoel daaroor nie jy weet dit is deel van die lewe jy weet, ek het nie die geld nie so ek kon dit nie gedoen het nie...ek aanvaar dit maar net so jy weet (pa)	509-511
		o maar mens wil ook die beste vir jou kind hê nê want sy praat nou net oor die finansiële effek as ons daardie geld gehad het (ma)	535,536
		o sou ons dit gedoen het vir hom want kyk maar daardie Sue Thomas daai FBI agent op die televisie nou en dan sy het daardie spraak lesse het sy gekry haar ouers het vir betaal daarvoor dit is hoe nog sy daardie bietjie kan...kon praat ja	538-540 542
	3	o ... ek voel nogals skuldig party dae want ek dink ek kan seker baie meer vir Anton* gedoen het as wat ek gedoen het in die sin van rerig sit met hom en hom help en vir hom vat na allerhande goeters toe....	715-717
		o ...ek dink miskien mis ek iets daar, daar is baie ouers wat verskriklik input lewer in hulle gestremde kinders se lewens en baie reg kry met kinders ... ek weet nie of ek meer nie of ek meer kon doen nie.	765-758
49. Complications during birth	1	o Hulle het die X-strale gedoen en die volgende oggend 10uur het hulle 'n keisersnit gedoen.	419,420
		o Want my buik was te nou.	422
	2		
	3		

