Mothers' experiences of their child's diagnosis with an autism spectrum disorder

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November 2014

It all starts here ™

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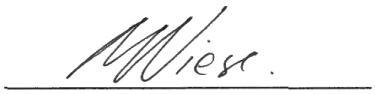
I herewith declare that the dissertation entitled *Mothers' experiences of their child's diagnosis with an autism spectrum disorder* is my own, original work, and that I am the soul author (except where specifically stated otherwise). I further declare that I have not in the past, whether in part or in its entirety, used this document to attain any other qualification and that all references used or quoted were indicated and acknowledged by means of citing it in the text and also in a comprehensive reference list.

Signature: 

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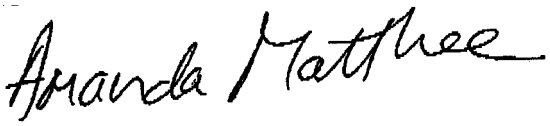

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SUMMARY

Autism or autism spectrum disorder (ASD) is a multifaceted neurological condition that impairs social interaction, communication and behaviour. The current increase in the prevalence of ASD is alarming. A large population of parents is left searching for answers regarding their child's developmental delays. Once their child has been diagnosed, they have to deal with the challenge of raising such a child. Parenting a child with ASD is particularly challenging for mothers as it has been reported that they struggle with poor health and wellbeing as well as high stress levels. Literature has also shown that the maternal interaction style impacts the prognosis for the child's development, again highlighting the importance of the mother's wellbeing. Several studies refer to the severe impact of ASD on the family as a unit, yet the unique challenges that mothers face are often overlooked. To address the wellbeing of these mothers, it is necessary to understand their experiences of their child's diagnosis with ASD.

This qualitative phenomenological study explored and described mothers' experiences of their child's diagnosis with ASD by using the Process-Person-Context-Time model from Bronfenbrenner's bioecological theory as a framework. Unstructured interviews with seven mothers were conducted, voice recorded and transcribed. Data was analysed using thematic content analysis. Findings revealed four interrelated themes: 1) the mother's experience of the interactions and relationships within her immediate family (*Proximal Process*), 2) the mother's experience of her internal and external characteristics and resources (*Person*), 3) the mother's experience of her environment (*Context*), and 4) the mother's experience of the journey through time (*Time*). Bronfenbrenner's theory in its matured form also proved to be of value in understanding these mothers' daily lives and challenges.

The key findings provide valuable insight that may inform professionals who develop support programmes aimed at mothers with ASD children or that may guide such professionals' therapeutic interventions with mothers with ASD children.

Keywords: autism diagnosis, autism spectrum disorder (ASD), Bronfenbrenner's bioecological theory, mothers' experiences, phenomenology, Process-Person-Context-Time (PPCT), qualitative research

OPSOMMING

Outisme of outistiese spektrum versteuring (OSV) is ‘n komplekse neurologiese toestand wat gekenmerk word deur swak sosiale interaksie, kommunikasie en gedrag. Die huidige toename in die voorkoms van outisme is kommerwekkend. 'n Groot groep ouers is soekend na antwoorde oor hul kind se ontwikkelingsagterstand. Ná die diagnose moet hulle die uitdagings hanteer wat met die opvoeding van 'n OSV-kind gepaard gaan. Navorsing het bewys dat ouerskap van 'n kind met OSV besonder uitdagend is vir moeders omdat sulke moeders swakker gesondheid op 'n fisieke en psigiese vlak beleef en hoë stresvlakke moet hanteer. Die literatuur dui aan dat die moeder se interaksie met haar OSV-kind 'n direkte invloed op die prognose vir die kind se ontwikkeling het, wat die belangrikheid van die moeder se algemene gesondheid beklemtoon. Verskeie studies verwys na die impak wat OSV op die gesinseenheid het, maar die unieke uitdagings wat die moeders moet hanteer word dikwels oor die hoof gesien. Om aandag aan die welstand van sulke moeders te skenk, is dit belangrik om hul ervarings van ’n OSV-kind te verstaan.

Hierdie kwalitatiewe fenomenologiese studie ondersoek en beskryf moeders se ervarings van hul kind se diagnose met OSV binne die raamwerk van die Proses-Persoon-Konteks-Tyd model van Bronfenbrenner se bio-ekologiese teorie. Ongestruktureerde onderhoude is met sewe moeders gevoer. Hierdie onderhoude is opgeneem en getranskribeer. Die data is deur middel van tematiese inhoudsanalise ontleed wat tot die identifisering van die volgende vier temas gelei het: 1) die moeders se ervarings van hul interaksies en verhoudings met hul onmiddellike gesin (*Proksimale Prosesse*), 2) die moeders se ervarings van hul interne en eksterne karaktereienskappe en hulpbronne (*Persoon*), 3) die moeders se ervarings van hul omgewing (*Konteks*), en 4) die moeders se ervarings van hul ervarings met verloop van tyd (*Tyd*). Bronfenbrenner se teorie in die ontwikkelde vorm het 'n waardevolle bydrae gelewer om moeders se daaglikse lewe en uitdagings te help begryp.

Die belangrikste bevindinge van hierdie studie bied waardevolle insigte wat professionele persone kan lei wanneer daar ondersteuningsprogramme ontwikkel word wat spesifiek op moeders met OSV-kinders gerig is. Dit kan ook professionele persone help wat terapeutiese dienste aan hierdie moeders lewer.

Sleutelwoorde: Bronfenbrenner se bio-ekologiese teorie, ervarings van moeders, fenomenologie, kwalitatiewe navorsing, outisme diagnose, outistiese spektrum versteuring (OSV), Proses-Persoon-Konteks-Tyd (PPKT)

ABBREVIATIONS

APA	American Psychiatric Association
ASA	Autism South Africa
ASD	Autism Spectrum Disorder
C.A.R.D.	Centre for Autism and Related Disorders
DSM-V	Diagnostic and Statistical Manual of Mental Disorders (fifth edition)
MMR	measles, mumps and rubella (vaccination)
MMWR	Morbidity and Mortality Weekly Report
NWU	North-West University
PDD-NOS	pervasive developmental disorder not otherwise specified
PPCT	Process-Person-Context-Time
SACSSP	South African Council for Social Service Professionals

CONTENTS

DECLARATION BY RESEARCHER ii
DECLARATION BY LANGUAGE EDITOR iii
ACKNOWLEDGEMENTS iv
SUMMARY vi
OPSOMMING vii
ABBREVIATIONS viii
FOREWORD xiii

SECTION A: ORIENTATION TO THE RESEARCH

PART 1: INTRODUCTION 1

1.1 PROBLEM STATEMENT 2
1.2 THEORETICAL FRAMEWORK 6
1.3 AIM OF THE STUDY 8
1.4 CENTRAL THEORETICAL STATEMENT 8
1.5 RESEARCH METHODOLOGY 8
1.5.1 Literature review 8
1.5.2 Research design 9
1.5.3 Sampling 10
1.5.3.1 Population 10
1.5.3.2 Sample method 10
1.5.3.3 Sample size 11
1.5.4 Data collection 11
1.5.4.1 Method of data collection 11
1.5.4.2 Procedures 12
1.5.5 Data analysis 13
1.6 ETHICAL ASPECTS 14
1.6.1 Review of literature 15

1.6.2 Avoidance of harm 15
1.6.3 Voluntary participation, information and consent forms 15
1.6.4 Privacy, anonymity and confidentiality 16
1.6.5 Benefits and compensation 17
1.6.6 Feedback to participants 17
1.6.7 Expertise of the researcher to do research 17
1.6.8 Possible subjectivity by the researcher 18
1.7 TRUSTWORTHINESS 18
1.7.1 Credibility 18
1.7.2 Transferability 19
1.7.3 Dependability 19
1.7.4 Confirmability 19
1.8 FRAMEWORK FOR THE RESEARCH REPORT 20
1.9 SUMMARY 20

PART 2: LITERATURE STUDY

2.1 INTRODUCTION 22
2.2 AUTISM SPECTRUM DISORDER 22
2.2.1 Definition 22
2.2.2 Impairments associated with ASD 23
2.2.2.1 Social interaction 23
2.2.2.2 Communication 24
2.2.2.3 Stereotyped behaviour 24
2.2.2.4 Sensory integration problems and other comorbid conditions 25
2.2.3 Theories of causality 26

2.2.4 Treatments 27
2.2.5 Parenting a child with ASD 29
2.2.5.1 ASD-associated parenting stress in mothers and fathers 30
2.2.5.2 The marital relationship 32
2.2.6 Grief and loss 34
2.2.7 Support to families living with ASD children 35
2.3 THEORETICAL FRAMEWORK FOR THE STUDY 35
2.3.1 Phenomenology 36
2.3.1.1 Transcendental phenomenology 37
2.3.1.2 Hermeneutic phenomenology 38
2.3.1.3 Existential phenomenology 38
2.3.2 Bronfenbrenner's bioecological perspective 39
2.3.3 Bronfenbrenner's bioecological theory 41
2.3.3.1 Proximal processes 41
2.3.3.2 Person 42
2.3.3.3 Context 43
2.3.3.4 Time 43
2.4 SUMMARY 44
REFERENCE LIST 45

SECTION B: ARTICLE

ABSTRACT 62
Mothers' experience of receiving their child's diagnosis of an autism spectrum disorder 63
Theoretical framework 66
Aim of the study 69

Method 69
Participants 70
Procedures 70
Data analysis 70
Trustworthiness 71
Discussion of findings 72
Theme 1: The mother's experience of interactions and relationships within her immediate family (Proximal Process) 74
Mother-Child 74
Mother-Father 75
Mother-Other children 76
Theme 2: The mother's experience of her internal and external characteristics and resources (Person) 77
Internal challenges 77
Internal strengths 77
Internal characteristics 78
External resources 79
Theme 3: The mother's experience of her environment (Context) 79
Micro level 79
Meso level 80
Macro level 81
Theme 4: The mothers' experience of the journey through time (Time) 82
Before diagnosis 82
Diagnosis 82
Current 83
Future 83
Throughout the process 84
Conclusions 85
Limitations 87
Future research 87
Reference list 88

SECTION C: CONCLUSIONS AND RECOMMENDATIONS

1. INTRODUCTION 98

2. AIM OF THE STUDY **98**

3. CONCLUSIONS AND RECOMMENDATIONS **99**

3.1 Conclusions based on the themes emerging from the study **99**

3.2 Conclusions regarding Bronfenbrenner's bioecological theory as framework **104**

4. REFLECTIONS ON THE RESEARCH PROCESS **104**

5. LIMITATIONS OF THE STUDY **106**

6. IN CLOSING **106**

SECTION D: ANNEXURES

Annexure 1: Consent form for research **108**

Annexure 2: Declaration of confidentiality by transcribe **112**

Annexure 3: Example of transcription **113**

Annexure 4: Table of themes, subthemes and categories **129**

Annexure 5: Technical guidelines for journal **144**

List of tables and figures:

Table 1: Thematic presentation of mothers' experiences of their child's diagnosis with ASD **73**

FOREWORD

This dissertation is presented in an article format according to the General Academic Rules (Rule A.5.4.2.7) as set out in North-West University's Potchefstroom Campus Yearbook. Therefore, this document comprises three sections. Section A provides an orientation to the research, including an introduction, the problem statement and literature study. Section B contains the article that will be submitted to *Focus on Autism and other Developmental Disabilities* for publication. Section C includes conclusions and recommendations. Please note that the references provided in Section B are in line with the author guidelines of the journal (Annexure 5) which requests APA referencing style, while sections A and C is referenced according to the Harvard method, as provided by North-West University's referencing manual.

SECTION A: ORIENTATION TO THE RESEARCH

This section comprises two parts:

Part 1: Introduction, problem statement, research methodology and ethical aspects

Part 2: Literature study

PART 1: INTRODUCTION

1.1 PROBLEM STATEMENT

Autism spectrum disorder (ASD)[1] is a childhood developmental disorder that is characterised by a triad of deficits in social reciprocity, communication, and restricted, repetitive behaviours or interests (Barker, Hartley, *et al.*, 2011:1-2; De Alba & Bodfish, 2011:633; Farrugia, 2009:1011; Janzen, 2009:6-10; Lin *et al.*, 2008:2733-2734; Martin, 2010:12-13; Quin, 2006:5-15; Siklos & Kerns, 2007:9-10; Swanepoel, 2003:ii; Woodgate *et al.*, 2011:1075). The latest *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V, APA, 2013:50) made significant changes to the diagnostic criteria for autism, and now identifies ASD through impairments in only two major domains: social communication and interaction, and "restricted, repetitive patterns of behaviour, interests, or activities".

Autism is a term that many people have become familiar with because of its increasing prevalence (King & Bearman, 2009; NHSR, 2013:5; Posavad, 2009:2). According to the Centre for Disease Control and Prevention's latest study in 2008 (MMWR, 2012:1) one in 88 children in the United States was diagnosed with ASD, while the prevalence during the six-year period from 2002 to 2008 increased by 78% for the American population. According to Bateman (2013:276), the United States Department of Health estimated that cases of autism have increased by 500% over the past five years.

Accurate and recent national autism statistics in South Africa are hard to come by (Bateman, 2013:276). In South Africa in 2006 the prevalence of autism alone was 88 896 out of an estimated population of 44.5 million people, with an incidence of 490 new cases being diagnosed every year (Adviware Pty Ltd, 2006). These alarming statistics are confirmed by Autism South Africa, which claims that in South Africa one child with autism will be born every hour (ASA: 2012). In his study, Bateman (2013:276) spoke to the director of Star Academy of Learning in Johannesburg[2], who receives on average ten calls and/or emails per week from parents with tentatively or newly diagnosed ASD children. Bateman also mentioned that in the

[1] **Note about terminology**
A variety of terms are used to discuss autism, the most popular being Autistic Spectrum Disorder (ASD). This study will use the term ASD, except where authors have specifically referred to autism.

[2] **Star Academy of Learning**
Johannesburg based private school for children with ASD. The Star Academy is an affiliate of the Centre for Autism and Related Disorders (C.A.R.D.) based in the USA.

Western Cape, ten children a week are collectively diagnosed with ASD at the Red Cross Children's Hospital, Lentegeur and Tygerberg Hospitals.

These statistics conclude that a very large population of parents is searching for answers regarding their child's developmental delays, eventually receiving an ASD diagnosis followed by the challenge to raise such a child. Some international studies have shown that parents awaiting a diagnosis and parents who had just received a diagnosis often experienced very high levels of stress, loneliness and uncertainty (Banach *et al.*, 2010:69-70; Estes *et al.*, 2009:375; Montes *&* Halterman*,* 2007:1040; Shu, 2009:81; Siklos & Kerns, 2007:20; Vidyasagar & Koshy, 2010:245; Woodgate *et al.*, 2011:1075-1076). These high stress levels often resulted in poor marital relationships (Brobst *et al.*, 2009:38; Martin, 2010:88-89), communication problems (Wachtel, 2006:3) and concerns about whether the autistic child will be accepted by society (Hornstein, 2011:4; Kalash, 2009:xii). The stereotyped and repetitive behaviours of children with ASD often limited the families' opportunities for social activities (Estes *et al.*, 2009:376; Gane, 2008:13), consumed the energy of family members and caused anxiety (Brobst *et al.,* 2009:38-39). According to the preceding literature, there is no doubt that having a child with ASD is life changing for parents and their families, and that the challenges and stressors associated with an ASD child can significantly reduce the prognosis for effective interventions. A study done by Osborne *et al.* (2007:1092) found that parenting stress reduced the effectiveness of early teaching interventions for autistic spectrum disorders significantly. Osborne and Reed (2009:54) mentioned that the recognition of the role of parenting stress and its connection to behavioural problems in ASD children has increased, as confirmed by the studies of Blacher and McIntyre (2006), Eisenhower *et al.* (2005), and Osborne *et al.* (2007).

There also seems to be notable differences in the way mothers and fathers experienced these stresses. Hornstein (2011:3) agreed with the view of Gray (2003:632) that mothers were more likely to feel guilt or shame and experience depression, whereas fathers were more likely to suppress their feelings. According to a study conducted by Vidyasagar and Koshy (2010:245), parenting a child with a developmental disability is especially exhausting for mothers as they are more involved with care giving, and therefore mothers need to make the most dramatic adjustment to a child's exceptionality. Vidyasagar and Koshy (2010:245) concluded that mothers run a higher risk of succumbing to the effects of long-term stress than fathers. A study by Mourisden *et al.* (2007) also showed significantly higher rates of depression and alcohol abuse among mothers of children diagnosed with autism than among the fathers of such children. This study showed that mothers in particular experienced a significant degree of guilt and depression after diagnosis. Another study by Wachtel and Carter (2008:577-578) showed

evidence that the maternal interaction style may impact a child's developmental course, which highlights the importance of the way in which the mother handles the ASD diagnosis. Gane (2008:2) stated that although this was not always the case, mothers are generally the primary caregivers, yet their stories mostly go untold. This study will therefore specifically focus on mothers of children diagnosed with ASD.

For the purpose of this study, the researcher undertook extensive literature searches and concluded that autism is one of the most researched childhood disorders. As confirmed by Ritchie (2008:17) and Wilkinson (2009:22), most of the research on autism focuses on searching for causes, looking at intervention strategies and unpacking the diagnostic criteria. Parenting children diagnosed with ASD does get recognition in literature (Gane, 2008:2; Rarity, 2007:9) as the focus mostly falls on managing intervention strategies and coping with behavioural changes.

A considerable amount of ASD literature also focused on marital satisfaction and the experiences of siblings living with ASD (Bishop, 2012; Brobst *et al.,* 2009). A small amount of international literature was found on parents' experiences of their journey leading up to diagnosis, as well as receiving the ASD diagnosis (Braiden *et al.*, 2010; De Alba & Bodfish, 2011; Ducey, 2009; Evans, 2010; Feliciano, 2008; Gane, 2008; Holdt, 2008; Lin *et al.*, 2008; Milshtein *et al.*, 2010; Rose, 2011; Siklos & Kerns, 2007; Wachtel, 2006; Wachtel & Carter, 2008). Within the South African context, only eight studies could be found that were related to parental experiences regarding children diagnosed with ASD. These studies focused on the ASD diagnosis (Holdt, 2008; Mitchell & Holdt, 2014), raising children with ASD (Balfour, 2007; Hoffman, 2012; Swanepoel, 2003), parental challenges and strategies (Olivier & Hing, 2008) and resilience in families with an autistic child (Greeff & Van der Walt, 2010). One study by Dawson (2011) specifically focused on parents' experiences, but her study was done in Gauteng Province. Not one study focusing on mothers' experiences was undertaken within the borders of the Western Cape.

The Western Cape is one of nine provinces in South Africa and it has an estimated population of 6.02 million people (Statistics South Africa, 2013). At present, the Western Cape only has two government-funded Special Schools specifically geared toward ASD, namely Vera School and Alpha School. The growing demand for schools catering for children with ASD (Bateman, 2013:276) has seen some private institutions come to light; however, these are often very expensive and beyond the reach of most of the population (Enos-Matheny, 2012; Solidarity Helping Hand, 2011). As each province has different resources available to support families

with ASD children, this can notably change the experiences of mothers dealing with such a diagnosis. This emphasises the need for further studies in the Western Cape as a demographical area.