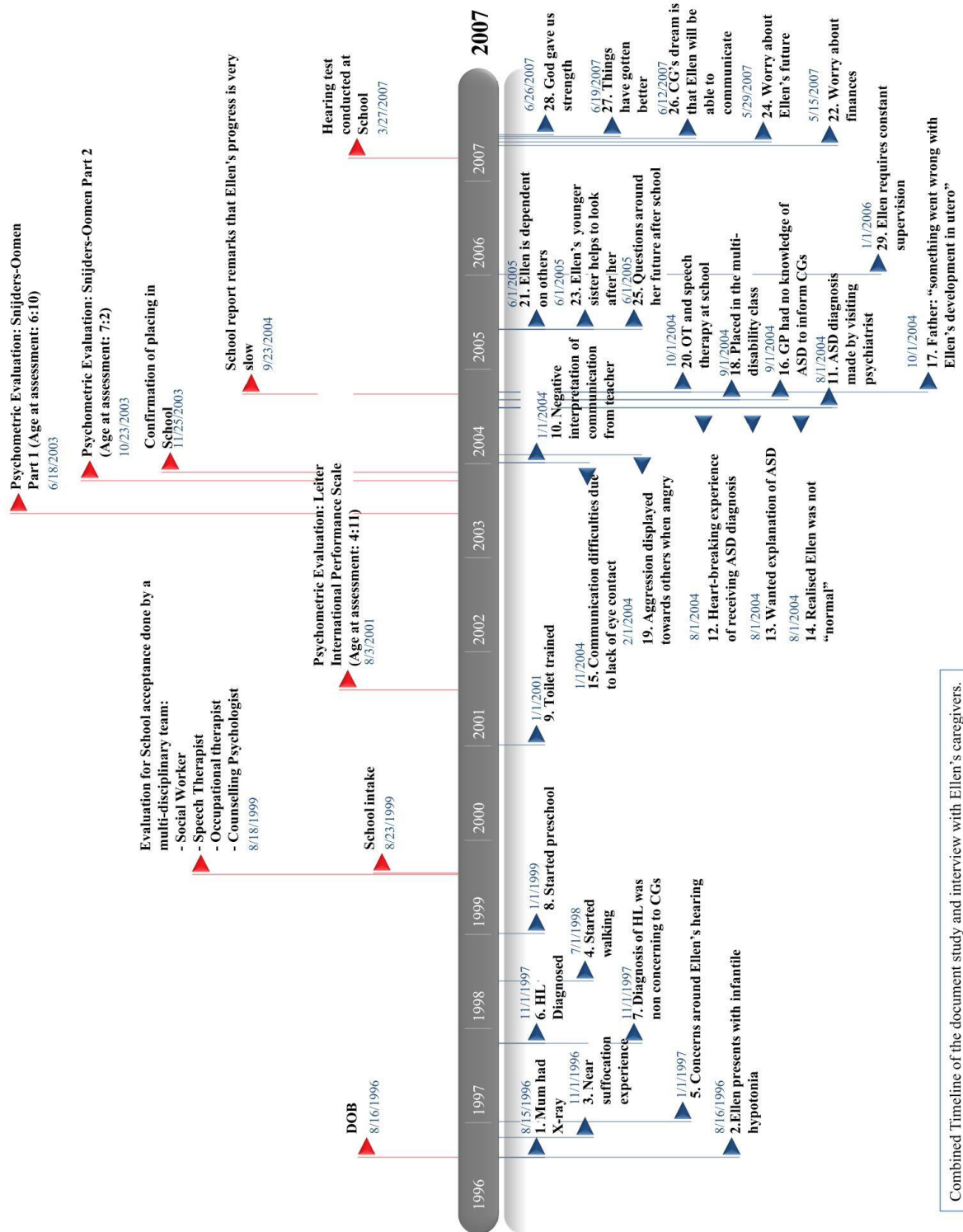|			
50. Interventions for H.I and experiences thereof	1	○ Gehoor daar by Tygerberg sy is doof wat gebeur toe? Wie het gehelp, wat? ○ Ook net getoets, Skool vir Die Dowes toe gestuur. ○ Haar sussie ook, dieselfde.	432 447 446
	2	○ ... ons het nie 'n motor gehad daai tyd nie, ek moet nou stap met hom hy is net so klein, shorty, met sy tasse en sy goed hier af tot by Steers en dan moet ek hom nou daar gaan af sien... dan is ek in trane nê, hoe laat het oom D*gewoonlik gekom, so half sewe nê? ○ So ons moes al van net na ses af moes ek en hy in die oggende daar gewees het en winter tye was moeilik sy jassie en sy coat oor sy kop en so-aan.	216-219 221-222
	3	○ Sy het ons verwys na Carl du Toit (audioloog) ○ En toe het hulle nou natuurlik ja aanbeveel dat ons die koglêre... ○ pad stap en ons het met die program begin, maar ons het redelik probeer uitvind en oplees en maar weer leiding gevra en ons het ervaar baie baie sterk dat dit nie die roete vir ons is om te stap nie uhm en ons het toe na die Skool vir Die Dowes toe gekom en daar was toevallig 'n meisietjie wat besig was met haar meestersgraad, uhm ek kan nie presies onthou wat haar onderwerp was nie maar dit was taalontwikkeling by dowe kinders. ○ hy was ses maande toe ons hom laat toets het en toe het ons onmiddellik