The limited literature on parental experiences and more specifically mothers' experiences of children diagnosed with ASD within the South African context failed to recognise the importance of understanding the parent's journey, which may pose a threat to the way in which professionals[3] support ASD-impacted parents throughout this process. Ritchie (2008) mentioned that the parents interviewed during her research expressed that therapy would have helped them to deal with the diagnostic process and to better cope with having a child with ASD. Rarity (2007:5-6) confirmed this and added that this gap in literature has led to the misunderstanding of parental responses to having a child with a disability.

A personal experience also contributed to the researcher's interest in the study, as the researcher is the mother of a child diagnosed with ASD. This gap in ASD-related literature based on the South African context is also confirmed by the fact that at the time the researcher's son was diagnosed, no local literature could be found on the experiences of parents whose children had been diagnosed with ASD. A lack of understanding of such experience prior to, during and after diagnosis was evident as not one professional recommended therapy or parental guidance to the researcher. The limited resources for services and support within South Africa, and specifically within the Western Cape, became evident once the researcher was faced with the ASD diagnosis of her child. Holdt (2008:4) confirmed this when she said that access to resources for diagnosis and interventions for ASD children in South Africa appeared to be limited to a few families. Her findings highlighted a lack of knowledge among professionals, an unwillingness to diagnose and a lack of support for such families. Limited resources within the Western Cape significantly impacted the experience of the researcher after the ASD diagnosis of her son because it created uncertainty with regard to future planning and interventions and it caused severe financial strain.

This study therefore aims to add to current literature focused on the South African context with specific reference to the Western Cape, endeavouring to add to the understanding of mothers' experiences of the ASD diagnosis of a child to the benefit of both the mothers as well as

[3] **Note about terminology**
For the purpose of this study, professionals refer to medical professionals, allied health professionals and other trained individuals involved in the treatment of ASD or rendering a support service to such families.

professionals rendering services to such mothers. This understanding may give professionals new information that could guide the way in which they plan treatment when working with mothers of children diagnosed with ASD.

In summary: The increase in the prevalence of ASD (King & Bearman, 2009; NHSR, 2013:5; Posavad, 2009:2) and the parental stress associated with the journey of seeking a diagnosis (Banach *et al.*, 2010:69-70; Estes *et al.*, 2009:375; Shu, 2009:81) are clearly indicated in literature. The studies on parental experiences of receiving a diagnosis for their child is limited, and even more so when the focus shifts to the South African context with limited resources for such disabilities (Bateman, 2013:276). This study will focus on ASD-affected mothers because mothers are usually the primary caregivers (Gane, 2008:2) and because literature confirms the higher rate of depression, alcoholism and parental stress (Mourisden *et al.*, 2007) among mothers. The South African context is characterised by limited resources for families with ASD-diagnosed children, insufficient support to parents parenting such children and a general lack of knowledge and understanding by professionals of mothers' experiences when receiving their child's ASD diagnosis. Therefore, understanding mothers' experiences could hold value for mothers with newly diagnosed children as well as for professionals who need to understand the unique struggles that such mothers face. This understanding could guide the way in which professionals plan treatment and support for families of children diagnosed with ASD.

Based on the above-mentioned, the following research question can be formulated: *What are mothers' experiences of their child's diagnosis with an autism spectrum disorder?*

1.2 THEORETICAL FRAMEWORK

The researcher utilised the phenomenological approach as both a method and a theoretical framework for this study. According to Tymieniecka (cited in Wojnar & Swanson, 2007:173), phenomenology has unfolded throughout the past 100 years, and as a philosophical perspective it has thrown light on previously ignored phenomena of the human experience. Phenomenological reality is comprehended through embodied or lived experience as only those who have experienced the phenomena can communicate them to the outside world (Roberts, 2013; Starks & Trinidad, 2007).

Lichtman (2010:79), Hamill and Sinclair (2010:16) and Roberts (2013:215) described the idea of the German philosopher Edmund Husserl (1859-1938) that phenomenology would enable the phenomenologist to come into contact with matters, the actual lived experiences. This particular study was selected to focus on the lived experiences of mothers after receiving the diagnosis of

an ASD child. Kafle (2011:188) explained that phenomenology was shaped by Husserl and others, and classified into three major schools: transcendental phenomenology, existential phenomenology and hermeneutic phenomenology. In its original form, transcendental phenomenology specifically speaks to bracketing (Roberts, 2013:215). In line with transcendental phenomenology, Lichtman (2010:79) and Hamill and Sinclair (2010:16) indicated that Husserl suggested that researchers must set aside their own views about the phenomenon by using the process of bracketing. According to them, bracketing ensures that researchers do not allow their assumptions to shape data or impose their understanding on the data. The school of hermeneutic phenomenology believes that interpretations and descriptions are inherently interpretive, and that reduction is impossible (Kafle, 2011:188). As described by Warthal (cited in Kafle, 2011), existential phenomenology shares the view of the hermeneutic phenomenologists, namely that reduction is not completely possible. Yet, existential phenomenologists firmly believe in focusing on re-achieving a direct and primitive contact with the world.

In this study, the existential phenomenological theoretical framework was utilised as it best suited the purpose of the study. The researcher herself has a "lived experience" of having a child diagnosed with ASD, but will "attempt to re-achieve a direct and primitive contact with the world", as described by Kafle (2011:188). The researcher took reasonable steps to ensure that presuppositions were brought to the level of consciousness, acknowledged and then bracketed. The process of bracketing will be discussed under the ethical considerations in 1.6.8.

The bioecological perspective will be utilised as a second theoretical framework. Henning *et al.* (2013:2) stated that a theoretical framework positions the research in terms of the discipline or subject in which the researcher is working. As mothers are the unit of analysis in this study, the application of this theory gave insight into the interrelatedness of mothers' experiences across systems and time, and created an understanding of their experiences within these contexts. Urie Bronfenbrenner's (1917-2005) theory of human development was in a continual state of evolvement until he died in 2005. His theory, although being altered, revised and constantly extended, was always and explicitly ecological, stressing person-context interrelatedness (Tudge *et al.*, 2009). Given the extent of the changes to his theory, and to avoid theoretical incoherence, Rosa and Tudge (2013) and Tudge *et al*. (2009) advised scholars to be cautious about stating that their research is based on Bronfenbrenner's theory without specifying which version they are using. In this study, the final version of Bronfenbrenner's theory was applied, named the bioecological theory. During this phase Bronfenbrenner coined the Process-Person-Context-Time (PPCT) model, which deals with the interactions among these concepts

(Bronfenbrenner & Morris, 2006; Tudge *et al.*, 2009). Using the PPCT model, the researcher sought to understand the mothers' experiences of receiving their child's ASD diagnosis.

1.3 AIM OF THE STUDY

The aim of this study can be formulated as follows:

To explore and describe mothers' experiences of their child's diagnosis with an autism spectrum disorder (ASD).

1.4 CENTRAL THEORETICAL STATEMENT

Understanding mothers' experiences of their child's diagnosis with ASD within the South African context, and specifically the Western Cape, may produce findings that could be helpful to other mothers of children diagnosed with ASD. It could also enhance professionals' understanding of the unique struggles and needs of these mothers. For mothers with children who are newly diagnosed with ASD the research findings could be of value to identify with other mothers within the same context, to help normalise their own experience and/or emotions and possibly to guide them to resolution. For professionals, this study may produce findings that can guide the way in which they plan treatment and support when working with mothers of children diagnosed with ASD.

1.5 RESEARCH METHODOLOGY

1.5.1 Literature review

A literature review was conducted in order to consider various aspects of the problem statement in greater depth. According to Gay *et al.* (2009:80) as well as Maree and Van der Westhuizen (2007:3), a literature review involves the systematic identification, location and analysis of documents containing information related to the research problem, determines what has already been done in terms of the topic and identifies gaps in research. Henning *et al.* (2013:2) described the literature review as the contextualisation of the study to identify a niche to be occupied. For this purpose, literature from a variety of sources was consulted. This included national and international journals, books, websites, research reports, theses and seminars. Databases such as EBSCOhost, PsycLit, PsycINFO, Academic Search Premier, ScienceDirect, ERIC and ProQuest were utilised to gather information.

For the purpose of this study, the following topics guided the literature review:

- ASD terminology and definitions (Janzen, 2009; Martin, 2010; Department of Health Rhode Island, Resource Guide for Families of Children with Autism Spectrum Disorders, 2011; Keen & Rodger, 2012)
- Diagnosing a child with ASD (APA, 2013; Braiden *et al.*, 2010; Siklos & Kerns, 2007; Taylor, 2011)
- Parenting a child with ASD (Balfour, 2007; Constantino, 2010; Keen & Rodger, 2012; Woodgate *et al.*, 2011)
- Phenomenology as philosophical framework (Ducey, 2009; Hamill & Sinclair, 2010; Kafle, 2011; Roberts, 2013)
- Bioecological theory by Urie Bronfenbrenner (Bronfenbrenner, 1994; Bronfenbrenner; 1995; Bronfenbrenner & Morris; 2006; Tudge *et al.,* 2009).

As described by Delport, Fouché and Schurink (2011:305), a literature control was also done to verify data findings. This included literature on parent experiences of the diagnostic process and raising a child with ASD (Gane, 2008; Posavad, 2009; Siklos & Kerns, 2007; Swanepoel, 2003).

1.5.2 Research design

For this study, the researcher made use of a qualitative phenomenological design. The purpose of the qualitative method is to explore, describe, generate deeper understanding and gather theoretically rich observations (Babbie, 2011:67; Creswell *et al.*, 2007:252; Fouché & Delport, 2011:64-65; Fouché & De Vos, 2011:95-96; Gay *et al.*, 2009:7; Lichtman, 2010:5).

Phenomenology aims to reduce individual experiences of a phenomenon to a rich description of the universal essence (Creswell, 2006:58). Various authors – Botma *et al.* (2009:190), Creswell *et al.* (2007:252), Fouché and Schurink (2011:316) and Gay *et al.* (2009:12) – explained the root of phenomenology as the intent to understand the phenomena under study and to carefully describe ordinary conscious experiences of everyday life from the participants' perspective. The researcher studied the phenomena of mothers' experiences of their child's diagnosis with an autism spectrum disorder, and aimed to give rich descriptions by exploring and describing these experiences.

1.5.3 Sampling

1.5.3.1 Population

The population of a study is all the individuals that meet certain criteria for inclusion in a given universe (Botma *et al.*, 2009:200; Gay *et al.*, 2009:604; Gerring, 2007:216; Guthrie, 2010:54-55). For the purpose of this study, the criteria for inclusion in the population consisted of:

- Mothers of children who have been diagnosed with ASD
    - Within the past five years
    - Who speak either Afrikaans or English
    - Who reside in the Northern Suburbs of Cape Town.
- Together with the above mentioned, the mothers taking part in this study were those who gave written consent to participate voluntarily and to have the interviews voice recorded (see Annexure 1).

1.5.3.2 Sample method

Sampling is defined by Botma *et al.* (2009:199), Nieuwenhuis (2007a:79), Strydom and Delport (2011:390) and Babbie (2011:528) as the means of taking any portion of a population as representative of that population. Creswell (2006:125), Neuman (2007:142) and Nieuwenhuis (2007a:79) explained purposive sampling as a particular case being chosen because it illustrates some features, interest or knowledge regarding the study or the lived experience. Henning *et al.* (2013:71) described it as choosing individuals who fit the criteria of “desirable participants”. This study made use of the non-probability sampling technique, and used purposive sampling methods as described by Gay *et al.*, (2009:136-137), Strydom (2011:232) as well as Strydom and Delport (2011:392).

An educational psychologist from the Northern Suburbs of Cape Town who specialises in ASD was asked to act as intermediary in identifying mothers who fall within the scope of the above-mentioned criteria. She made initial contact with prospective participants, described the scope of the research project in brief, ascertained their willingness to participate voluntarily, and asked permission to forward their details to the researcher. The researcher contacted the mothers telephonically and set times and dates aside for interviews. The consent forms (Annexure 1) were forwarded to participants via email or post for their perusal before the interviews took place.

1.5.3.3 Sample size

The size of the sample in a phenomenological study is discussed in depth by Englander (2012:20). He highlighted the importance of asking the right questions and stated that asking "how many participants are needed" is irrelevant due to the fact that the research is qualitative. The goal of a phenomenological study is not to generalise, but rather to identify the essential structure of a phenomenon. Englander (2012:21) recommended that one uses at least three participants. For this study, seven mothers were selected from the sampling frame as discussed above. Interviews were conducted until information gathered from the participants became saturated. According to Gay *et al.* (2009:137), this happens when the researcher begins to hear the same thoughts, perspectives and responses from participants.

1.5.4 Data collection

1.5.4.1 Method of data collection

Unstructured interviews were conducted to gather data as these interviews allowed for the individual meanings and understandings of each individual to be brought to the fore (Greeff, 2011:342; Neuman, 2007:296; Scott & Morrison, 2007:134). These interviews were unstructured or in-depth which, according to Greeff (2011:351-352) and Guthrie (2010:119), can also be referred to as a conversation with a purpose. Unstructured interviews require a general plan, but the interviewer used the flexibly of open-ended questions to avoid directing the flow of the comments (Guthrie, 2010:119; Wellington & Szczerbinski, 2007:84) and to understand the experiences of other people and the meaning they make of such experiences (Gay *et al.*, 2009:371; Greeff, 2011:348). Gay *et al.* (2009:371) suggested that researchers should use prompts like who, what, where, when, why and how. Greeff (2011:349) agreed with Gay *et al.* (2009:371) but added that in a bracketed interview the research question is not pre-determined; instead, it flows within a clue-and-cue taking process after the first question has been asked. The following main question was asked to participants: *"Tell me about your experience of having your child diagnosed with an ASD."*

Academic literature abounds with interview guidelines, techniques and tips for researchers on how to go about conducting effective interviews (Babbie, 2007:307-308; Gay *et al.*, 2009:371; Greeff, 2011:343-346; Guthrie, 2010:125-126; Lichtman, 2010:145-146; Neuman, 2007:190-194; Ruben & Babbie, 2011:463-467; Wellington & Szczerbinski, 2007:81-86). Some of these guidelines were implemented during the interviews for this study:

- Listen more, talk less.

- Do not interrupt, and tolerate silence.
- Avoid leading questions.
- Keep participants focused and follow-up on what participants say.
- Keep a neutral demeanour, and do not debate with the participants over their responses.
- Questions must be brief, clear, open-ended and asked one question at a time.
- "Funnel" questions from general to specific.
- Use communication techniques such as paraphrasing, clarification, reflection, encouragement, probing and acknowledgement.

The interview included field notes of observations made by the researcher during the interviews (facial expressions, emotions observed during interview, et cetera). Babbie (2007:310) reminded that both empirical observations and interpretations should be noted during the interview, and explained that notes should be made on what the researcher "knows" has happened, as well as what the researcher "thinks" has happened. Neuman (2007:289-292) and Guthrie (2010:112) relayed the importance of making notes as soon as possible after leaving the field – while the researcher's memory is still fresh. For this study, field notes were taken and clarified during interviews to curb making assumptions. The field notes were incorporated during the data analysis process.

Interviews for this study lasted between 35 and 105 minutes each. Participants were notified that should the researcher feel that a second interview would be of value and could bring new information to the fore, this would be arranged at their convenience. For this study, participants were only interviewed once; there was no need for a second interview as the data obtained was sufficient. Interviews were voice recorded by means of a dictaphone after permission was obtained from participants. Gay *et al.* (2009:372) noted that voice recordings are convenient and reliable, and ensured that original data is available if needed. Neuman (2007:292) agreed and elaborated that these recordings served as "jotted notes" to help the researcher recall events and observe what is easy to miss.

Interviews were held where they were most convenient for the participants. Two participants preferred that interviews be conducted at their homes while their children were not present. The other interviews were held in the researcher's private practice in Bellville in the Northern Suburbs of Cape Town.

1.5.4.2 Procedures

The procedures below were followed during the data collection process:

- Ethical approval was obtained from North-West University (Ethics number: NWU-00125-14-S1).
- The researcher contacted and informed an educational psychologist, who specialises in autism, about the planned research project.
- The researcher requested the educational psychologist to act as intermediary in identifying possible mothers who fall within the criteria of this study, to make initial contact with them, to obtain permission from them to be contacted by the researcher, and to supply the researcher with the names and contact details of those mothers who were willing to participate voluntarily.
- Participants who volunteered to be involved in the study were contacted to ensure their availability to participate in interviews.
- After initial contact, participants were provided with an informed consent form (Annexure 1) via email or post to complete, highlighting their participation as voluntarily and confidential.
- The research question was validated with one non-participant who falls within the criteria of the study population.
- Participants were contacted to arrange times and venues suitable to them to conduct the interviews.
- The transcription of the one-to-one interviews commenced after the first interview was concluded. Voice recordings were sent to be transcribed as interviews were finalised.
- The transcription and collation of the data obtained for documentation in the research project were concluded.
- After data analysis the preliminary themes, subthemes and categories were emailed to all the participants to peruse as part of member checking, and with the purpose of verifying the research findings.

1.5.5 Data analysis

Analysing qualitative data is the process of bringing order, structure and meaning to a mass of collected data in order to make sense of the research question (Creswell, 2012:236). This entails reducing the quantity of raw information, sifting significant data from trivia, identifying patterns and constructing a framework for communicating the essence of what the data reveals (Botma *et al.,* 2009:220-221; Schurink *et al.*, 2011:397).

Interviews for this research project were voice recorded by means of a dictaphone and then transcribed. Gay *et al.* (2009:449) described the procedures after data collection as a multi-

stage process of organising, categorising, synthesising, analysing and writing. Transcriptions together with field notes and observational notes were read multiple times while making notes in the margins. Creswell (2012:238) explained that qualitative researchers analyse data by reading through it several times and by gaining a deeper understanding of the information with each read. For this study the data analysis method as proposed by Creswell (2006:156-157) and Gay *et al.* (2009:449) were utilised. This method entailed a number of interrelated steps: 1) Data was managed and organised by creating a file with all the transcribed interviews and field notes; 2) transcriptions and field notes were read and re-read in order to become familiar with the data and to identify possible themes by using coloured highlighters and notes in the margins (i.e. reading/memoing); 3) detailed descriptions were provided after an in-depth examination of the data (i.e. describing); 4) data was categorised and coded into themes or meaningful units (i.e. classifying); 5) a textural description or the "essence" was developed and 6) this was presented in a table (see Annexure 3).

The goal of the coding process is described by Creswell (2012:243) as making sense of the data by dividing it into text or segments, labelling the segments with codes, examining the codes for overlap or unnecessary information and then collapsing these codes into broad themes. The identified themes or categories were critically examined and compared with existing literature to confirm or challenge the emerging themes. These themes were also taken back to participants in the form of member checking. The goal of member checking (Botma *et al.,* 2009:231; Creswell, 2006:208) was to determine the accuracy of the findings in order to give credibility to the researcher's understanding and interpretation of the data. Member checking was done via an email to all participants who then had the opportunity to verify or reject the preliminary findings. Participants did not reject any of these preliminary findings.