gegaan Carl du Toit toe en ons het baie vinnig eintlik daardie besluit geneem... (en ja binne twee weke na blootstelling aan gebaretaal het hy sy eerste gebaartjies begin maak en het ons begin kommunikeer, binne twee weke).	327 329 331-335 341-344
51. Support from family and close friends	1	○ Uhm.......(35:31) en sy broer F* het saamgegaan ook gehelp ○ My ma help baie as skoolvakansie, ek vat Ellen* na my ma, my ma kyk vir haar niemand by die huis, ek is bang sy kan nie self doen nie my ma kan iets vir haar gee,dis ok. Klaar gewerk dan kom haal ek haar...	431 653-655
	2	○ En dan haar suster het nou onlangs haar ontferm oor hom....	840
	3	○ baie traumaties en baie emosioneel vir my gewees en baie mense het vir ons gesê dat ons was gehoorsaam soos ons geestelike ondersteuners ons naby vriende mediese vriende uhm ons was gehoorsaam met geluister om aan te gaan met die swangerskap maar dit is nou tyd om 'n einde daaraan te maak, ons kan mos nou nie basies weer gesinspeel dat ons onverantwoordelik is en uhm ons het toe maar baie gebid daaroor en ons het weereens ervaar ons het in die begin ja gesê...	174-179
52. Intervention (some with positive outcome/	1	○ Mnr D*die audioloog het getoets ○ Ja...4 jaar ○ Audiogram ja en apparate gegee en met taal ontwikkeling wie het vir julle gehelp? Wie het	451 452 453

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improvement)		vir haar taal geleer?	
		○ Die kleuterskool begin	455
		○ Sy het geleer daar by die kleuterskool maar dit was stadig, sy het nie vinnig ontwikkel nie.	457
		○ (Gebare taal by die huis) Ja. Sy praat baie oor en oor, maar praat baie	462
		○ Sy is moeilik,ag jaar oud, stadig stap, nie maklik nie, in multi-gestremde	488
		○ Handwerk, plak papiertjies, maak krale of enige handwerk goed, haar skoolwerk dit is stadig	491,492
		○ Arbeidsterapie by die skool ja, spraakterapie	518
		○ Ek het nie altyd in die rapport terugvoer gesien van terapeut wat hulle daar geskryf het	520
	2	○ Carel du Toit toe, die audioloog*het vir ons aangeraai om hom daar in te skryf toe het ons hom daar ook gehad	187
		○ Hulle werk mos met die kinders wat geleidelik doof is, maar hy is mos omtrent heeltemal doof en dit daai het nie gewerk by hulle nie toe sê hulle vir ons die beste gaan wees as hy na die Skool vir Die Dowes toe gaan.	189-191
		○ Ayesha: sign language	473
		○ Ja en lippe taal	474
		○ Hy het daar by die skool het hy spraak ek is nie seker of hy arbeidsterapie gekry het nie, ek dink hy het maar ek is nie seker daarvan nie, ek kan nie onthou nie.	567,568
	3	○ sy borsie is net so klein ek vat hom vir swemoefeninge	535
		○ baie oulik hulle help my nogals met hom uhm maar dit is ook nou maar net een maal 'n week maar dit help baie, dit het baie gehelp met sy selfvertroue	536-537
		○ en hulle sê hulle kan sien by die skool hy het baie verander rondom sy uhm body consciousness hy neem baie meer deel aan die LO en hy het baie meer selfversekering	539-540
		○ ja hy swem nie net nie, dit is water oefeninge sy laat baie onder die water goed uit duik en uhm met 'n rek na die kant toe om goeters af te haal en hy geniet dit, hy kry aandag en sy is oulik, baie oulik goed vir hom	542-544
		○ Uhm so programme en, ek het hom gevat vir fisio, ek het hom gevat vir arbeidsterapie, maar hulle het almal vir my gesê hy het nie rerig 'n probleem wat hulle kan diagnoseer wat hulle hom mee kan help nie, orals waar ek probeer het het dit eintlik nie rerig gehelp nie.	719-721
		○ en omdat hy doof is is dit so beperk want hy's ingrypend doof hy kan niks hoor nie, so hy kan ook nie... ek dink hy sal byvoorbeeld goed kon doen in 'n skool vir kinders met leergestremdheid soos Alta du Toit... daar is skole, spesiale skole maar omdat hy doof is, hy is primêr doof	723-726
		○ kyk hy het ook 'n sig probleem hy kan nie so goed skryf nie, hy sukkel geweldig om van die	769-

bord af af te skryf, hy moet eintlik hier onderrig kry dis vir hom moeilik in 'n klas situasie met die aandag wat gaan en dis hoekom hy vir R* (fasiliteerder) het	771
o Ek wil amper sê dis ons intervensie dis R*. R* is die een wat heeltyd vir hom terug bring… kalmeer. In die begin het sy hom uitgevat uit die klas uit as daar tantrums was het sy hom fisies uit die klas gevat en alleen met hom gaan sit en werk of 'n draai met hom geloop en weer teruggekom, so R* is hierdie konstante stabiliteit in sy lewe wat nou al 'n paar jaar saam met hom kom, sy doen ook huiswerk met hom want ek kan nie huiswerk met hom doen nie.	773-778