1.6 ETHICAL ASPECTS

The following ethical practices were taken into consideration for the purpose of this study:

The Health Research Ethics Committee of the Faculty of Health Sciences of the North-West University (Ethics number: NWU-00125-14-S1) granted ethical clearance for this study, ensuring that all ethical aspects of this study were considered. The researcher is also a social worker by profession, and thus governed by the Social Services Professions Act (No 110 of 1978, as amended in 1998) as well as the Ethical Code of the South African Council for Social Work Professions (1986).

Procedures and considerations to ensure an ethical and reciprocally beneficial research project are described by Botma *et al*. *(*2009*:*4-27), Gay *et al.* (2009:19-24), Guthrie (2010:15-23), Henning *et al.* (2013:73-74), Lichtman (2010:52-58), Neuman (2007:50-65), Ruben and Babbie (2011:76-84), Scott and Morrison (2007:87-89), Strydom (2011:115-129) and Wellington and Szczerbinski (2007:58-63). For this study, the following aspects will be described in more detail: the review of the literature, the avoidance of harm, voluntary participation, information and consent forms, privacy, anonymity, confidentiality, benefits and compensation, feedback to participants, the expertise of the researcher and the possible subjectivity of the researcher.

1.6.1 Review of the literature

Care was taken to ensure that when dealing with literature, authors of the sources used were acknowledged by citing their names to identify the source of the idea. For this study, Sections A and C used the Harvard style of referencing (NWU: Referencing Guide, 2012), whereas Section B used the APA style of referencing which is in line with the requirements of the journal to which the article will be submitted (Annexure 4).

1.6.2 Avoidance of harm

The mothers of children diagnosed with ASD might have had to revisit the strong emotions and/or the possible trauma they experienced during this period of receiving their child's diagnosis. It was therefore possible that these emotions could resurface. As a precautionary measure, participants were provided with referral information for psychological counselling and containment services in the event that they might require such assistance. If needed, the psychological counselling would have been offered by a colleague of the researcher, who also had an interest in working with families affected by ASD. No costs would have been involved and the number of sessions would have been determined by the psychologist after an initial assessment. None of the participants made use of this service, but they knew that they could contact the researcher should they have the need to do so. This service was available to participants for three months after the interviews were conducted.

1.6.3 Voluntary participation, information and consent forms

Research participants were provided with and asked to sign a written consent form informing them about what the study entailed and providing an honest and accurate description of the aims and nature of the study (Annexure 1). This consent form reiterated that participation was voluntary, that interviews would be voice recorded and that participants had the right to withdraw without prejudice until such time as the interview was transcribed. This was also

verbally communicated during the recruitment of participants. After the participants had received the copy of the information and consent form the researcher allowed them time to consult with others and think about their participation. The researcher also allowed for a question-and-answer opportunity should the participants have any concerns or queries.

1.6.4 Privacy, anonymity and confidentiality

Various researchers have noted in literature (Botma *et al.,* 2009:17) that the key concepts of any research findings should be grounded in ensuring the protection of participants' privacy and identity. According to Henning *et al.* (2013:73) it is necessary for participants to know that their privacy will be protected and what will happen to their information after the data has been collected. This information was conveyed to participants orally as well as on the informed consent form as described above (Annexure 1).

Interviews for this study were conducted at a venue that allowed for the necessary privacy. Two participants preferred having the interviews at their homes when their children were not present, but the other five mothers felt that it was more convenient for them to have the interviews at the researcher's private practice office.

According to Botma *et al.* (2009:17) confidentiality refers to, among others, personal information, biographical details, medical history, personal characteristics and sexual practices. To maintain confidentiality, Botma *et al.* (2009:18) guide researchers to take the following four areas into account:

The content of the data-capturing forms

This study ensured that content or data was handled confidentially as the person who transcribed the interviews signed a declaration to upkeep confidentiality (Annexure 3). An example of a transcript is submitted as an appendix to this dissertation (Annexure 2).

Access to data

Information was kept on the researcher's personal computer in a password protected file to which only the researcher had access.

Safe and secure storage of data

Physical data is kept safe in a locked filing cabinet at North-West University for a period of five years, after which the data will be destroyed.

The anonymous reporting of data

No identifying details of participants are evident in the research report based on this study. Anonymity of information obtained was ensured by using pseudonyms on all data records, analysis sheets and result records. In the transcript that is attached as an appendix (Annexure 2) all names or other identifying particulars where blocked out by highlighting these areas in black.

1.6.5 Benefits and compensation

The researcher was obligated to maximise possible benefits for participants, and eventually the population of parents with a child with ASD. This study might have benefited the participants in the following ways:

1) Participants could have felt that they were contributing to knowledge that could assist other parents and professionals in managing the process of an ASD diagnosis. Their altruism could therefore lead to enhanced personal worth and improved self-esteem.

2) Participants might have gained insight into their own experience, social circumstances and emotional resilience leading to improved psychological functioning.

3) Mothers could find that the research process gave them the opportunity to reflect on their own journeys, allowing them to acknowledge their own growth and strengths.

No compensation or remuneration was given to participants.

1.6.6 Feedback to participants

Feedback will be given to participants by emailing them the findings in the form of the article manuscript, as all participants have access to email. The email will be accompanied by an invitation to participants to contact the researcher should they have any questions or uncertainties regarding the findings, or should they want to discuss the content.

1.6.7 Expertise of the researcher to do research

The researcher is a social worker by profession and is registered with the South African Council for Social Service Professionals (SACSSP). This registration bounds the researcher to conduct ethical practices at all times. The researcher's studies also covered research methodology and research practice. In addition, the researcher conducted this research under the supervision of a qualified social worker.

1.6.8 Possible subjectivity by the researcher

The researcher is the mother of an ASD-diagnosed child. Hence, she attempted to make sure that her own assumptions and understandings did not shape the data or data analysis process. In line with existential phenomenology, as described by Warthal (cited in Kafle, 2011), the researcher acknowledged that complete reduction or bracketing of own experiences and assumptions was not completely possible, but aimed to re-achieve a direct and primitive contact with the phenomenon under study by applying bracketing. The process of bracketing, as described by Husserl (cited in Lichtman, 2010:79, cited in Hammill & Sinclair, 2010:16), was implemented by doing reflective journaling, establishing regular contact with the researcher's supervisor and doing member checking.

1.7 TRUSTWORTHINESS

According to Nieuwenhuis (2007b:113), trustworthiness in qualitative research is of utmost importance. To ensure trustworthiness, Schurink *et al.* (2011:419) and Loh (2013:5) referred to the following four constructs as proposed by Lincoln and Cuba:

1.7.1 Credibility

Botma *et al.* (2009:232) explained that trustworthiness has four epistemological standards, and that adherence to the strategies and criteria of each standard will ensure rigour in research. Credibility is a strategy to attain the epistemological standard of the truth value. According to Botma *et al.* (2009:234), the criteria to achieve credibility include prolonged engagement in the field, the reflexivity of the researcher, member checking and interview technique.

In terms of this research, credibility was ensured by conducting the inquiry in a manner that accurately identified and described the phenomenon. This was attained by conducting unstructured interviews with no time constraints, allowing participants to give rich descriptions of their experiences, persistent observation (field notes, observational notes, reflective journaling) and member checking. Nieuwenhuis (2007b:113) elaborated on the verification of raw data and mentioned that during subsequent interviews the researcher may ask participants to verify the data gathered. The researcher made notes during the course of the interviews, and verified uncertainties at the end by asking participants to clarify the data. To minimise subjectivity, researcher was reflective by attempting bracketing as described in 1.6.8.

1.7.2 Transferability

Transferability refers to the degree to which findings can be transferred to another setting (Botma *et al.,* 2009:233). However, according to Nieuwenhuis (2007b:115), transferability is not about generalising findings across a population. Transferability in research enables studies to be duplicated elsewhere, and possibly yield similar results. The phenomenological nature of this study minimises the likelihood of yielding similar results elsewhere, but the study does give a thick and dense description of the setting in which the research was conducted, as explained by Scott and Morrison (2007:251) when they described transferability in qualitative research. Transferability in this study was further attained by the researcher clearly stating and describing the theoretical parameters of the study.

1.7.3 Dependability

The epistemological standard of consistency as described by Botma *et al.* (2009:233) can be attained by implementing dependability as a strategy. Dependability refers to whether findings will be consistent if the inquiry would be simulated with the same participants in a parallel context (Botma *et al.,* 2009:233). This research project attained dependability by documenting and giving detailed descriptions of how the data was collected (procedures and methodology were described in detail, notes were kept of research decisions taken) and it adhered to strict procedures as set out previously. Findings were verified and validated by doing member checking. The research was also conducted under the supervision of a qualified social worker who is objective and helped to ensure that the methodology was followed as set out in the procedures.

1.7.4 Confirmability

The concept of confirmability refers to the researcher's concern with objectivity and neutrality. According to Houghton *et al.* (2013:13), confirmability is the extent to which the findings of the study are shaped by the respondents and not by the researcher's bias, motivation or interest. Here, steps must be taken to help ensure as far as possible that the research findings are the result of the experiences and ideas of the participants, and not that of the researcher. The school of existential phenomenology, as described by Kafle (2011:187), firmly believes in the attempt to concentrate upon re-achieving a direct and primitive contact with the world, but that complete reduction and bracketing is not possible. Because of the researcher's pre-existing "lived experience" (having an ASD-diagnosed child), objectivity was attempted throughout the research process. This was done by taking reasonable steps to ensure that presuppositions

were brought to the level of consciousness through reflective journaling, acknowledging them and then bracketing these assumptions.

Nieuwenhuis (2007b:114) mentioned that controlling for bias is important as researchers build strong relations with participants and might be tempted to see what they wanted to see, running the risk of missing aspects that do not conform to their expectations. Again, the verification of data with members (member checking) and a conscious attempt to apply bracketing minimised the researcher's own assumptions to shape data (Lichtman, 2010:79; Hamill & Sinclair, 2010:16).

1.8 FRAMEWORK FOR THE RESEARCH REPORT

The research report will be published in article format with the following framework:

Section A: Background to study and literature orientation

Section B: Article for journal: *Focus on Autism and Other Developmental Disabilities.*

Title of article: *Mothers' experiences of their child's diagnosis with an autism spectrum disorder (ASD)*

Section C: Conclusion and recommendations.

The article will be submitted for possible publication in *Focus on Autism and Other Developmental Disabilities.* This international academic journal is accredited, peer reviewed and also interdisciplinary in nature, addressing issues concerning individuals with developmental disabilities such as autism, and striving to be responsive to professionals and families of individuals with developmental disabilities.

1.9 SUMMARY

Part 1 of this document provided insight into the motivation for the research by arguing the problem statement and explaining in brief the challenges that families and specifically mothers experience when they have a child with ASD. An overview of autism prevalence was given in terms of an international and national context. The theoretical frameworks, namely Bronfenbrenner's bioecological theory as well as phenomenology, were described. The research methodology was explained, unpacking the literature review, research design,

sampling, data collection, procedures and the process of data analysis. Lastly, ethical considerations were described including strategies to attain an ethically sound research project.

Part 2 of Section A will now follow, providing a more detailed literature overview of the theoretical frameworks for the study and of autism.

PART 2: LITERATURE STUDY

2.1 INTRODUCTION

The literature review is described by Scot and Morrison (2007:141) as a guiding light for the whole research process. A literature review can therefore guide readers and writers of research in creating an understanding of the phenomenon under study. Randolph (2009:2) added that conducting a literature review is a means of validating an author's knowledge about a topic, including vocabulary, theories, key variables and phenomena. The literature review further represents the systematic identification, location and analysis of information related to the research problem (Gay *et al.,* 2009:80; De Vos & Strydom, 2011:35).

In this chapter, literature on autism spectrum disorder will be explored: definitions, impairments connected to the disorder, theories of causality, treatments and the many challenges that parenting a child with ASD implicates. Furthermore, the phenomenological approach and Bronfenbrenner's bioecological perspective as theoretical frameworks for this research project will be discussed.

2.2 AUTISM SPECTRUM DISORDER

The following discussion will aim to inform the reader about autism definitions, causality, impairments of children with ASD, possible treatments of the disorder and autism-related research that gives insights into the parenting of a child with ASD.

2.2.1 Definition

Autism spectrum disorder (ASD) and autism are both broad terms for a group of neurodevelopmental disorders characterised by impairments (commonly referred to as displaying a triad of impairments) in social interaction, delayed and/or abnormal language and communication, and a preoccupation with repetitive, stereotyped behaviours or interests (Janzen, 2009:5; Martin, 2010:20; Woodgate *et al.*, 2011:1075). The latest *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V, APA, 2013:50) made significant changes to the diagnostic criteria for autism, and now identifies ASD through impairments in only two major domains: social communication and interaction, and "restricted, repetitive patterns of behaviour, interests, or activities". The DSM-V (APA, 2013) also merged all autism disorders under one umbrella diagnosis of ASD. Previously ASD was distinctly categorised into subtypes, including

autistic disorder, childhood disintegrative disorder, pervasive developmental disorder not otherwise specified (PDD-NOS) and Asperger syndrome. For the purpose of this study, ASD will refer to all subtypes that are in line with the DSM-V diagnostic manual. ASD is therefore characterised by core impairments in communication, socialisation, and restricted and repetitive behaviours. Additional areas are also consistently associated with the disorder. A description of these core and associated impairments follows.

2.2.2 Impairments associated with ASD

No single behaviour is indicative of autism, nor will any child show all of the behaviours that will be listed. Professionals working with ASD often say that when you have seen one child with autism you have in fact only seen one child with autism. Taylor (2011:20) confirmed this when he compared ASD to fine wine: “wine can be anything from a generic type of grape beverage to something unique, specific and unreproducable”. He further stated that no two people with ASD are exactly alike. This clearly indicates the differences in temperament, behaviours, characteristics and impairments displayed by these children. The indicators described below may range from intense to mild, yet it is the display of the pattern of indicators from each category that is significant (Janzen, 2009:7) when making a diagnosis. These indicators will now be discussed.

2.2.2.1 Social interaction

Children with ASD often act in socially inappropriate ways. Examples include limited and fleeting eye contact or gaze avoidance, failure to respond to their name, intrusively touching or licking others, using an adult’s hand as a tool to do something, appearing not to hear others and being unaware of others’ feelings, a reduced sharing of interests, resistance to cuddling and holding, and struggling to play appropriately with other children as they often retreat into their own world (APA, 2013; Dawson, 2011: 20; Dolev *et al.*, 2009:184; Evans, 2010:6; Janzen, 2009:7; Kalash, 2009:1; Martin, 2010:20; Ritchie, 2008:7; Wachtel, 2006:3). Carpenter (2013:3) also mentioned the following in terms of children with ASD: They often do not try to establish friendships, they do not have preferred friends, they lack cooperative play, and they are unaware of being teased or ridiculed by other children. They do sometimes have an interest in friendships, but then lack the understanding of the customs of social interaction.

2.2.2.2 Communication

The ability of children with ASD to communicate varies from being totally non-verbal to having relatively well-developed speech (Keen & Rodger, 2012:39). Children with ASD usually start to talk later than other children and sometimes lose their previously acquired ability to say words or sentences (Martin, 2010:20). Many children with ASD have the ability to remember and formulate words, yet they struggle to understand their meaning (Dolev *et al.*, 2009:184). Speech is often not used in the right context and words are understood literally (APA, 2013). Other indicators are flat facial expressions and seldom or never using gestures or initiating communication, failing to imitate actions or sounds, repeating or echoing words and phrases, and having unusual vocal intonation and/or rhythm (Evans, 2010:6; Janzen, 2009:7; Kalash, 2009:1; Ritchie, 2008:7; Wachtel, 2006:3).

2.2.2.3 Stereotyped behaviour

Descriptions of ASD, from as early as those of Leo Kanner in 1943, refer to the presence of ritualistic behaviour, reliance on non-functional routines and restricted and prescribed obsessions (Keen & Rodger, 2012:39). An extensive range of literature (APA, 2013; Dolev *et al.*, 2009:184; Evans, 2010:7; Kalash, 2009:1; Ritchie, 2008:7; Wachtel, 2006:3) describes this impairment of stereotyped behaviour as follows:

The behaviours of children with ASD are often inappropriate (in nature and frequency) for their age. They may perform repetitive, inappropriate movements such as rocking, spinning or hand flapping, hand clapping, finger-flicking, spinning and jumping, banging their head or biting their wrists. This repetitive or stereotyped behaviour also manifests in speech, and may include the repetition of words, phrases or more extensive songs or dialog, “jargon” or gibberish. Specific routines and rituals are performed, and they may become very disturbed at the slightest change in routines and rituals. They may also exhibit rigid thinking and the inability to understand humour. Exploratory, symbolic, imitative and/or abstract play is usually absent. They may also be fascinated by parts of an object, for instance the spinning wheels of a car. Non-functional play with objects may include waving sticks, dropping items, lining up of toys or objects, repetitively opening and closing doors or turning lights on and off. They may also display interests that are abnormal in intensity and focus on the same few objects, topics or activities such as a preoccupation with numbers, letters or symbols.

It is indicated in literature (Estes e*t al.*, 2009; Gane, 2008) that these repetitive behaviours and/or rituals often limit families' opportunities for social activities. The display of inappropriate behaviour makes the child with ASD "unacceptable" in the conforms of society, and parents are often reluctant in having to deal with society's remarks or assumptions.

2.2.2.4 Sensory integration problems and other comorbid conditions

Although the above-mentioned impairments form the bulk of the diagnostic criteria for ASD, some behaviours and symptoms are often described to be significantly visible. Keen and Rodger (2012:40) specifically referred to the idiosyncratic responses of ASD-diagnosed children to sensory stimuli. They explained that children with ASD struggle to make sense of the information that is received from the various senses as they have difficulty disregarding specific inputs, resulting in behavioural, emotional or motor responses.

Carpenter (2013:6) described an array of other features that often accompanies the child with ASD: a high tolerance for pain, a preoccupation with texture or touch (the child does not like to be touched by certain objects or textures and has a significant aversion to having hair or toenails cut or to brushing teeth), unusual visual exploration or activity (close visual inspection of objects or self for no clear purpose, looks at objects or people out of the corner of their eyes, unusual squinting of eyes and a fascination with watching the movement of things) and some sensory input impairments (becoming extremely distressed by atypical sounds, unusual sensory exploration of objects via smell, sound, taste or vestibular).

ASD can also be associated with difficulties in motor coordination and attention as well as physical health issues such as sleep deprivation and gastrointestinal disturbances (Dzubay, 2011:18-19; Pauc, 2006:31). Intellectual disability is also a comorbid condition associated with ASD (Capone *et al.*, 2005:374).