ADDENDUM H: CODES CLUSTERED ACCORDING TO CATEGORIES
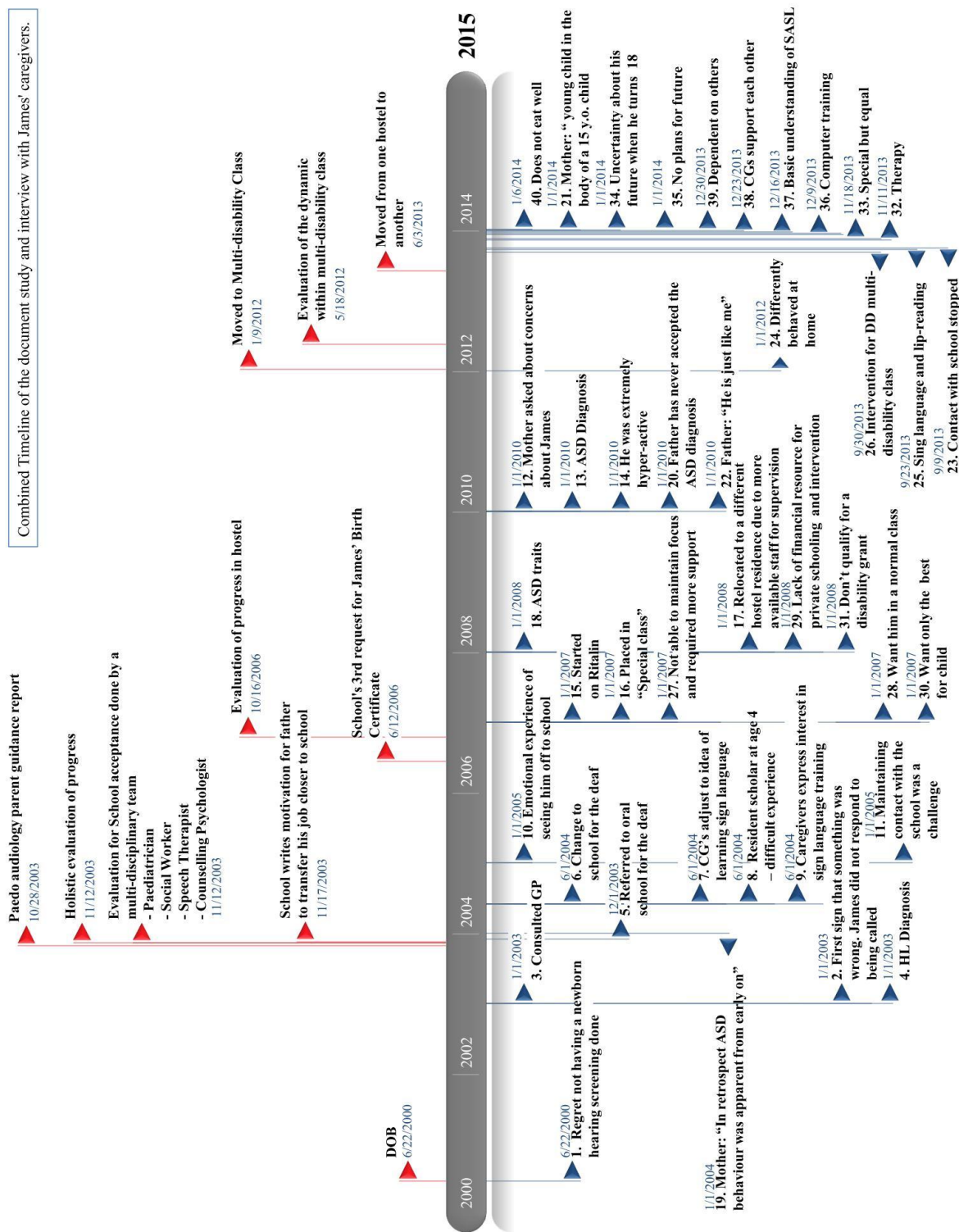
Athemes / sub-themes	PERSONAL EXPERIENCE OF THE DIAGNOSTIC PROCESS		PERSONAL EXPERIENCES of challenges, coping and expectations desires needs				INTERVENTION AS PART OF PROXIMAL PROCESSES			
	first diagnosis hearing loss	second diagnosis ASD	emotional experience	everyday challenges	overcoming challenges	fears, hopes and dreams	therapeutic intervention	health & medical	school	social
1.Particulars	20. First diagnosis 21. Who made the diagnosis 27. Experience of first diagnosis 28. Family history of HL	29. Second diagnosis 30. Experience of 2nd diagnosis 31. Who made the 2nd diagnosis 41. Behaviour observed related to ASD 43. Not knowing what ASD is 44. Knowing that the ASD diagnosis/ fits my child 46. Seek advice from doctor but no answers/ explanations 47. Own ideas/ conceptualisation of what caused ASD 32. Familiar behaviours observed in child/ I had this/ this is similar to what I was like	6. Emotions, experience as a caregiver 8. Hurt, heart ache due to treatment of child 48. Parental guilt 61. Special treatment because of his/ her disability 24. School for the deaf residence 36. Sacrifices	3. Child's behaviour 13. Struggles/ challenges/ experiences at home 14. Feeding & eating habits 17. Life threatening experience, anxiety, danger 59. Challenging behaviour	4. Cg response to child's behaviour/ dealing with the child's behaviour 60. Dealing with challenging behaviour 7. Role division of cgs/ difference in coping or facing of challenges 35. Coping as a couple 72. Coping what sustained you 73. Support network 11. Support with dealing with child 16. Knowing how to handle child 37. Spiritual experiences 26. Friends and family 51. Support from family and close friends 69. Having to push through	54. Desired intervention 63. Dependency 64. Worries/ needs 65. Financial needs 66. Future 67. After school care 68. Waiting list/ no space 70. Aspirations/ dreams for child 78. Perspectives as a result of life experience 79. Perceptions of disability, integration into society. 69. Having to push through	10. Therapy 52. specific Intervention 22. Decisions/ interventions based on the diagnosis 50. Interventions for HL and experiences thereof 57. Hearing aids 42. Intervention proceeding ASD diagnosis	2. First sign 9. Child's health 49. Complications during birth 19. Doctors medics and hospital 18. First child inexperienced 46. Seek advice from doctor but no answers/ explanations 56. Medication	23. First school age 25. Communication between school and cg 33. Teacher/ class teacher 38. Bad, difficult or challenging experience 36. Sacrifices 39. Adjustment to school 53. Decisions and interventions at school 71. As time progresses 55. Slow progress 40. Relationship with school 58. Class for children with multiple disabilities 75. Scholastic/ academic ability	78. Friendships Interest ability/ skill 77. Special bond 78. Friendship/ relationships/ social interaction/ socialisation