These impairments are usually the first signs and symptoms that parents witness when becoming aware that a child is experiencing delays in development. Once the diagnosis has been made, most parents want to investigate the possible causes. Next, the theories of causality will be discussed in brief.

2.2.3 Theories of causality

With the rapid increase in the prevalence of ASD (King & Bearman, 2009; Posavad, 2009:2), the immediate question becomes: What is causing this disorder? It has been established that it is not caused by cold and distant mothers as previously proposed by Kanner who coined the term “refrigerator mothers” (Grinker, 2007:72).

Scientists continue to look for causes. Janzen (2009:11) argued that anything that makes the central nervous system develop abnormally, either before or after birth, can cause autism. Zander (2004:1) agreed and stated that although autism is a behaviourally-defined condition, it is caused by a number of known and unknown biologically based dysfunctions that affect the developing brain’s ability to handle information. He further explained that there is a genetic component in many cases. Keen and Rodger (2012:33) confirmed the above when they concluded that both genetic and environmental factors (including *in utero*) are implicated. Research by Evans (2010:9) makes particular reference to the consensus among professionals that turned to genetics, indicating a genetic error as underlying cause, but also indicates that scientists have not been able to isolate a single gene as being responsible due to the unrecognisable patterns of manifestation.

The latest contributions to possible causality (Kaplan, 2006:44) include the hypothesis that autism results from early life brain damage, the theory that autism is the result of neuro-immune dysfunction, and the theory that it is the result of autistic enterocolotitis, which may be linked to the measles, mumps and rubella vaccination (MMR vaccine). Evans (2010:10) referred to the controversy regarding the MMR vaccine and its correlation with autism, and argued that there is no solid epidemiological evidence that supports this.

Medical advances have certainly removed some guilt felt by parents when causes of ASD were considered to be psychogenic in origin. However, researchers still face huge challenges pinning down causality theories when it comes to ASD. Evans (2010:10) concluded that although the specific etiology of autism is still unknown, the predominant view is that autism has a biological origin and that it may also be affected by environmental factors.

It is further noted by Evans (2010:10) that because the causality of autism is not fully understood, it creates an environment in which parents are left isolated, helpless and overwhelmed as they may not know what to read and what to disregard. She further accounted that because other childhood conditions can provide answers regarding possible causes,

appropriate treatments and an expected prognosis, autism is particularly difficult to deal with as the answers are fewer than the questions.

One of the questions that many parents struggle with after an ASD diagnosis is with regard to treatment options. Taylor (2011:21) mentioned that because none of the theories of causality has ever been proven, some parents spend huge amounts of emotional energy and money in the hope that some miraculous treatment might help their affected child. Keen and Rodger (2012:208) echoed this when they stated that there has been a variety of controversial treatments claiming high rates of success, or even cure, yet it is in the absence of evidence. Next, the range of interventions and treatment options available will be illustrated in brief.

2.2.4 Treatments

It has been reported that during the early stages following an ASD diagnosis, parents are usually highly motivated to do anything they can to help their child, and they may even be keen to experiment with new and often untested treatments (Keen & Rodger, 2012:216; Taylor, 2011:21). For this reason, Keen and Rodger (2012:216) suggested that parents should be provided with a framework that can help them weigh up pros and cons of treatment approaches, and that can assist in them making informed decisions. They suggested the following "best practice" principles as developed by Prizant and Rubin, and Roberts and Prior:

- Interventions should be individualised to match the profile of the specific child's developmental delay, learning strengths and weaknesses.

- Early intervention should be formed by our current knowledge base of child development.

- Intervention approaches should predominantly address core ASD characteristics.

- Interventions should incorporate systematic instruction and generalisation strategies.

- Learning environments should be highly structured, predictable and supportive.

- Transitions between settings in activities should be supported.

- A functional approach to the management of behaviour should be included.

- Interventions should demonstrate logical consistency between long-term objectives and teaching protocols.

- Intervention approaches should be eclectic and include a variety of sources.

- Family involvement is paramount.

Parents should use these guidelines to make decisions regarding appropriate treatment for their child. According to Janzen (2009:47), the only treatment that helps *every* child with autism is a structured early intervention and educational programme. This is confirmed by Fombonne (2006:84) who reiterated the importance of early, intensive intervention programmes as such programmes have shown to produce better outcomes. With early intervention, many families see dramatic improvements in their child's expressive and receptive language and social relatedness (Martin, 2010:174).

As every child with autism has unique impairments and needs, therapies and treatments should be structured according to each individual. A resource guide developed by the Department of Health, Rhodes Island (2011:50), acknowledges that there are over 400 different treatments and interventions for ASD. This guide also recognises that it is important to match a treatment or intervention with the needs and strengths of the child as no one treatment works for all children with ASD. The authors of the guide mentioned the following factors to consider when choosing a treatment: the child's age, level of ability (mild, moderate or severe autism), type of learner (visual/seeing or auditory/hearing), behaviours and previous treatments.

Literature concludes that treatments and interventions can be separated into three categories (Department of Health, Rhodes Island, 2011:51):

- Behavioural approaches
- Biomedical and dietary approaches
- Medications.

Most often, a therapeutic programme includes a therapy or intervention from all three categories. A young child with ASD may receive up to 30 hours of intensive therapy per week.

Wachtel and Carter (2008:575) discussed the burden of coordinating and managing treatment decisions and plans. They mentioned that it is often the responsibility of the parent, and therefore many parents stop working to coordinate their children's treatment. This in turn results in an added financial burden at a time when the family is already stressed.

Ultimately, the parents will make the final decision regarding the treatments and interventions they wish to pursue for their child. Keen and Rodger (2012:220) concluded that professionals should inform parents about the efficacy of interventions and intervention practice, as this can significantly assist in their decision making, and help guard against intervention or treatment options that promise much but deliver little to children with ASD.

The stress parents experience after diagnosis is now heightened by the responsibility of choosing the best options for treatment or intervention, as well as the possibility of an added financial burden (Keen & Rodger, 2012:217). Therefore, the parenting of ASD children is made particularly challenging by having to decide on appropriate treatment and coping with additional financial expenses in addition to handling the emotional, behavioural and communication problems of such children. The next section will look at parenting a child with ASD in more detail.

2.2.5 Parenting a child with ASD

Becoming a parent of any child is stressful as it requires a role change. Vidyasagar and Koshy (2010:245) stressed that the birth of an exceptional child may result in an unanticipated or even traumatic event beyond parents' control. Literature shows that when a child is diagnosed with ASD parents experience a range of feelings, from relief that their suspicions have finally been validated to grief over the loss of the life they envisioned for their child and themselves (Milshtein *et al.*, 2010:89; Wachtel & Carter, 2008:575). Dowling (2004:8) provided the following poignant answer to the question: What does it mean to have an autistic child?:

> *"It means watching the beautiful, perfect baby you gave birth to, who carried all the usual hopes and dreams and proud ambitions that parents bestow on their children, quietly slop away, … until all those dreams have utterly disappeared. It means having to learn to live with and accept a stranger who wears your child's face – a ghost who prefers staring at blank walls to picture books, who never meets your gaze or seeks your touch, who is driven by urges and instincts that nobody else can*

begin to comprehend. Autism means the bleak realization that a mother's love isn't always enough."

Literature indicated (Braiden *et al.*, 2010; Ducey, 2009, Evans, 2010, Gane, 2008, Rose, 2011) that parents encountered a variety of experiences and emotions related to caring for a child who is diagnosed with ASD.

The following discussion will unpack the stress associated with parenting a child with ASD, the impact of parenting an ASD child on the marital relationship, the grief associated with an ASD diagnosis and, lastly, the importance of support to such families.

2.2.5.1 ASD-associated parenting stress in mothers and fathers

Parenting stress associated with ASD has been widely reported as very high (Banach *et al.*, 2010; Estes *et al.*, 2009, Vidyasagar & Koshy, 2010). Mourisden *et al.* (2007) conducted a study that examined the rates of psychiatric disorders in parents who have a child diagnosed with ASD. Findings indicated that having a child with ASD is more stressful than parenting a child with any other disability. Results further indicated that depression and alcohol abuse appeared to have higher rates among parents of autistic children than among the general population.

The most significant sources of stress for parents of ASC children can, according to Pisula (2011:88), be divided into three groups: 1) child characteristics and in particular behavioural symptoms associated with ASD, 2) a lack of adequate professional support, and 3) social attitudes towards individuals with autism and a general lack of understanding of what these families experience on a daily basis. Pisula (2011:97) concluded that this parenting stress comes from, among others, lateness and difficulty in obtaining a diagnosis, the untypical development of the child and behavioural problems. Furthermore, she argued that parents were also hampered by the lack of systemic solutions for people with autism, the ignorance of professionals and the fact that intervention methods often fall short of parents' expectations.

The study by Estes *et al.* (2009) confirmed Pisula's findings and agreed that ASD children's problem behaviour was one of the biggest contributors to increased parenting stress, and specifically in mothers of children with ASD. They recommended that professional services should aim to support parents by reducing problem behaviours in these children. In their study, Barker, Seltzer, *et al.* (2011) showed that raising an adolescent or adult child with ASD presented exceptional care-giving challenges for parents. They also indicated the direct

correlation between the ASD adolescent or adult's challenging behaviour and the depressive symptoms or anxiety experienced by the parents. Furthermore, they argued that social support networks helped with the resolution of these stressful life events.

A number of studies indicated the vast differences that exist between mothers and fathers with regard to the stress levels they experience as well as the coping strategies they employ in terms of ASD children. Mourisen *et al.* (2007) examined the differences in mothers' and fathers' experiences, and showed that mothers have much higher rates of depression and alcohol abuse than fathers. Another study by Dabriwsja and Pisula (2010) found that mothers of children with ASD typically experienced higher levels of stress than fathers. Mothers were also found to use emotion-orientated coping and social diversion strategies more frequently than fathers. A study by Vidyasagar and Koshy (2010) indicated that mothers specifically employed more aggressive efforts to alter challenging situations when more stress was experienced. They recommended that an intervention programme should be designed for mothers of children with autism, and that special schools for ASD learners should employ a counsellor or psychologist to work with mothers in dealing with the stressors they encounter during the daily care of their autistic children. This recommendation was supported by Dabriwsja and Pisula (2010) who highlighted the need to take into account the nature of gender differences in parental stress associated with ASD.

Consistent with prior literature, Phelps *et al.* (2009) reported that caregivers of children with ASD have higher levels of strain, but also indicated that some enrichment and growth was reported. In their study, caregivers revealed higher means of enrichment in the way they viewed themselves as parents and in the way they viewed their religious or spiritual life. They concluded that stress and enrichment or growth coexisted in the caregiving experience or parenting of an ASD child, and that caregivers' positive insights and self-awareness may assist in the development of coping mechanisms and serve as a motivation to embrace their responsibility as mentors and advocates for their child. These results are in line with a study done by Kayfitz *et al.* (2010) who reported that although raising a child with autism is a stressful experience, parents of such children also have co-occurring positive experiences and that these experiences are related to lower levels of parenting stress.

It is clear that parenting a child with ASD is highly stressful. However, some literature suggested that this experience can still be rewarding or have some positive attributes for parents. The stress associated with parenting an ASD child has implications for a variety of relationships, of

which the most notable is the marital relationship. Next, the impact of parenting an ASD child on the marital relationship will be discussed.

2.2.5.2 The marital relationship

For most people, balancing the roles of parent and partner is already challenging. The additional time and effort required to parent an ASD child has been reported to put additional strain on marital relationships (Brobst *et al.*, 2009). The study by Brobst *et al.* (2009) indicated that parents of ASD children experienced higher child behavioural problems, increased parenting stress, and lower levels of relationship satisfaction. Their study highlighted that mothers and fathers experienced parenting their ASD children differently. Mothers who had the most intense behavioural problems with their children reported lower levels of spousal support, respect for their partners and commitment to their marriages. Mothers of ASD children were also reported to struggle with the demands of managing their various roles (Safe *et al.*, 2012:299), and felt that "something's got to give". One of the respondents in their study spoke about being unable to fulfil her role as wife and to support her husband due to the high demands of her child with autism. Various studies (Brobst *et al.,* 2009; Gane, 2008; Martin, 2010; Zablotsky *et al.*, 2013) showed that the marital relationship in families with an ASD child is harder to maintain. This has implications for the way in which parents experience the support they receive, and ultimately directly correlates with the amount of stress parents of ASD children experience.

While trying to cope with the stressors associated with parenting an ASD child, managing the child's treatment plan and attempting to fulfil the role of husband or wife, having a child diagnosed with a disability also implies that parents will grieve (Boushey, 2001:27). Boushey wrote about her experiences as she learnt to accept her child's differences after he was diagnosed with ASD.

Next, the process of grieving the loss of dreams and expectations for the child with ASD will be discussed.

2.2.6 Grief and loss

Many parents have reported experiencing the diagnosis of their child with ASD as a period of grief or a feeling of loss (Constantino, 2010:87; Martin, 2010:30-32). Martin (2010:30) described this process by identifying the stages of grief as set out by Elisabeth Kübler-Ross in her book

On Death and Dying. Martin (2010:30) strikingly reflected on this process by looking at the four stages of grief and applying them to resolve an autism diagnosis:

1) Shock, denial and isolation: “My child doesn’t have autism. He’s just different.”
2) Awareness and emotional release: “Is this my fault? Did I do something to cause my child to have autism?”
3) Depression: “Nothing will ever be the same. The future is grim.”
4) Acceptance: “Autism is a challenge, but we can cope with it together.”

Martin (2010:32) reflected on these stages by describing that Stage 1 is often the most difficult for parents and that the two most common forms of denial is refusing to call the condition by the name and clinging to false hope. However, eventually, parents may become comfortable enough to take initiative and start telling people that their child has autism. She argued that once people know and the mystery is removed, people can be remarkably kind and sympathetic. Constantino (2010:92) herself has two disabled children. She stated that life offered no guarantees to anyone, and that any parents who have hopes and expectations for their children may experience loss and sadness.

The grieving process of parents with disabled children is often referred to as chronic sorrow (Nicoll, 2004:5). In 1962, Olshansky (cited in Nicoll, 2004:5) suggested that the typical stages of grief do not necessarily apply to those who mourn, for instance, a disabled child. Instead, such parents may never achieve real acceptance, but rather remain in a state of emotional flux, at times appearing content with their lives and at other times (such as receiving a bad school report) returning to full-fledged grief, simply because the source of their grief – a disabled child – remained a tangible presence in their lives. Nicoll (2004:5) provided tips on coping with grief, such as eating healthily and getting regular exercise, but concluded that although we grieve alone, we heal with one another. The importance of healthy relations and support networks was once again reiterated.

This support comes in many forms, from professionals to extended family, colleagues and friends. Keen and Rodger (2012:49) mentioned that the family network usually extended beyond relatives to include friends, neighbours, paid carers and other members of the community with whom the family has regular contact. They stated that this network had the potential to be an important source of support to ASD children and their families. This much-needed support will be discussed next.

2.2.7 Support to families living with ASD children

While the importance of family and extended family networks are restated, Keen and Rodger (2012:49) explained that their capacity to be supportive is directly related to their acceptance of the child with ASD as well as their ability to acknowledge the many challenges faced by parents in raising such a child. This may not happen that easily. Mirnfin-Veitch and Bray, as cited in Keen and Roger (2012:49), explained that grandparents, for instance, could fall into one of two categories: those who do and those who do not provide the much-needed support to families. Mirnfin-Veitch and Bray also mentioned that in most cases grandparents who are less supportive or involved seemed to struggle with accepting their grandchild's disability.

When support is extended to professionals, research has found that about 37% of parents felt dissatisfied with the way in which professionals disclosed to them that their child had a disability (Keen & Rodger, 2012:16). Davey in Keen and Rodger (2012:16) articulated some of the experiences of parents regarding their frustrations that marked the diagnostic process. One of the parents clearly indicated the lack of support he received when he described the process as excruciating. He considered professionals as having a general lack of understanding with regard to autism and giving limited advice on managing difficult behaviours, and he felt that parents are sent home with "no useable information, no support and basically a terminal diagnosis".

Keen and Rodger (2012:17) acknowledged the needs of children with ASD as extensive and demanding, especially on parents as they need a new set of skills and knowledge to deal with their child's impaired communication and social interactions. Many other studies (Braiden *et al.*, 2010; Gane, 2008; Safe *et al.*, 2012; Siklos & Kerns, 2007) implicated this perceived lack in the support parents receive from professionals. Findings in the study of Gane (2008:42) also demonstrated how difficult it was for parents to obtain an ASD diagnosis from medical professionals, even when the parents felt they knew what the diagnosis would be. According to the study by Siklos and Kerns (2007), parents reported seeing an average of four clinicians before obtaining a diagnosis. Gane's (2008:43) study further showed that a number of mothers felt blamed or disrespected by medical professionals.

From the above it is clear that parents may experience ambivalent support from family or the extended family network as this depends on their acceptance and understanding of the challenges that ASD presents (Keen & Rodger, 2012:49). Parents further reported dissatisfaction with medical professionals regarding diagnosis (Gane, 2008:42; Keen & Rodger,

2012; Siklos & Kerns, 2007), the giving of adequate information and the general lack of understanding for what the family as a system or the caregivers might be experiencing (Braiden *et al*, 2010; Safe e*t al.*, 2012). This suggests that parents need to cope with inadequate support while their relationships with healthcare professionals may place an additional burden on them and while they find the management of their day-to-day activities challenging.

Having an ASD child puts a substantial amount of strain on parenting. Studies indicated that the stress parents experienced in having an ASD child is higher than those of parents with children with other disabilities. Hence, the significant strain that ASD children have on marital relationships is noteworthy. It was also described how having the child diagnosed can result in experiences of loss or grieving. When these parents do not receive adequate support from professionals in terms of managing ASD children as well as their own emotions, it puts them in a situation where they might feel helpless, overwhelmed and totally inadequate in fulfilling their role as parents.

To assist in understanding mothers' experiences of their child's diagnosis with an autism spectrum disorder, two theoretical frameworks were applied to this study, namely phenomenology and Bronfenbrenner's bioecological theory, with specific reference to his Process-Person-Context-Time (PPCT) model. These theoretical frameworks will now be discussed.

2.3 THEORETICAL FRAMEWORK FOR THIS STUDY

A theoretical framework can be described as a general set of ideas that guide the researcher's actions, and it is usually derived from the researcher's disciplinary orientation which in turn informs what is being studied and how it is studied (Gay *et al.,* 2009:429). In this study, phenomenology and Bronfenbrenner's bioecological theory were applied as theoretical frameworks. These frameworks will therefore underpin the study. Metaphorically speaking, these frameworks become the 'lenses' through which the researcher observes, describes and understands the phenomenon.

Firstly, phenomenology will be discussed in terms of three schools of thought: transcendental phenomenology, hermeneutic phenomenology and existential phenomenology. Reference to the current study will be made throughout the discussion to aid readers in their understanding of how this theoretical framework was applied in practice.

Secondly, Bronfenbrenner's bioecological theory will be described. Again, some historical background will guide readers in understanding the development and evolution of this theory to the matured form that was utilised for the purposes of this study. The Process-Person-Context-Time (PPCT) model will be elaborated on, and also how this was applied to the current research.

2.3.1 Phenomenology

Phenomenology originated as a school of philosophical thought during the 18th century. According to Groenewald (2004:3), the German philosopher Edmund Husserl (1859-1938) was regarded as the founder of phenomenology in the 20th century. Crotty, as cited in Roberts (2013:215), explained that Husserl's drive for this type of enquiry came from his belief that experimental scientific research could not be used to study all human phenomena and experiences as this had become so detached from the core of the human experience that it was hindering the understanding of ourselves. The term *lived experience* is used synonymously with phenomenology and, according to Clark (cited in Roberts, 2013:215), ultimately aims to develop insights from the perspectives of those involved by them detailing their experiences of a particular time in their lives.

Literature further suggested that although Husserl founded the phenomenological approach, this was not the only phenomenological method (Groenewald, 2004:3-6; Hamill & Sinclair, 2010:16-19; Kafle, 2011:1-10; Roberts, 2013:215). Other phenomenologists who shaped this philosophy and research method into an existential approach included Garbriel Marcel (1889-1973), Jean-Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1908-1961). According to Annells (cited in Roberts, 2013:215), Martin Heidegger developed another phenomenological approach known as hermeneutics, meaning interpretation.

The various phenomenologists who were involved in shaping this philosophy and research method gave birth to three distinct schools associated with phenomenology. The phenomenological tradition can thus be classified under three major headings: transcendental phenomenology, existential phenomenology and hermeneutic phenomenology (Kafle, 2011:185). Next, a brief description of these three schools will be provided.

2.3.1.1 Transcendental phenomenology

This form of phenomenology is the original form as conceptualised by Edmund Husserl. According to Kafle (2011:188), the basic premise of this school of thought is the notion that "experience is to be transcended to discover reality". He explained that: "Husserlian phenomenology is built up around the idea of reduction that refers to suspending the personal prejudices and attempting to reach the core or essence through a state of pure consciousness". The essence of this school of phenomenology is therefore to discover and describe the "lived world" (Fouché & Schurink, 2011:316-317; Groenewald, 2004:3-6; Jones *et al.*, 2012:374; Kafle, 2011:188; Roberts, 2013:215-216; Zenobia *et al.*, 2013:1).

While critically examining the literature on Husserl's approach, the debate on how to practise reduction and the perceived difficulties in achieving bracketing came to the fore. Bracketing is a procedural principle that is associated with this process and that aims to ensure that researchers do not allow their assumptions and personal opinions to shape the data collection or to impose their understanding and construction on the data (Hamill & Sinclair, 2010:16; Kafle, 2011:188; Zenobia *et al.,* 2013:1). Hamill and Sinclair (2010:17) conceptualised it well:

> *"In mathematics, brackets are used to separate one part of an equation from another, allowing you to focus on that part in isolation from the others. In phenomenological research, brackets are used to temporarily hold in abeyance the foreknowledge of the researcher."*

Bracketing also curbs the researcher from influencing the participants' understanding in the search for the essence of things through their lived experiences. Hamill and Sinclair (2010:17) talked about "an outsider's view". This seems to be in contrast with Heideggerian or hermeneutic phenomenology (described below) where meaning is interpreted (Hamill & Sinclair, 2010:17; Roberts, 2013:215).

There is an interesting debate on whether bracketing continues to have an effect throughout the research process, or just during data collection and analysis, and the degree to which bracketing affects trustworthiness and rigour (Hamill & Sinclair, 2010:17; Kafle, 2011:188; Roberts, 2013:215). The researcher is of the opinion that the foreknowledge of the researcher can hamper the ability to thoroughly investigate the topic as assumptions, interpretations and expectations will constantly be brought to the fore. This will influence the researcher's ability to be open to the "lived experiences", understandings and meanings that participants bring to the

process. Hamill and Sinclair (2010:17) argued that bracketing enabled researchers to temporarily suspend what they think they already know and to actively listen to participants and their individual realities. Critique against the effectiveness of and the ability to apply bracketing saw the hermeneutic school of phenomenology come to light.

2.3.1.2 Hermeneutic phenomenology

Hermeneutics – meaning interpretation – has evolved under the guidance of Martin Heidegger (1889-1976), a student of Husserl (Jones *et al.*, 2012:375; Kafle, 2011:187; Roberts, 2013:215). Heideggarian phenomenology contextualises human lives within meaningful activities, relationships, and the experience of being raised and living within a particular timeframe, culture and family (Jones *et al.*, 2012:375). Kafle (2011:187) maintained that this school was based on the premises that reduction was impossible, and that hermeneutic phenomenology attempted to get beneath the subjective experience in order to find the genuine objective nature of the things as realised by the individual, yet accepting endless interpretations. The foundation of this school of phenomenology is that interpretations encompass our existence, and that description itself is already an interpretive process (Kafle, 2011:188). Existential phenomenology seems to marry transcendental and hermeneutic phenomenology as it draws from both schools of thought.

2.3.1.3 Existential phenomenology

According to Kafle (2011:187), existentialists see themselves as carrying on the tradition first anticipated by Blaise Pascal's (1623-1662) rejection of Cartesian rationalism, in which he tried to define human beings in terms of rational capacities. Pascal's theory regarding human beings was that of an essential paradox or contradiction between the body and the mind. This theory was shared by Søren Kierkegaard (1813-1855) who contributed to the "common" thought of Heidegger, Jean-Paul Sartre and Maurice Merleau-Ponty as well as other philosophers influenced by them (Kafle, 2011:187). These scholars did their projects in related ways, therefore justifying the grouping of these philosophers together under the heading "existential phenomenology".

According to Warthal (cited in Kafle, 2011:188), existential phenomenologists shared the view that philosophy should not be conducted from an objective, detached or disengaged standpoint as they contended that certain phenomena only show themselves to those who engage with the world in the right way. This school of phenomenology can thus be distinguished from other schools as it rejects Husserl's belief in the possibility of complete reduction, yet firmly believes in

the attempt to concentrate upon re-achieving a direct and primitive contact with the world (Kafle, 2011:188).

Existential phenomenology will be utilised as a theoretical framework in this investigation as it best suits the purpose of this study. The researcher herself has a "lived experience" of having a child diagnosed with ASD, and thus argues the possibility of complete reduction through bracketing. According to the hermeneutic school of phenomenology, it is possible not to achieve trustworthiness and rigour as a result of interpretation. Therefore, the existential phenomenological school of thought best suited the researcher as well as the research question, and, as Kafle (2011:188) described it, "will attempt to re-achieve a direct and primitive contact with the world".

Next, the second theoretical framework for this study will be discussed, namely Bronfenbrenner's bioecological theory.

2.3.2 Bronfenbrenner's bioecological perspective

Bronfenbrenner's theory of human development was in a recurrent state of evolvement until he died in 2005. Bronfenbrenner (1989:187) noted and reflected on the changing nature of his theory when he wrote: "I have been pursuing a hidden agenda: that of re-assessing, revising and extending – as well as regretting and even renouncing – some of the conceptions set forth in my 1979 monograph." His theory, although being altered, revised and constantly extended, was always and explicitly ecological, stressing person-context interrelatedness (Tudge *et al.*, 2009:198). At the core, the ecological approach to human development is concerned with continuous and reciprocal impact of individuals and their environment on each other (Bronfenbrenner, 1994:1644; Rosa & Tudge, 2013:246; Ungar, 2002:482). Later modifications to his theory paid more attention to the role of the individual, and were more concerned with developmental processes (Rosa & Tudge, 2013:243). Rosa and Tudge (2013:243) described the development of Bronfenbrenner's theory from an ecological to a bioecological theory in three distinctive phases. This evolution of his theory will be discussed in short.

Phase 1 (1973-1979)

This phase culminated in the publication of *The Ecology of Human Development* (1979). During this phase, Bronfenbrenner argued that contemporary studies of human development were studies out of context rather than ecological studies that should examine the interrelations between the developing person and the changing micro and macro context (Bronfenbrenner,

1979). He provided the following names for the four interconnected structures that enclose the individual being: microsystem, mesosystem, exosystem and macrosystem (Bronfenbrenner, 1976, 1978). Because Bronfenbrenner viewed the environment as intrinsically connected to the individuals within it, he often used the qualifier *ecological* when referring to the environment. His focus therefore was not simply on the environment or context, but on the ecological system that included the developing individual.

Phase 2 (1980-1993)

This phase saw almost immediate modifications to the theory, with more attention given to the role of the individual and greater emphasis on the developmental processes. In addition to this, he explicitly focused on the passage of time. He also revised his concepts of the development of ecological environments (particularly the microsystem and macrosystem) and formulated a new research paradigm for the study of human development – a model first termed the Person-Process-Context model (1986) and thereafter the Process-Person-Context model (1988-1989). This model was revised and broadened in the final phase of the theory's development. During this phase, Bronfenbrenner also emphasised the notion of the person as a highly complex biopsychological organism (Bronfenbrenner, 1993).

Phase 3 (1993-2006)

In this final version of Bronfenbrenner's theory, named both the bioecological theory and the bioecological model of human development, he included the Process-Person-Context-Time (PPCT) model of how to conduct bioecological research (Bronfenbrenner & Morris, 2006). Bronfenbrenner and Morris (2006:793) defined the bioecological model as "an evolving theoretical system for the scientific study of human development over time". This suggested that the four elements of this model (process, person, context, time) simultaneously influenced the development outcomes of human beings.

Given the extent of these changes, and to avoid theoretical incoherence, Rosa and Tudge (2013:243) as well as Tudge *et al.* (2009:199) advised that scholars should be cautious about stating that their research is based on Bronfenbrenner's theory without specifying which version they are using.

For this study, the final phase of Bronfenbrenner's theory, also known as the mature form, will be utilised as a theoretical framework. Tudge *et al.* (2009:202) stated that the appropriate use of Bronfenbrenner's mature theory would be to use at least three of the four PPCT concepts,

including proximal processes. A discussion will follow to unpack the PPCT concepts of Bronfenbrenner's mature theory.

2.3.3 Bronfenbrenner's bioecological theory

Bronfenbrenner's bioecological model of human development can be applied to both children and maturing adults, and thus offers a lifespan approach to development. Various scholars have used his theory in settings other than child development (Adamsons *et al.*, 2007; Campbell *et al.,* 2002; Hayes *et al.,* 2012; Riggins-Caspers *et al.*, 2003; Tudge *et al.,* 2003). Using the Process-Person-Context-Time model as theoretical framework and mothers' experiences of receiving their child's ASD diagnosis as the unit of analysis, mothers' experiences of their child's diagnosis with an autism spectrum disorder could be explored and described.

The full theory in its matured form (Phase 3) deals with the interrelations among the four PPCT concepts. These concepts will now be explained and integrated with the current research topic.

2.3.3.1 Proximal processes

At the heart of Bronfenbrenner's framework are what he termed "proximal processes", referring to the everyday interactions between the developing persons and the symbols, objects and (most importantly) people in their everyday contexts (Tudge *et al.,* 2003:46). According to Bronfenbrenner (1995:620), typical examples of everyday activities that involve children and those around them are parent-child or child-child interaction, group or solitary play, learning new skills, reading and watching television. These everyday activities are the building blocks of development.

In this study, proximal processes refer to the naturally occurring everyday activities and interactions between mothers and their ASD children (mother-child), mothers and their partners (mother-father), and mothers with their other children (mother-other children). Although proximal processes also include reciprocal interactions with objects and symbols, this study focused on the role of others in the mothers' immediate external environment.

Bronfenbrenner's publications during this phase provided two propositions that lay out the properties of proximal processes:

> *"Proposition 1 states that development takes place through processes of progressively more complex reciprocal interactions between an active, evolving biopsychological human organism and the persons, objects and symbols in its immediate external environment. To be effective, the interaction must occur on a fairly regular basis over extended periods of time. Such enduring forms of interaction in the immediate environment are referred to as proximal processes"* (Bronfenbrenner, 1995:620).

Here, *proximal interactions* occur on a fairly regular basis, and include face-to-face and sustained relationships which are important in shaping lasting aspects of development, for example interaction that occur in a family.

> *"Proposition 2 states that the form, power, content, and direction of the proximal processes that affect development vary systematically as a joint function of the characteristics of the developing person and the environment (both immediate and more remote) in which the processes are taking place and the nature of the developmental outcomes under consideration"* (Bronfenbrenner, 1995:621).

Proposition 2 focuses on *reciprocal interactions*. Here, relationships are complementary, mutual, reciprocal and one influencing the other and vice versa.

2.3.3.2 Person

Person in Bronfenbrenner's Process-Person-Context-Time model refers to the individual and his/her characteristics. Bronfenbrenner described three types of person characteristics as part of the second P of PPCT, namely *demand, resource*, and *force* characteristics (Rosa & Tudge, 2013:253; Tudge *et al.*, 2009:200).

Demand characteristics referred to personal attributes such as age, gender, skin colour and physical appearance. According to Tudge *et al.* (2009:200), this may influence initial interactions because of the expectations that are formed immediately. *Resource characteristics* by contrast to demand characteristics are not immediately visible. These include mental and emotional resources (past experiences, skills, attitudes, beliefs and intelligence) as well as social and material resources (food, housing, education and opportunities) (Rosa & Tudge, 2013:253; Tudge *et al.*, 2009:200). Lastly, *force characteristics* refer to differences in temperament, motivation and persistence (Rosa & Tudge, 2013:253; Tudge *et al.*, 2009:200).

2.3.3.3 Context

Context refers to the environment that involves four interrelated systems that are termed the microsystem, mesosystem, exosystem and macrosystem (Bronfenbrenner, 1994:1646-1647; Bronfenbrenner & Morris, 2006:820; Christensen, 2010:102; Härkönen, 2007:7-13; Rosa & Tudge, 2013:253; Stranger, 2011:171; Tudge *et al.*, 2009:201).

The m*icrosystem* marks the reciprocal interplay between individuals and their immediate setting including their family, school and peer group – all the activities and interpersonal relations that exist in the immediate physical and social environment as well as community (Bronfenbrenner, 1994:1646; Bronfenbrenner & Morris, 2006:820). In this study, the mother's microsystem would refer to her immediate family.

The *mesosystem* is seen as a system in which microsystems are interacting with each other. This may involve interaction between school and home, for example (Bronfenbrenner, 1994:1647). The mesosystem of mothers' of ASD-diagnosed children would include the broader family, circle of friends, colleagues at work and medical professionals involved in her family's life.

The *exosystem* encompasses various social structures that the individual does not relate to directly, but that impacts upon the individual's immediate setting, for example a parent's place of work (Bronfenbrenner, 1994:1647). Because the unit of analysis in this study is mothers, typical exosystems for mothers could be the child's school or daycare centre.

Lastly, Bronfenbrenner (1994:1647) explained that the *macrosystem* consisted of the overarching pattern of microsystems, mesosystems and exosystems of a given culture or subculture, with particular reference to belief systems, knowledge, material resources, life-styles and beliefs and values. The macrosystem represented the societal blueprint. For this particular study, macrosystem can refer to society's belief systems or perceptions in terms of ASD, or to the government structures supporting or not supporting the management of ASD as a disability.

2.3.3.4 Time

Building on what Bronfenbrenner earlier termed *chronosystem*, time is now included in the model. In the bioecological model, the concept of time was broadened to include what happens over the course of activity or interaction and historical time (Rosa & Tudge, 2013:253-254).

Bronfenbrenner and Morris (1998) wrote about time as constituting *micro-time* (what is occurring during the course of an activity or interaction), *meso-time* (the extent to which activities and interactions occur with some consistency in a person's environment) and *macro-time* (the chronosystem where interactions between systems influence the individual's development). To put time within the framework of this study, micro-time could refer to the mothers' interactions with medical professionals over the course of one session while meso-time could refer to the process of diagnosis or interventions as experienced by the mothers. Lastly, macro-time can refer to a change in expectations in the larger society, both within and across generations, impacting on the perception of ASD. The findings of this study only reflected on the concept of meso-time.

Bronfenbrenner's bioecological theory goes beyond providing a framework for identifying and conceptualising the multi-system of ecology as it also considers individuals in their settings and defines the construct of the development of the system in the environment and the nature of the processes that influence development (Lewthwaite, 2011:1). Bronfenbrenner's bioecological theory in its matured form provided a good fit for describing the phenomena under study, namely mothers' experiences of their child's diagnosis with an autism spectrum disorder.

2.4 SUMMARY

Part 2 of Section A provided the reader with much-needed information and literature regarding ASD, as well as the theoretical frameworks for this study. Where applicable, certain concepts were applied to the research project. This information should be considered as a literature background to the study.

The next part of this document (Section B) presents the article that will be submitted for possible publication in *Focus on Autism and Other Developmental Disabilities.*

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SECTION B: ARTICLE

Mothers' experiences of their child's diagnosis with an autism spectrum disorder (ASD)

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Abstract

Raising a child with an autism spectrum disorder (ASD) is specifically challenging for mothers as such mothers have been reported to experience poor health and wellbeing and higher stress levels. Studies indicated that mothers of ASD-diagnosed children are more likely to abuse alcohol and have higher rates of depression than fathers. The unique challenges that these mothers face are often overlooked in literature. Understanding these mothers' experiences is necessary to address their wellbeing.

This study explores and describes mothers' experiences of receiving their child's diagnosis of an ASD by using the Process-Person-Context-Time model from Bronfenbrenner's bioecological theory as a framework. Unstructured interviews with seven mothers were conducted and data was analysed using thematic content analysis. Findings revealed four main themes, namely: 1) The mothers' experience of interactions and relationships within their immediate families (*Proximal Process*), 2) The mothers' experiences of their internal and external characteristics and resources (*Person*), 3) The mothers' experiences of their environment (*Context*), and 4) The mothers' experiences of the journey through time (*Time*).

Bronfenbrenner's theory in its matured form demonstrated to be of value in understanding these mothers' daily lives. The key findings offered valuable insight that may assist professionals in improving service delivery to mothers of ASD-diagnosed children and that may provide the foundation required to develop support programmes for such mothers.

Keywords: autism diagnosis, autism spectrum disorder (ASD), Bronfenbrenner's bioecological theory, mothers' experiences, qualitative research, phenomenology, process-person-context-time (PPCT)

Mothers' experiences of receiving their child's diagnosis of an autism spectrum disorder

The increase in the prevalence of autism is alarming. The latest international statistics according to the Centre for Disease Control and Prevention's study in the United States in 2010 (Developmental, D.M.N.S., Y. & 2010 Principal Investigators, 2014), found that one in sixty-eight children are identified with an Autism Spectrum Disorder (ASD), and that this disorder is five times more common in boys. Accurate and recent national autism statistics in South Africa are challenging to find (Bateman, 2013). National statistics that are available show that in South Africa in 2006 the prevalence of autism was 88 896 out of an estimated population of 44.5 million people, with an incidence of 490 new cases being diagnosed every year (Adviware Pty Ltd., 2006). These startling statistics are confirmed by Autism South Africa (ASA, 2012), which stated that in South Africa, one child with autism will be born every hour. Bateman (2013) mentioned that every week in the Western Cape, ten children are collectively diagnosed with ASD at the three government-funded hospitals rendering specialised services to children. These statistics concluded that there is a large population of parents who needs support services.