ADDENDUM I: TIMELINES OF INTERVIEW AND DOCUMENT STUDY

2007

1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007

DOB
8/16/1996

8/15/1996
1. Mum had X-ray

11/1/1996
3. Near suffocation experience

8/16/1996
2. Ellen presents with infantile hypotonia

11/1/1997
6. HL Diagnosed

7/1/1998
4. Started walking

11/1/1997
7. Diagnosis of HL was non concerning to CGs

1/1/1997
5. Concerns around Ellen's hearing

1/1/1999
8. Started preschool

Evaluation for School acceptance done by a multi-disciplinary team:
- Social Worker
- Speech Therapist
- Occupational therapist
- Counselling Psychologist
8/18/1999

School intake
8/23/1999

1/1/2001
9. Toilet trained

Psychometric Evaluation: Leiter International Performance Scale (Age at assessment: 4:11)
8/3/2001

1/1/2004
15. Communication difficulties due to lack of eye contact

1/1/2004
10. Negative interpretation of communication from teacher

2/1/2004
19. Aggression displayed towards others when angry

8/1/2004
12. Heart-breaking experience of receiving ASD diagnosis

8/1/2004
13. Wanted explanation of ASD

8/1/2004
14. Realised Ellen was not "normal"

Psychometric Evaluation: Snijders–Oomen Part 1 (Age at assessment: 6:10)
6/18/2003

Psychometric Evaluation: Snijders–Oomen Part 2 (Age at assessment: 7:2)
10/23/2003

Confirmation of placing in School
11/25/2003

School report remarks that Ellen's progress is very slow
9/23/2004

10/1/2004
20. OT and speech therapy at school

9/1/2004
18. Placed in the multi-disability class

9/1/2004
16. GP had no knowledge of ASD to inform CGs

8/1/2004
11. ASD diagnosis made by visiting psychiatrist

10/1/2004
17. Father: "something went wrong with Ellen's development in utero"

6/1/2005
21. Ellen is dependent on others

6/1/2005
23. Ellen's younger sister helps to look after her

6/1/2005
25. Questions around her future after school

1/1/2006
29. Ellen requires constant supervision

Hearing test conducted at School
3/27/2007

6/26/2007
28. God gave us strength

6/19/2007
27. Things have gotten better

6/12/2007
26. CG's dream is that Ellen will be able to communicate

5/29/2007
24. Worry about Ellen's future

5/15/2007
22. Worry about finances

Combined Timeline of the document study and interview with Ellen's caregivers.

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Combined Timeline of the document study and interview with James' caregivers.

ADDENDUM J: CAREGIVER NARRATIVES

Background and context of Ellen

Ellen was born a healthy girl in August 1996 to a mother and a father. They are both hard of hearing and respectively attended schools for the Deaf where they matriculated. She was born in a private hospital. Ellen is the couple's first child. Ellen's father has worked as a motor mechanic in the same workshop for the last thirty years. Her mother is a general worker in a school kitchen where she has helped prepare meals for 14 years. The first sign that something could possibly be wrong was soon after her birth when her caregivers noticed that she had a "floppy neck". Besides this there were no other signs warranting concern.

When Ellen was approximately 18 months old a close family friend became concerned about her hearing. The family sought help and Ellen was seen by an audiologist at Tygerberg Hospital. The audiologist found that Ellen had bilateral total sensorineural hearing loss and made a referral for the family to be seen at a school for the Deaf. This first diagnosis did not come as a shock.

> *"I am also deaf so I can communicate with her so it was not a problem for me."(Ellen's father, interview, 214-215)*
>
> *[Ek is ook doof so ek kan met haar kommunikeer so dit was nie vir my 'n probleem nie.]*
>
> *"...so our whole family is deaf, my brother, mother, father so for me it wasn't a problem that she was deaf." (Ellen's father, interview, 217-218)*
>
> *[...so ons hele familie is doof, my broer, ma, pa so vir my was dit nie 'n probleem dat sy doof was nie.]*

She first started attending the school for the Deaf at the age of 3 years in August 1999. Initially she started attending school on a Thursday from 07:30 – 10:00 until the end of the year and enrolled as a full time learner in January 2000. During the initial multi-disciplinary assessment in August 1999 Ellen spoke a few words and made use of general signs to communicate her needs. Based on the psychometric evaluation done in August 1999 Ellen's mental age was estimated between 18 and 24 months. The recommendations made by the team were that Ellen be admitted to the school for the Deaf as soon as possible in order to receive the necessary stimulation; and that she would benefit from school routine and

language stimulation. She would also receive occupational therapy. This information was gathered through the document study done by the researcher.

The second diagnosis was ASD and was made in 2004 when Ellen was eight years old. A team of psychiatrists visited the school for the Deaf's clinic where they interviewed several people. Ellen's mother attended the clinic on her own. This was the first time that she heard of autism and also the day that she was told that her child was autistic. Ellen's caregivers are unable to speak English. The head of the psychiatrists team spoke English and another doctor who had experience of working with the deaf had to translate what was being said to Ellen's caregiver. This experience was a big shock for Ellen's mother and she found it difficult to process the information. It took her time to come to terms with the diagnosis and this was as she explains a painful process. Ellen's father had the need for someone to explain to him what autism was.

> *"Yes I remember, I was alone, he was not with me." (Ellen's mother, interview, 257)*
> *[Ja ek onthou, ek was alleen gewees, hy was nie by nie.]*
> *"...will never accept it, a whole year not accept...starting to accept it now." (Ellen's mother, interview, 241-244)*
> *[...sal dit nooit aanvaar nie, een jaar lank nooit aanvaar...begin dit nou aanvaar.]*
>
> *"Yes tearful, could not take it, from hearing the news to taking it home was a long road...a year and a half...heartache, painful." (Ellen's mother, interview,339-340)*
>
> *[Ja huilerig, kan nie vat nie. vandat ek gehoor het en huis toe geneem het is 'n lang pad... een jaar en 'n half...hartseer, pynvol.]*

Experiences as reported during the interview with the
Caregivers of Ellen
Dad (mechanic) 28 at her birth and Mom (works in a school kitchen) 27 at her birth.
Two girls (18-scholar; 15-scholar)

TIME	CAREGIVER EXPERIENCE	TIMELINE REFERENCE
15/08/1996	Mum had an x-ray taken of her abdomen due to concerns by the doctor that her "buik" was to narrow.	1
birth (16/08/1996) *155-156*	The baby had a floppy neck and received regular physiotherapy. She was very heavy. "The beginning was very difficult because her neck was very floppy." "I had to go to physiotherapy every time" / Regular physiotherapy to address her floppy neck and to get exercises. Mom did not understand what she wanted or needed when she cried or screamed. Mother and neighbour/friend were both of big help to her in raising Ellen.	2
11/1996 *167*	Ellen's life was saved by the family neighbour when she choked/suffocated. This was an experience the mother will never forget. "Uhm *** het vir Ellen se lewe gered sy was amper dood sy was drie maande…"	3
07/1998 *133*	She walked at 1 year 11 months. "Walked at 1 year 11 months."	4
1997-1998 Btwn 1-2 yrs *201*	The family friend/neighbour first noticed that something was amiss with Ellen in terms of her hearing.	5
214-215	Ellen was diagnosed with hearing loss at the age of two at Tygerberg Hospital.	6
443	Receiving the diagnosis of HL was not concerning/ problematic as both parents are deaf.	7
447	The doctor (audiologist) at Tygerberg referred the parents to the school for the deaf for support.	
453	This was the same for her younger sister. She was found to be deaf and referred to the school for the deaf.	
455	Audiogram was done and hearing aids were fitted.	
457-458	Language intervention was done at the preschool for the deaf.	
462, 464	Progress in the development of sign language was slow. Development was slow.	
482-483	Ellen would repeat sign language phrases over and over (echolalia). Only wears her hearing aids at school. Takes them out when she gets home.	
1999 299	First started attending kindergarten at the school for the deaf. At first she only attended a few hours a week until she got used to it.	8
2000-2001 *133-135*	Potty-trained between age 3 and 4. Independent at school but not at home. Fussy eater. She did not eat the cooked meals at school and this meant mom had to prepare special meals for her for lunch. Mealtimes at crèche was challenging due to food preferences.	9