Parents of children with ASD, or those awaiting a diagnosis, have been reported to struggle with a myriad of challenges, including high levels of stress, isolation, uncertainty and a general sense of feeling totally overwhelmed (Banach, Iudice, Conway & Crouse, 2010; Estes, Munson, Dawson, Koehler, Zhou & Abbott, 2009; Montes & Halterman, 2007; Shu, 2009; Siklos & Kerns, 2007; Vidyasagar & Koshy, 2010; Woodgate, Atea & Secco, 2011). This often results in poor marital relationships (Brobst, Clopton & Hendrick, 2009; Martin, 2010) and communication problems (Wachtel, 2007). Parents have also been reported to have concerns about whether the child with ASD will be accepted and tolerated by society (Hornstein, 2012; Kalash, 2010). The typical stereotyped and repetitive behaviours of children with ASD often limits the family's opportunities for social activities resulting in an added sense of loneliness and limiting the family's opportunities for possible support (Estes *et al.*, 2009; Gane, 2008).

Sufficient evidence supports the fact that having a child with ASD is life changing for parents. Studies have also shown that the challenges and stressors associated with having an ASD child can substantially reduce the effectiveness of early teaching interventions for the child (Osborne, McHugh, Saunders & Reed, 2007) and result in increased behavioural problems (Osborne & Reed, 2009; Blacher & McIntyre, 2006; Eisenhower, Baker & Blacher, 2005;

Osborne *et al.*, 2007). Parental adjustment and functioning are therefore important issues that are associated with parental ability to care for and teach children with autism. This confirms that effective support is highly important to families (Braiden, Bothwell & Duffy, 2010; Smith, Seltzer, Tager-Flusberg, Greenberg & Carter, 2008) and that professionals should take cognisance of the fact that the wellness of parents with ASD children has a direct impact on the prognosis for the effective management of the behaviour of such children (Osborne & Reed, 2009).

The differences in the way that mothers and fathers experience and react to these stresses and challenges are significant. It has been reported that mothers feel more guilt and shame than fathers, have higher rates of depression and are also more likely to suppress their feelings (Hornstein, 2012; Gray, 2003). Mourisden, Rich, Isager and Nedergaard (2007) added to this, showing significantly higher degrees of alcohol abuse in mothers than fathers of children diagnosed with autism. Vidyasagar and Koshy's study (2010) also highlighted these differences when they concluded that parenting a child with a developmental disability is especially exhausting for mothers, leaving them at higher risk of long-term stress than fathers. It can be concluded that the wellbeing of mothers is at greater risk than the wellbeing of fathers when parenting a child with ASD, and although mothers are generally the primary caregivers (Gane, 2008) their stories often go untold.

A significant amount of research on autism focuses on causality, intervention strategies and the unpacking of the diagnostic criteria (Ritchie, 2008). Parenting children diagnosed with ASD has been studied (Gane, 2008; Rarity, 2008), focusing on intervention strategies for ASD children and coping strategies for the behavioural challenges associated with the diagnosis. Ample ASD literature was found on marital satisfaction (Brobst *et al.*, 2009) and experiences of siblings living with ASD (Bishop, 2012). Limited international literature was found on parents' experiences of their journey leading up to diagnosis as well as receiving the ASD diagnosis (Braiden *et al.*, 2010; De Alba & Bodfish, 2011; Ducey, 2010; Evans, 2010; Feliciano, 2009; Gane, 2008; Lin, Tsai & Chang, 2008; Milshtein, Yirmiya, Oppenheim, Koren-Karie & Levi, 2010; Mitchell & Holdt, 2014; Rose, 2011; Siklos & Kerns, 2007; Wachtel, 2007; Wachtel & Carter, 2008).

The literature search produced only eight recent studies on parental experiences regarding their ASD-diagnosed children within the South African context. These studies concentrated on the ASD diagnosis (Holdt, 2008, Mitchell & Holdt, 2014), raising children with ASD (Balfour, 2007; Hoffman, 2012; Swanepoel, 2003), parental challenges and strategies associated with ASD (Olivier & Hing, 2008), and resilience in families with an autistic child (Greeff & Van der Walt, 2010). The study by Dawson (2011) did focus on parents' experiences, but her study was done in Gauteng Province. The study by Mitchell and Holdt (2014) also implicated a lack of services and support within the KwaZulu-Natal province, and found that participants in their study had to implement their own measures to provide an adequate educational environment for their children with ASD.

No studies were found that reflected on parental experiences within the Western Cape, one of nine provinces in South Africa. The Western Cape has an estimated population of 6.02 million people (Statistics South Africa, 2013), but at present only has two Special Schools specifically geared toward ASD that are funded by government (Enos-Matheny, 2012). The growing demand for schools catering for children with ASD (Bateman, 2013) has resulted an increase of private institutions supporting these children. However, the financial burden that these private institutions place on parents makes access to such institutions a privilege for only a small section of the population (Enos-Matheny, 2012; Solidarity Helping Hand, 2011).

Mitchell and Holdt (2014) confirmed the significant financial implications that are involved when having a child with ASD and raised the concern that most of the population will be unable to afford these services. The differences between provinces regarding access to available resources to support families with ASD-diagnosed children may notably change the experiences of mothers in dealing with such a diagnosis. The gap in literature on parental experiences, and more specifically mothers' experiences within the Western Cape, motivates for more studies.

The limited literature on parental experiences of children diagnosed with ASD within the South African context poses a threat to the way professionals support such parents throughout this process. Ritchie (2008) mentioned that parents interviewed during her research expressed that therapy would have helped them to handle the diagnostic process and to better cope with having a child with ASD. Mitchell and Holdt (2014) stressed the importance of empowering

parents whose child has ASD, as it is an important part of coping and acceptance. Their findings further implicated that professionals generally have limited information about ASD, and seldom explain this disorder in a way that is acceptable to parents. Rarity (2008) added that the gap in literature regarding parents' experiences of ASD children has led to the misunderstanding of the parental responses to having children with a disability.

This study aimed to add to the current literature within the South African context with specific reference to the Western Cape, hoping to contribute to the understanding of mothers' experiences of their child's diagnosis with ASD for both the mothers and the professionals rendering services to the mothers. This understanding may give professionals new information that could guide the way in which they plan treatment for mothers of children diagnosed with ASD.

From the above-mentioned, the following research question can be formulated:
What are mothers' experiences of their child's diagnosis with an autism spectrum disorder?

Theoretical frameworks

To contribute to the understanding of mothers' experiences, the *phenomenological* approach was applied as both a method and a theoretical framework. Phenomenological existence is understood through a personified or lived experience (Roberts, 2013; Starks & Trinidad, 2007). The German philosopher Edmund Husserl (1859-1938) believed that phenomenology would enable the phenomenologist to encounter the actual lived experiences of participants (Hamill & Sinclair, 2010; Lichtman, 2010; Roberts, 2013). This study focused on these lived experiences of mothers after receiving an ASD diagnosis. Lichtman (2010) and Hamill and Sinclair (2010) further referred to Husserl's proposal that researchers must set aside their own views about the phenomenon by using a process of bracketing, as it limits researchers' own assumptions to shape data or impose their understanding on the data.

The three schools of phenomenology, as described by Kafle (2011), have different ideologies in terms of bracketing. Transcendental phenomenology has at root that bracketing should be used to set aside the researcher's own views (Lichtman, 2010; Hamill & Sinclair, 2010), while the school of hermeneutic phenomenology believes that even descriptions are interpretive, making reduction by means of bracketing impossible (Kafle, 2011). As described by

Warthal (cited by Kafle, 2011), existential phenomenology, as the third school, shares the view with hermeneutic phenomenology that reduction is not completely possible, but believes in attempting to re-achieve a direct and primitive contact with the world. For this study, the existential phenomenological theoretical framework was utilised.

The bioecological perspective of Bronfenbrenner was used as a second theoretical framework for this study. Urie Bronfenbrenner's theory of human development continued to evolve until he died in 2005. His theory did however stay explicitly ecological in character, highlighting the person-context interrelatedness (Bronfenbrenner, 1989; Tudge, Morova, Hatfield & Karnik, 2009). These changes to his theory could create theoretical confusion, and therefore Rosa and Tudge (2013) and Tudge *et al.* (2009) advised scholars to be cautious when stating that their research is based on Bronfenbrenner's theory without specifying which version is being used. Bronfenbrenner (Bronfenbrenner & Morris, 2006) defined the last phase of his theory, the bioecological model, as "an evolving theoretical system for the scientific study of human development over time". For this study, the final version of his theory was applied, namely the bioecological theory.

As part of the final or matured form of his theory, Bronfenbrenner coined the Process-Person-Context-Time (PPCT) model, which deals with the interactions among these concepts (Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Tudge *et al*., 2009). The PPCT model was applied to this research in an effort to gain an understanding of mothers' experiences of receiving their child's ASD diagnosis.

The concept *proximal process* lies at the core of Bronfenbrenner's PPCT model. Bronfenbrenner (1995) explained proximal processes as the everyday interactions between the persons and symbols, objects and (most eminent) people, and stressed that these interactions are reciprocal, complementary and mutually influential. He further argued that proximal processes among people who develop a strong emotional relationship can be powerful (Bronfenbrenner, 2000, 2001; Bronfenbrenner & Morris, 2006). Examples of this include parent-child interactions, solitary play, reading, learning new skills and studying. For the purpose of this study, proximal processes in the everyday activities of mothers refer to mothers and their children with ASD (mother-child), mothers and their partners (mother-father), and mothers with their other children (mother-other children).

Relatively early in the development of his theory, Bronfenbrenner (1995) highlighted the importance of the personal characteristics that individuals bring with them to any social situation, referring to *person* in the PPCT model. He later differentiated between three types of *person* characteristics that were termed *demand, resource* and *force* characteristics (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013; Tudge *et al.,* 2009). *Demand characteristics* indicate personal attributes such as age, gender, skin colour and physical appearance (Tudge *et al*., 2009). *Resource characteristics* may include mental and emotional resources (past experiences, skills, intelligence) as well as social and material resources (food, housing, education and opportunities) (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013; Tudge *et al*., 2009). *Force characteristics* have to do with disparities in people's temperament, motivation and persistence (Rosa & Tudge, 2013; Tudge *et al.,* 2009). This study examined mothers' resource characteristics (past experience, skills, faith, finances, mothers' instinct) as well as their force characteristics (persistence to obtain information, personality).

The environment, which involves four interrelated systems, refers to *context*. These systems are termed the *microsystem, mesosystem, exosystem and macrosystem* (Bronfenbrenner, 1994; Bronfenbrenner & Morris, 2006; Christensen, 2010; Härkönen, 2005; Rosa & Tudge, 2013, Tudge *et al.,* 2009). Microsystem marks the reciprocal relationship between individuals and their immediate setting, including family, school and peer group (Bronfenbrenner, 1994; Bronfenbrenner & Morris, 2006). For this study, microsystem would refer to the mother's immediate family, such as her child and husband. The mesosystem is the context in which microsystems interact, for example school and home (Bronfenbrenner, 1994). For this study, mesosystem would include the mother's broader family, circle of friends, colleagues at work and medical professionals involved in her family's life. The exosystem includes the variety of social structures that the individual does not relate to directly, but that impacts upon the individual's direct or immediate setting, for example the impact of the parent's place of work on the child. The unit of analysis in this study is mothers, and therefore an exosystem for her could be her child's school or daycare facility. Lastly, the macrosystem is explained by Bronfenbrenner (1994) as the overarching pattern of micro, meso and exosystems of a given culture or subculture with particular reference to belief systems, knowledge, material resources, lifestyles, beliefs and values. This represents the societal blueprint. For this study, the macrosystem indicates society's

belief systems or perceptions of ASD, or the government structures supporting or not supporting the management of ASD as a disability.

In this model, the concept of *time* was extended to include the happenings over the course of an activity or interaction as well as historical time (Bronfenbrenner & Morris, 1998, 2006; Rosa & Tudge, 2013). Bronfenbrenner and Morris (1998) explained the concept of time as comprising *micro time* (what is occurring during the course of an activity or interaction), *meso time* (activities and interactions that occur with some consistency in a person's environment) and *macro time* (the chronosystem where interactions between systems influence the individual's development). Time within the framework of this study represents micro time as mothers' interaction with, say, medical professionals during a therapy session for their child, and meso time as, say, the process of diagnosis or the practice of interventions over a timeframe. Macro time for this study could refer to a change in expectations in the larger society, both within and across generations, impacting on the perception of ASD, as well as mothers' future hopes and dreams for their child.

Aim of the study

The aim of this study is to explore and describe mothers' experiences of their child's diagnosis with an autism spectrum disorder.

Method

The researcher made use of a qualitative phenomenological design (Babbie, 2011; Creswell, Hanson, Plano & Morales, 2007; Fouché & Delport, 2011; Fouché & De Vos, 2011; Gay, Mills & Airasian, 2009; Lichtman, 2010). The purpose of the qualitative method is to explore, describe, generate a deeper understanding and gather theoretically rich observations (Babbie, 2011; Fouché & Delport, 2011; Fouché & De Vos, 2011; Gay *et al*., 2009; Lichtman, 2010). Phenomenology has at root the intention to give a rich description of the universal essence (Botma, Greeff, Mulaudzi & Wright, 2009; Creswell, 2006; Creswell *et al*., 2007; Fouché & Schurink, 2011; Gay *et al*., 2009), which for the purpose of this study, is the essence of mothers' experiences of their child's diagnosis with ASD.

Participants

Seven mothers were interviewed to describe their experiences of having their child diagnosed with ASD. Participants were all mothers of children who were diagnosed with an autism spectrum disorder within the past five years, who speak either Afrikaans or English, who reside in the Northern Suburbs of Cape Town within the Western Cape Province and who gave written permission to partake in the research and to have the interviews voice recorded.

Procedures

Approval for the study was received from the Ethics Committee at the North-West University (Ethics No: NWU-00125-14-S1). Mothers were recruited by contacting an educational psychologist in the Northern Suburbs of Cape Town who specialise in autism. The educational psychologist was requested to act as an intermediary to identify possible mothers who fall within the criteria for this study, to make initial contact with them, obtain permission from them to be contacted by the researcher, and to supply the researcher with the names of those mothers who were willing to participate voluntarily. Seven mothers were contacted by the researcher and provided with a consent form via email or post to complete, highlighting their participation as voluntary and confidential. One unstructured interview was conducted with each mother, and interviews lasted between 35 and 105 minutes. The research question was piloted with one non-participant who falls within the criteria of the population to ensure that it is clear and relevant, and that it provided direction regarding the aims of the study. Interviews were completed at a mutually agreeable time and location. Mothers gave consent for the interviews to be voice recorded and transcribed. After data-analysis, member-checking was done via email to verify the research findings.

Data analysis

Transcripts of interviews conducted were analysed using thematic content analysis. The researcher utilised the data analysis method as proposed by Creswell (2006) and Gay *et al*. (2009). This method entails organising the data (transcripts) and field notes in a file, becoming familiar with the data by reading and re-reading the transcripts and field notes, and identifying possible themes (reading/memoing) by using colours and making notes in the margins. Next, detailed descriptions were provided (describing) and data was categorised and coded into themes or meaningful units (classifying). A textural description of the essence was developed and presented in a table.

The theoretical framework of Bronfenbrenner, as previously discussed, informed, at least to some degree, the themes which developed. However, the researcher did ensure that the data drove the themes, and not vice versa. This was done by intensive reviewing, revising and immersing in the interview transcriptions used for the data analysis, consulting with the researcher's supervisor and keeping a reflective journal.

Trustworthiness

The following concepts are described by Schurink, Fouché and De Vos (2011) and Loh (2013), and relate to trustworthiness: credibility, transferability, dependability and confirmability. For this research, various strategies were undertaken to ensure adherence to these concepts.

Credibility was promoted by conducting the inquiry in a manner that accurately identified and described the phenomenon. This was attained by conducting unstructured interviews with no time constraints, allowing participants to give rich descriptions of their experiences, persistent observation (field notes, observational notes), reflexivity and a member check. Reflective journaling was done in an attempt to isolate perceptions based on personal experience (Corbin & Strauss, 2008). The researcher clearly described the theoretical parameters and context of the study, and provided a thick description of the setting in which the research was conducted in an attempt to attain *transferability* (Nieuwenhuis, 2007; Scott & Morrison, 2006). To address *dependability*, the research was well documented (detailed field notes, observational notes and reflective journaling) and the researcher adhered strictly to procedures as set out previously. Findings were verified and validated by doing member-checking and by the researcher applying bracketing in an attempt to prevent own assumptions from shaping the data (Lichtman, 2010; Hamill & Sinclair, 2010). Lastly, to account for the bias and subjectivity of the researcher, the concept of *confirmability* was sought through extensive documentation and reflection of the researcher's bias and subjectivity via reflective journaling, regular consultation with the supervisor and doing a literature control to confirm data analysis and correlate findings and interpretations (Houghton, Casey, Shaw & Murphy, 2013). The school of existential phenomenology, as described by Kafle (2011:187), focuses on re-achieving a direct and primitive contact with the world even though it holds that complete reduction and bracketing is not possible. This was done by taking reasonable steps to ensure that presuppositions were

brought to the level of consciousness by writing about them in the reflective journal, acknowledging them, and then bracketing them.

Discussion of findings

The analysis of the interview transcripts revealed four main themes, namely: 1) mothers' experiences of interactions and relationships within their immediate family (*Proximal Process*), 2) mothers' experiences of their internal and external characteristics and resources (*Person*), 3) mothers' experiences of their environment (*Context*), and 4) mothers' experiences of the journey through time (*Time*). The themes are illustrated in Table 1 below to give insight into how they specifically refer to the PPCT concept of Bronfenbrenner. It is important to note that subthemes within the four categories are fluent and could easily fit some of the other main themes as they are all interrelated and reciprocal, as is the proximal process described by Bronfenbrenner (1995). These themes, with their subthemes and categories, will be discussed, illustrated with examples from interviews, and compared with relevant literature. For the purpose of this discussion, participants will be referred to as mothers.

Table 1: Thematic presentation of mothers' experiences of their child's diagnosis with ASD

Theme	Subtheme	Category
1. Proximal Processes Mother's experience of interactions and relationships within her immediate family	Mother-Child	Connectedness Linked emotions Child's challenging behaviour Child's isolation
	Mother-Father	Father's response Father's involvement Marital relationship
	Mother-Other Children	Challenges for other siblings
2. Person Mother's experience of her internal and external characteristics and resources	Internal challenges	Guilt regarding causality Feeling uninformed
	Internal strengths	Informing themselves Faith / Religion Gut / Instinct
	Internal characteristics	Personality / Temperament
	External resources	Finances
3. Context Mother's experience of her environment	Micro level	Life-changing decisions for the family Multiple roles
	Meso level	Support from family Support from friends Support from colleagues Support from professionals
	Macro level	Society's perception of ASD Society's perception of delayed development in boys
4. Time Mother's experience of the journey through time	Before diagnosis	First signs and symptoms
	Diagnosis	Moment of diagnosis
	After diagnosis	Interventions Child's development
	Current	Child at present
	Future	Hopes, dreams, visions for child's future
	Throughout the process	Own growth / journey

The mother's experience of interactions and relationships within her immediate family (Proximal Processes)

The first theme that is notable is the mother's experience of interactions and relationships within her immediate family. As the immediate family is the inner circle from which the mother interacts, all the interviews focused on the relationships on this micro level. This theme of the mother's experience of interactions and relationships in her family refers to the *proximal processes* that occur on the level of the immediate family (Bronfenbrenner, 1994; Rosa & Tudge, 2013; Tudge *et al.*, 2003). At this level, the focus was on mother-child, mother-father and mother-other children interactions.

Mother-Child

In terms of the mother-child relationship, mothers referred to *connectedness* to their children as being problematic from as early as the day they were born: "And I felt that almost from the day he was born. I can't hundred per cent connect with him."

Research by Estes *et al.* (2009) and Hornstein (2012) confirmed the unique challenges mothers face because of the impaired social relatedness of children with ASD, and mentioned that this may be emotionally painful for mothers. As this connectedness relates to mother-child attachment, many studies have confirmed the challenge that mothers and children with ASD have regarding attachment (Dolev, Oppenheim, Koren-Karie & Yirmiya, 2009; Goodman & Glenwick, 2012, Sakaguchi & Beppu, 2007). Together with mothers' incapacity to connect with their child, it also emerged that mothers experienced their *child's behaviour as difficult or challenging*, and at times felt incapable of managing this (Seymour, Wood, Giallo & Jellett, 2013). Mothers in this study reported that this also influenced the marital relationship as some fathers had the expectation that the mothers should be able to manage the child's behaviour. Mothers then presented with feelings of guilt regarding their capacity to parent, which in turn had implications for the mothers' wellbeing (Brobst *et al*., 2009; Gray, 2003; Seymore *et al*., 2013; Smith *et al.*, 2008). Mothers further experienced their children as *distant or isolated*, which is again in line with the impaired social relatedness and lack of social or emotional reciprocity that forms part of the diagnostic criteria of ASD (Rodger & Keen, 2012).

Although feeling that their children are distant or isolated, mothers reflected on their own *emotions as being directly linked to their child's*, implicating the proximal process as being reciprocal: "If it's a bad day for him [child], it's a bad day for me. If it's a good day for him, it's a good day for me." Another mother commented: "If I take a dip, he takes a dip. So we dip together … and this is bad, because he rides this roller-coaster as he is with me."

A study by Cashin (2004) referred to this as existing together in a "vortex". Although this might be true for all mothers, it is confirmed by literature that mothering a child with ASD puts mothers at greater risk for depression and generally poorer health and wellbeing (Gray, 2003; Mourisden *et al*., 2007; Safe, Joosten & Molineux, 2012; Smith *et al*., 2008).

Mother-Father

Fathers' responses to the possibility of their child having ASD were experienced by the majority of mothers as the father being in denial: "He said there is nothing wrong with him [the child]. But that's my husband, he is very black and white." Other mothers even felt that using the word 'autism' in front of her husband was a sin: "And my husband, I mentioned it to him once [the possibility of an autism diagnosis], and he just flipped. Not at all … you just did not mention the word 'autism'."

Literature noted that fathers often suppressed their feelings or denied the initial diagnosis (Hornstein, 2012; Gray, 2003). A study by Allen, Terence, Bowles and Weber (2013) found that mothers experienced more stress related to ASD symptomatology than fathers, and that the differential effects of gender were noteworthy. It can be argued that fathers initially might experience less stress because they are still in denial. Rarity (2007) confirmed that every parent reacted differently to their child's diagnosis with ASD as they go through a period of adjustment where they are unsure of what it means to have a child with ASD, for themselves and for their child's future. Mothers further experienced fathers to generally take longer to digest the diagnosis, but that some fathers became supportive over time. Three mothers indicated that although their husbands were in denial at first, they eventually accepted the diagnosis, and even educated themselves.

Mothers' experiences of *fathers' involvement* was another discussion that emerged, and the majority of mothers experienced their husbands' involvement as minimal to totally absent,

leaving them with the sole responsibility of managing the interventions for their child. Greeff and Van der Walt (2010) affirmed that parents who reported that they were both committed to working together to achieve the best outcomes for their children experienced their environment as supportive. In this study, three mothers experienced their husbands' current involvement as positive and supportive: "My husband and I … we are an absolute winning team. He supports me 100% and he is also a wonderful support in the house, you know, he helps a lot."

Although some mothers experienced their husbands' involvement as positive, all of the mothers in this study mentioned the impact of an ASD-diagnosed child on the *marital relationship*. All of the mothers acknowledged that this relationship experienced challenges, that they had to work harder to maintain the relationship and also that the available time for their husbands were limited: "We must work much harder at our marriage, and we need to be more punctual, … to make time and to say okay, now it is time for our marriage." Another mother commented on the limited time available for the marital relationship: "… to stay sane … to keep your marriage going, together with everything else … I can see that marriages can break up under this kind of pressure, because you just don't have the time."

Studies by Brobst *et al.* (2009), Gane (2008), Martin (2010) and Zablotsky, Bradshaw and Stuart (2013) confirmed these findings. All seven mothers in this study were still married to the fathers of their ASD children. One mother disclosed that her relationship was so strained at the time that she would be starting divorce procedures soon.

Mother-Other children

Out of the seven mothers, five had other children. One mother's two children were both diagnosed with ASD. All five mothers discussed the difficulties of managing the impact of an ASD child on the other siblings, for example: "I feel very guilty about Janice [sibling sister] in that respect because there's a lot of things she can't to because Ryan can't do it."

One mother in particular experienced the relationship between her two children as very positive: "… and how she [sibling sister] just embraced her brother from day one … it was so beautiful to see, and not embarrassed by him at all."

Literature has extensively covered the *challenges faced by the siblings* of an ASD child (Bishop, 2012; Gane, 2008; Zablotsky *et al.*, 2013). Again, mothers experienced feelings of guilt toward the other child, questioning their capacity to parent and reflecting on the struggle to make time for the other sibling in between all the interventions for the ASD child.

The mother's experience of her internal and external characteristics and resources (Person)

The second theme captured the *person* characteristics as set out by Bronfenbrenner (Rosa & Tudge, 2013; Tudge *et al*., 2009). This included not only the mental and emotional resources, but also material resources and temperament. Hence, this theme describes the mother's experiences of her internal and external characteristics and resources.

Internal challenges

As part of the mothers' internal challenges, the mothers were searching for causality regarding the ASD diagnosis. In accordance with literature (Ferrugia, 2009), most of the mothers indicated that they experienced feelings of guilt as they thought they were somehow *responsible for their child's ASD diagnosis*: "You start thinking, oh my gosh, it's something I did, I influenced his environment to the point that he became autistic." Another mother described it as: "I think one wonders why me. Did I do something wrong? Maybe I should have done something different, or maybe … you know, you try to figure it out."

Mothers also experienced a sense of *feeling totally uninformed* regarding the diagnosis as well as the interventions needed. These feelings of "not having a clue", ignorance and, at times, being overwhelmed, were also confirmed by other research (Rodger & Keen, 2012, Martin, 2010). Some mothers indicated that prior to the diagnosis, they had never even heard of the word autism: "Autism was just a word for me. I just knew it was something that you don't want your child to have."

Internal strengths

Mothers addressed their feelings of being uninformed as part of their internal strengths. Mothers proactively *informed themselves* via channels such as the internet (Fleishman, 2005; Martin, 2010; Woodgate *et al*., 2011), or by speaking to other mothers who have been through similar experiences. Mothers indicated that this information enabled them to better assist their

child, but also to understand the interventions and to make informed decisions: "I think the most important thing is informing yourself as much as possible regarding the diagnosis … it helps you to understand your child better and helps you to cope better with the diagnosis."

Another aspect that was regarded as part of mothers' internal strengths was the prominent role of *faith or religion*. Mothers experienced a sense of renewed faith, felt empowered through knowing that they were not alone, and mentioned that this was often what carried them through the most difficult times: "… faith was the biggest thing for me … it opened doors that I did not think is possible." Another mother felt she was not fighting the autism battle alone: "… God is with us in this, we do not have to fight it alone." Interestingly, a study done by Shu (2009) revealed that mothers of children with ASD who practised religion tended to have a lower quality of life than those without religion, but indicated that this should be confirmed by further studies. This study, however, revealed that the majority of mothers felt their faith or religion was a tremendous support. These mothers used their faith or religion as a coping mechanism to carry them through trying times.

Another internal strength that was strikingly present in all interviews was mothers referring to their *gut* or their *mother's instinct.* Consistent with other research (Gane, 2008; Herbert, 2014; Hornstein, 2012; Woodgate *et al*., 2011), mothers noted throughout that they had a sense, a gut feeling or an instinct regarding their child's developmental delay, or even whether certain interventions were appropriate for their child. While all of the mothers indicated that they knew that they should have listened to their gut or instinct, some acknowledged that they listened to so many people's opinions, including some professionals, that at times they questioned this gut or instinct: "It is the most stupid things you listen to, instead of following your own gut."

Internal characteristics

The majority of mothers commented on their internal characteristics when referring to their *personality or temperament* as either being a strength or at times a challenge. A study by Seidman, Yirmiya, Mishtein, Ebstein and Levi (2012) found that mothers of ASD children were reported to be less "aloof" and more "rigid". They also indicated that anxiousness, impulsiveness, hypersensitivity to criticism, and irritability were found more often in parents of children with ASD, confirming the impact of these personality traits. Mothers in this study commented the following: "Luckily I have a strong personality and I am used to fighting on my

own." Another mother felt that she was driven and goal orientated, and that this sometimes posed a challenge when dealing with ASD: "And I think what makes it very difficult, is that I am a control freak."

External resources

Finances was a topic that all mothers touched on as part of their external resources. The affordability of the interventions was a challenge throughout: "And you could do it if you've got buckets of money, but you can't do it if you don't." Another mother commented on the fact that finances guided the interventions that were chosen:

> "Every therapy route you want to take with your child is expensive, and when you don't have a big disposable income, you pick which one is the best one … and which do I leave for later when there's more money in the pocket."

Gane (2008) confirmed the financial burden on families with a child diagnosed with ASD. In their study, Wachtel and Carter (2008) indicated that mothers who stopped working to coordinate their children's treatments were faced with financial pressure at an already stressful time. Some of the mothers experienced the financial burden as putting extra strain on the marital relationship.

The mother's experience of her environment (Context)

This third theme refers to the *context* as described by Bronfenbrenner (1994). Mothers' experiences were clearly noted as systemic across all interview transcripts. The systemic impact of ASD was clear on the micro level in particular, but also on meso and macro levels. This theme must also be read in conjunction with Theme 1 (proximal processes) as the interactions occurred across the systemic environment.

Micro level

On micro level, mothers indicated that they were *fulfilling multiple roles* within their immediate families, at times feeling overwhelmed. Mothers noted that they had to fulfil these roles as their children depended on them: "Because you are your child's doctor, his psychologist,

you are your child's … you don't have a cooking clue what you are doing, but you are everything, and you have to, and you have to … quickly."

Wachtel and Carter (2008) stated that a young child with ASD may receive up to thirty hours of intensive therapy per week. The burden of coordinating, advocating for, and managing treatment decisions and plans often falls on the parent, and in this study, more so on the mother of the ASD child (Vidyasagar & Koshy, 2010). This study indicated that this had a severe impact on the working mothers, resulting in three of them quitting their jobs and two others looking for different jobs to allow them more free time or to put them geographically closer to home to better manage their children's interventions. These *life-changing decisions* were not only related to mothers quitting their jobs ("I worked, and then I stopped working to be with him …"), but also to families relocating ("We moved … to be closer to his therapies.") and some even changing their home language to accommodate their son ("He does not speak Afrikaans, he prefers English, and so we changed our home language to English.").

Meso level

On meso level, mothers' discussed their experience of the support they received from various groups of people: family, friends, colleagues and medical professionals. Mothers' experiences of the support they received from *family* varied. Some indicated that the family were either in denial, or really did not understand what they as a family were going through:

> "Even in my own family, until they did not experience one of his meltdowns, they never accepted how severe his needs are. And this was sad, that it had to come to that, that they had to see how severe it is before they started supporting us."

Previous studies elaborated on the extended family minimising the problem, or implying that the mother's parenting was somehow not adequate (Banach *et al*., 2010; Hornstein, 2012). This again fed into the guilt feelings the mothers were already experiencing. However, most of the mothers in this study felt positive regarding the support they received from family: "My parents moved to Cape Town 8 years ago, and I told her that God knew she had to move closer, because I would not have been able to do this alone." Another mother reflected on her support as follows: "Our circle of friends became much smaller, but our family ties were strengthened."

As for the support mothers experienced from *friends*, all but one mother felt that their friends judged them. Safe *et al*. (2012) found that friends either withdrew their friendships because of limited understanding or the social inappropriateness of the child with ASD. Mothers in this study also experienced that their circle of friends declined in numbers because of their child's behaviour: "So, I lost all my friends, because not one of them understood."

The working mothers all experienced their *colleagues* as supporting them to the extent that the one mother mentioned that her colleague had become her psychologist: "My other saving grace was my work … the people at my work. The colleague that previously irritated me literally became my psychologist."

Lastly, all mothers discussed their experiences with the *professionals* involved in either the diagnostic process or the interventions. On average between three to nine medical professionals were consulted before making a diagnosis. Again, mothers' experiences were conflicting as only three of the mothers' experiences were positive. As confirmed by Safe *et al*. (2012), the other four mothers either mentioned that they did not think the medical professionals really understood what the mothers experienced, or they felt that they were being sent from the one professional to the next, all having conflicting advice and opinions:

> "I don't think they know [medical professionals]. It is very difficult for someone who does not have a child on the spectrum or that is in daily contact with such a child to have total empathy and to really understand the daily life of such a parent …"

Macro level

On the level of society as a whole, mothers specifically mentioned two categories: society's perceptions of ASD and society's perspective of delayed development in boys as being normal. Mothers experienced *society as not understanding ASD* and as not being accommodative toward special needs. Studies by Evans (2010), Farrugia (2009) and Woodgate *et al.* (2011) described society as being intolerant, lacking compassion, being senseless and being totally ignorant. Three of the mothers made specific mention of the fact that ASD is an invisible disability, making it even harder to understand or get support or empathy: "Because he does not have a physical disability, you are not judged in the same way as others with special needs, where you can actually see something is wrong."

Mothers specifically mentioned that society accepted that *boys' development was usually delayed* and that this was supposedly acceptable. Mothers felt that sometimes this was a way of trying to minimise the possibility of something being not right, or an attempt to reassure or comfort mothers: "And everybody was going, he's a boy, he's lazy, you know that sort of thing." Another mother reflected as follows: "Yes. And everybody kept telling me, he's a boy, don't worry, boys take longer …" Research could not be found to confirm or reject this finding.

The mother's experience of the journey through time (Time)

This last theme refers to what Bronfenbrenner earlier called the *chronosystem*, and indicates what happens over the course of an activity or interaction in historical *time* (Rosa & Tudge, 2013). This specific theme focused on meso-time, which refers to activities and interactions that occur with some consistency in these mothers' lives (Bronfenbrenner & Morris, 1998).

Before diagnosis

All mothers discussed in detail the signs and symptoms they witnessed in their child *before starting the journey to search for a diagnosis*. Again, here was some overlap with society's perception of delayed development in boys (Context – Macro), the mother's gut or instinct (Person – Micro) and the child often being distant or isolated (Proximal Process – Mother-Child). However, the focus was not on the signs and symptoms of ASD, but on the mothers' experiences when they first noticed something was different. Literature confirmed (Braiden *et al*., 2010; Feliciano, 2009; Fleischmann, 2005; Hornstein, 2012) that mothers described this time as feeling alone, misunderstood and constantly being worried, or as one mother stated:

> "I died inside, I was totally alone, and as I spoke to people everybody told me there is nothing wrong with him, boys do that, boys don't talk, and everybody laughed at the things he did, so did I, but as he grew older his differences became more pronounced."

Diagnosis

Mothers specifically made mention of *the moment of diagnosis*, and how they had experienced this. For the majority of the mothers this moment was experienced as negative or overwhelming. Although the majority of mothers also indicated that they knew what to expect,

getting the diagnosis was still a shock (Evans, 2010; Feliciano, 2009; Fleishmann, 2005; Hornstein, 2012). Some studies suggested that receiving the diagnosis could be empowering as families would then know how to support their child (Feliciano, 2009; Wachtel, 2007). Only one mother in this study referred to this moment as enlightening: "The diagnosis is like switching on a light. Now at least you know what you are facing."

After diagnosis

Mothers mostly described the intense interventions that were applied to their child *after diagnosis*. Interventions included a range of biomedical treatments (diets, supplements), behavioural therapies (applied behavioural analysis), and therapy to address the developmental delays (speech therapy) as well as the impairment in sensory integration (occupational therapy). Mothers spoke about the impact of the interventions as overwhelming and very time-consuming (Wachtel & Carter, 2008). This, together with witnessing the slow progress of the child, dealing with the financial cost of treatment and handling the impact on relationships, was really taking its toll, and mothers described this time as: "I cannot cope. I am not made for this [referring to the dietary interventions]." One mother specifically felt that this was her turning point. This was the point in time that she had accepted her child with his disabilities:

> "At this stage I still had my crying moments, but it started to get better. It was not daily anymore … and I think by this time I already buried my boy [symbolically]. He was dead. I had a new boy … a problem child that I needed to help."

Current

During the next stage, the interventions started to show results in the children's development, and mothers all mentioned this as positive and rewarding. The mothers' experience of their child *at the present moment* is significantly positive, and also refers to the above timeframe where they can now see the impact of the interventions: "I enjoy him endlessly. It feels like I am catching up on that cute … eighteen months, two years … now I get my chance. Because you feel, you were robbed of that …"

Future

Mothers all had *hopes, dreams and visions for their child's future*. One mother specifically believed that her child will be cured, where the other mothers mostly experienced

some fear regarding the future. This vast array of opinions regarding the child's future was also noted in the studies of Fleischmann (2005) and Ivey (2004). Mothers in this study all had hopes for their child to either be happy ("I want him to be a happy boy, he must have a good life.") or self-sufficient ("Is he gonna cope when we're not there one day anymore. Is he ever gonna reach a point where he's self-sufficient?")

Throughout the process

Towards the end of interviews, the majority of mothers reflected on *their journey as a whole*. Most mothers indicated that the process was a positive one, indicating a sense of growth and fulfilment and an experience of life as having a new or different meaning: "I think the whole process was more of a blessing to me than a curse." Another mother felt that she now appreciated the smaller things in life: "And then also … just teaches you to really focus on the little things, which I think I would never have probably done to this extent if we didn't have Ryan." Two of the mothers described their journey as the loss of their dream, or a specific life they had in mind:

> "… and I just got thrown a complete curve ball. And I think this is difficult. You know, you have your white picket fence and your two and a half kids and your blah, blah, blah, and then the realisation that you will never have this, this is a loss."

The grief or loss of a dream as described here has been the focus of extensive literature (Constantino, 2010; Martin, 2010). However, these mothers did feel that they have moved on, creating a new dream for their own lives as well as for their ASD child. Constantino (2010) referred to this as navigating through the storms when he said: "Parenting children with disabilities means coming to terms with feelings of loss and grief and balancing these with hope and resilience."

In closing, this study achieved the desired aim of creating an understanding of mothers' experiences of receiving their child's diagnosis of an autism spectrum disorder. The various aspects of Bronfenbrenner's PPCT model provided new insight into the various aspects of these mothers' experiences, and can aid professionals in supporting such mothers.

Conclusion

This study highlighted the numerous issues that mothers encountered when receiving their child's ASD diagnosis. Although highly individualistic with regard to certain aspects, common themes emerged. Clearly, the impact of a child with ASD on the immediate family is notable. It is important for professionals to take cognisance of these themes and to make parents aware of the possible challenges that they might face as a family. This could aid mothers to be proactive in terms of their marital relationship and their relationship with their other children. As the family is the micro system where the most important proximal processes take place, this has definite implications for the mothers' wellbeing and for the family system as a whole. If these relationships are nourished, it can provide a protective factor in supporting mothers, and it can empower mothers to cope with the unique challenges that they face. This has implications for the child with ASD as research has shown (Osborn *et al.*, 2007) that the challenges and stressors associated with having an ASD child can significantly reduce the prognosis for effective interventions for the child.

The mothers highlighted that they felt uninformed, uneducated and overwhelmed and that the medical professionals seemed to give different types of advice or support different types of interventions, which points to the gap in providing sufficient information to families regarding ASD. This justifies the need for a standardised support programme. The initiative that mothers took to inform themselves, be proactive, follow their gut / instinct and trust their faith / religion impacted their resilience to manage their journey, and it shows that mothers will leave no stone unturned in trying to create a space in which their ASD children can develop into their full potential. The mothers were willing to make radical and life-changing decisions regarding their ASD children and to bear the financial burden associated with this, which shows the impact of autistic children on the family. Without the necessary support, mothers would not have coped with their day-to-day struggles. The mothers in this study specifically mentioned the positive support they had received from some family members, friends and colleagues.

Although support from individuals in the mothers' immediate life space was acknowledged, society as a whole seemed to lack an understanding of ASD. Various organisations have launched campaigns to create awareness of autism, but the gap in the perceptions and knowledge of South African society regarding this disability was still evident.

As a result, the mothers in this study seemed to advocate for their ASD children, persistently trying to create a space in which these children could reach their full potential.

The demands of ASD children on their mothers are immense. Appropriate support to these mothers is of the utmost importance to manage their diverse roles in their families and to contribute to their wellbeing, which has a direct influence on the child with ASD behaviour (Osborne & Reed, 2009).

Professionals working therapeutically with mothers of ASD children should take cognisance of what these mothers are experiencing on a daily basis, motivate them to invest time in those relationships (proximal processes) that are the most meaningful to them (micro system) and make them aware of the value of their gut/instinct (Person). Although professionals might have extensive knowledge of ASD symptoms and interventions, each child differs, making the mothers the experts on their children and their unique situations. This gut/instinct mothers reflected on guided them in decisions regarding interventions. Professionals should therefore note that mothers should be guided to take responsibility for choosing appropriate interventions for their ASD children, taking into account the affordability of treatments. Mothers can also be supported by cautioning them about possible perceptions from family, friends, colleagues and society (Context) in general. By empowering such mothers, they can become advocates not only for their own children but for the community of families living with ASD. Lastly, professionals should note that the journey mothers experience over time (Time) is highly individual, but it does resemble the metaphorical “rollercoaster ride”. The mothers’ perseverance in terms of their children reaching their full potential, their meticulous planning of interventions and remarkable ability to juggle all the roles have led to a process of painful individual growth for the mothers themselves. The life lessons learnt mostly seemed to have overshadowed the hardships. As Constantino (2010) and Martin (2010) duly reflected, this journey can be accompanies by a process of grief and bereavement. Mothers can be assisted by professionals explaining this process and guiding mothers through the phases grief and loss.

Bronfenbrenner’s bioecological theory contributed to an understanding of mothers’ experiences of their children’s diagnosis with ASD. Because of the interrelatedness of the themes in Bronfenbrenner’s PPCT model, some themes could also have fit the description of

another concept within this model. The framework of proximal processes, people, context and time gave this study a scientific rubrick that guided the discussion and evaluation of the themes.

Limitations

While these findings are meaningful in understanding mothers' experiences of receiving their child's ASD diagnosis, there are limitations that should be noted. This study applied a phenomenological approach as framework, which allowed for the use of a small sample (seven) of the population of mothers with ASD children. Although the small sample size is not a limitation in this context, it should be noted that the small sample size cannot guarantee transferability to other settings.

An educational psychologist specialising in autism acted as an intermediary to recruit participants from their case loads. The sample demographics (white South African mothers who are married and who are part of middle-income to high-income households) were over-represented in this sample as these families either claimed for the assessments through medical insurance or they paid cash. Furthermore, respondent characteristics such as age, level of education and the child's specific diagnosis may have had an impact on the experiences of the mothers. Therefore, the results may not be representative of all mothers of ASD children.

Future research

Additional research could focus on cultural differences in terms of mothers' experiences of receiving their child's ASD diagnosis. This includes varying cultural approaches and attitudes toward disability, and specifically ASD. Future research can also focus on how mothers of ASD children respond to their environment and how their person characteristics can be influenced by their background.

Examining fathers' experiences of receiving their child's ASD diagnosis might also be insightful.

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SECTION C: CONCLUSIONS AND RECOMMENDATIONS

1. INTRODUCTION

Parenting a child with ASD has been reported as exceptionally challenging for mothers. The uniqueness of ASD with particular reference to behavioural challenges and the impaired communication adds to the stress that mothers experience in their day-to-day lives. Together with a perceived lack of support, a shortage of affordable intervention strategies and a general lack of understanding or tolerance by society make mothers vulnerable if they are not appropriately supported. When mothers' experiences of their child's diagnosis with ASD are understood, appropriate support and therapeutic guidance can follow. The aim of this study was to describe and explore mothers' experiences of their child's diagnosis with ASD. The research question was answered using a qualitative phenomenological research design, and utilising both existential phenomenology and Bronfenbrenner's PPCT model as theoretical frameworks. In-depth, one-on-one interviews were conducted yielding rich information which was analysed using thematic content analysis. The previous sections made it possible to conclude and give appropriate recommendations:

Section A provided an orientation to the research. Part 1 argued the gap in literature, provided a brief discussion of the theoretical frameworks utilised for the study, explained the research methodology and considered the ethical aspects of this research. Part 2 provided a literature background on autism spectrum disorders, including definitions, impairments associated with the disorder, theories of causality, treatments and the challenges that parents face when raising a child with ASD. The theoretical frameworks, namely phenomenology and Bronfenbrenner's theory with specific reference to his PPCT model, were reviewed.

Section B of this document contains the article that will be submitted for possible publication to an academic journal. In the article, the findings of the research were discussed comprehensively, together with a literature control. Brief conclusions and recommendations were also made.

Section C will now present the conclusions and recommendations, as well as a reflection on the research process. In closing, the limitations of this study will also be noted.

2. AIM OF THE STUDY

As stated in Section A, understanding the unique struggle of mothers with ASD-diagnosed children can be of value to other mothers and professionals in various contexts. The usefulness of this insight becomes even more pronounced if one looks at the increase in the prevalence of

ASD, the parental stressors associated with parenting an ASD child and the gap in adequate literature focusing on the South African context with specific reference to the Western Cape. The aim of this study was to explore and describe mothers' experiences of their child's diagnosis with ASD. This aim was accomplished by revealing the four main themes from this study. These key findings offer insight that can assist professionals to improve service delivery to mothers of ASD-diagnosed children and to angle their support or therapeutic services accordingly.

3. CONCLUSIONS AND RECOMMENDATIONS

Conclusions and recommendations that follows will be made on the themes that emerged from the study, and thereafter on the use of Bronfenbrenner's bioecoogical theory as a theoretical framework for this study.

3.1 Conclusions based on the themes emerging from the study

Conclusions and recommendations will be presented according to the themes that emerged from this study. Each theme will be presented with its own conclusions and recommendations for professionals. At the end of this section, general recommendations will be made to mothers of children with ASD.

Using Bronfenbrenner's bioecological theory of human development, four themes emerged from the data that provided insight into the lived experiences of mothers when receiving their child's ASD diagnosis.

Theme 1: The mothers' experiences of interactions and relationships within their immediate families (Proximal Processes)

Conclusion for this theme:

The impact of an ASD child on the immediate family is significant. This theme, namely the mother's experience of interactions and relationships in her immediate family, can be divided into the following three subthemes: mother-child, mother-father and mother-other children. The mother-child subtheme revealed that the mothers in this study encountered the following challenges: connecting with their child, finding the child's behaviour difficult or challenging, experiencing the child as distant or isolated, and feeling that their emotions were directly linked to their child's behaviour. The characteristics or signs and symptoms of ASD specifically refer to

impairments in social interactions, communication and stereotyped behaviours, which makes this finding understandable.

The mother-father subtheme gave insight into the mothers' experience of the fathers' response to their child's developmental delays and possible diagnosis, the fathers' involvement with the child and the process of diagnosis, and the challenges put on the marital relationship. Here, the majority of mothers experienced the fathers as either in denial or generally not involved. This, together with the extra strain that ASD puts on the family as a system, creates a demanding environment for the marital relationship.

The last subtheme, mother-other children, unpacked mothers' experience of how having an ASD-diagnosed child influenced the other siblings in the family. As the family is the micro system where the most important proximal processes take place, these findings have significant implications for the mothers' wellbeing and the family system as a whole. Healthy relationships can provide a protective factor and a source of support to empower mothers to cope with the unique challenges that they face. In addition, healthy relationships can create an environment in which children with ASD can develop to their full potential.

Recommendations for this theme:

Professionals working with mothers of children with ASD should give recognition to the many challenges this disorder poses to the immediate family. If mothers understand the disorder they will have insight into the way the signs and symptoms that are typical of ASD present in their child and not see the ASD diagnosis as a result of their shortcomings. Understanding the gender differences in the way mothers and fathers experience and cope with ASD can improve communication between parents and positively influence the marital relationship. Professionals dealing with ASD-affected parents should emphasise the importance of making an effort to maintain the marital relationship. Couple counselling with specific reference to managing such a relationship weighted by the added stressors of caring for an ASD child could also be of value.

Theme 2: The mothers' experiences of their internal and external characteristics and resources (Person)

Conclusion for this theme:

Internal challenges revealed that the mothers felt that the ASD diagnosis was somehow their fault and that they were totally ignorant regarding ASD. This implies a general gap in the provision of relevant ASD-related information to mothers.

The second subtheme refers to internal strengths of the mothers and showed how they informed themselves to address these internal challenges, relied on their faith / religion as an internal support or strength and trusted their gut / instinct in terms of beliefs regarding their child's developmental delays and decisions regarding interventions. The mothers implied that these strengths enhanced their resilience in managing their journeys.

The third subtheme refers to internal characteristics. In terms of the internal characteristics, the mothers indicated that they experienced their personality or temperament as supportive or at times challenging when processing the ASD diagnosis and managing the interventions.

Lastly, external resources referred to finances. The mothers mentioned the high cost of the interventions for ASD children and the impact of the additional expenses on family finances.

Recommendations for this theme:

Professionals should address the feelings of guilt when working with mothers of ASD children. Providing such mothers with appropriate information and a better understanding of the causes of ASD could resolve some of the blame these mothers take for their child's diagnosis. When working therapeutically with mothers, professionals could use the strengths-based approach to empower mothers by acknowledging their internal strengths as well as the assets of their personality or temperament. Lastly, professionals should be aware that the interventions are not within the financial reach of all ASD-affected families. However, professionals can try to be creative when advising parents on interventions, for instance by taking the initiative to establish support groups for mothers with autistic children.

Theme 3: The mothers' experience of their environment (Context)

Conclusion for this theme:

This theme summarises the ASD-affected mothers' experiences of their environment on micro, meso and macro level. On micro level, the mothers experienced that the immediate family had to make life-changing decisions – such as relocating or changing their home language to accommodate their ASD child, leaving no stone unturned in trying to create a space in which their child could reach his or her full potential. The mothers also described the financial implications of raising an ASD child. The mothers agreed that they would do what was required, at times making decisions that had huge financial implications. At times, the financial implications of the highly expensive ASD interventions impacted the ASD parents' marital relationships. Although most fathers owned up to being the providers, this has led to conflict regarding the need for such expenses. This study noted that fathers usually took longer to

accept the diagnosis, and were often in denial while the mothers felt they needed to advocate for their ASD child, even among their immediate families.

Still on micro level, the mothers had to fulfil multiple roles within their families to ensure optimal outcomes regarding interventions for their ASD children. Again, the impact of these decisions and the multiple roles the mothers had to play had a direct impact on their stress levels and general wellbeing. To cope with these stresses, support to such mothers is crucial.

On meso level, the mothers described their experience of support from family, friends, colleagues and medical professionals as diverse. While most mothers felt that they had lost most of their friends, they noted the significant role their extended family played. Still, some mothers indicated that they had to advocate for their child, even in their own family. Support from colleagues was overwhelmingly positive whereas support from medical professionals differed. The number of medical professionals consulted to reach a diagnosis caused concern for the mothers. On average, the mothers visited three to nine professionals before an accurate diagnosis was made. This raised questions regarding the professionals' knowledge and preference for certain interventions. One mother noted that she wished professionals could talk out of "one mouth" as she felt they all gave different opinions and supported different types of interventions.

On macro level, the mothers explained their experience of society's perception of ASD as well as the general perception that boys started to develop later than girls. The mothers implied that they often felt judged and misunderstood, and that society easily condemned without grounds because ASD is an "invisible" disability. The need for more awareness is therefore clear. The mothers further noted that there seemed to be a perception in society that boys' development is often delayed, and that this was used in an effort to minimise symptoms or to mitigate the mothers' concerns. A typical response was: "Don't worry, boys take longer to develop." By this time, most of the mothers in the study indicated that their gut / instinct had already indicated that something was wrong.

Recommendations for this theme:

Support for mothers is at the crux of this theme. Again, professionals can assist to create opportunities through support groups for ASD-affected mothers, allowing such mothers to interact with other mothers who are experiencing similar stressors. It could also be of value to present workshops for extended family members or friends who have little knowledge of autism. Creating such opportunities for family, friends and colleagues could help to turn around negative perceptions and ultimately result in better support for mothers. On macro level, various

organisations are advocating for autism and making society aware of the impact of ASD on families. Government funding for these organisations should be increased and supported. These organisations can run awareness campaigns and lobby for improved service delivery and government-funded interventions for families living with ASD.

Theme 4: The mothers' experiences of their journey through time (Time)

Conclusion for this theme:

The fourth and last theme highlights the mothers' experience of their journey through time (Time) and focuses on the time prior to, during and after the diagnosis. The mothers described their experience of becoming aware of the first signs and symptoms prior to diagnosis. The moment of diagnosis was also a significant moment in time in which mothers experienced emotions ranging from shock to feeling "a light has just been switched on". After diagnosis, the mothers explained their experience of the interventions and how these impacted their child's development. The mothers mostly felt overwhelmed by the interventions, but described a sense of excitement regarding their child's progress and development. The mothers also described their experience of their child at present, and most mothers indicated that they enjoy them and that they are catching up on time lost when their child was isolated or distant.

In terms of the future, the mothers revealed their hopes, dreams and visions for their ASD child. This was very individualistic with some mothers believing that their child will be cured while other mothers simply wanted their child to be happy. Lastly, the mothers reflected on their journey through time and their personal growth during this time. The concluding response from the majority of mothers was that the process has taught them gratitude and strength, and that they were hopeful for the future.

Recommendations for this theme:

Professionals can guide the mothers in their journey through time by educating them on the grieving process. Although mothers' experiences over time are highly individualistic, it is evident that this journey can metaphorically represent a "roller coaster ride" of emotions. As mothers come to terms with the diagnosis, new emotional challenges could arise – for instance preparing themselves emotionally that their child may not be able to cope in a mainstream school. It is recommended that mothers should have a trusting therapeutic relationship with at least one professional. In this way, professionals can guide mothers in decisions regarding interventions and make them aware of their own feelings and emotions during particularly stressful times.

These four themes encapsulated the mothers' experiences of their child's diagnosis with ASD. Bronfenbrenner's PPCT model helped to provide a framework for understanding these experiences and gaining insight into how the concepts of proximal processes, person, context and time interplay with each other.

General recommendations for mothers of children with ASD:

The mothers in this study indicated that throughout the process they were so busy managing the diagnosis and treatments for their ASD child that they lost track of their own emotions and how this impacted their wellbeing. Mothers should therefore stay in touch with their own emotions as a proactive way to gauge when they need to seek therapeutic support or attend a support group. Respite care is also crucial in giving mothers some time off as long as the mother feels that the person offering the respite care is capable of managing their child for this period of time.

Lastly, mothers could benefit from connecting with other mothers of children diagnosed with ASD. The mothers in this study noted that forming positive, nurturing relationships with other mothers whom they trusted without fearing judgement or criticism could counter feelings of isolation and rejection.

3.2 Conclusions regarding Bronfenbrenner's bioecological theory as framework

Bronfenbrenner's bioecological theory was applied as a theoretical framework for this study. Although this model is mostly applied to child development, this study proved that it can be successfully used in a different setting. By using mothers' experiences of receiving their child's ASD diagnosis as the unit of analysis, the interrelatedness among the four PPCT concepts was emphasised. The four themes that emerged could be explained with reference to the PPCT concepts, which gave the findings a scientific grounding. The study also enhanced the understanding of this theory, and demonstrated a good fit between the Bronfenbrenner framework and the data produced by studying the phenomenon of mothers' experiences of their child's diagnosis with ASD.

4. REFLECTION ON THE RESEARCH PROCESS

An initial literature study was performed that implied that limited emphasis was placed on mothers' experiences of receiving their child's ASD diagnosis, especially in the South African

context. The increased prevalence of autism and limited resources for ASD-affected families within South Africa, with specific reference to the Western Cape, imply that there is a large population of mothers finding it challenging to obtain a diagnosis and to provide their child with the required interventions. The fact that the researcher had to ask only one educational psychologist to act as intermediary to make contact with a sufficient number of ASD-affected mothers also underlined the high prevalence of ASD. The researcher experienced the educational psychologist as highly willing to support this research as the psychologist implied that this study could reveal significant information that could lead to a better understanding of these mothers' experiences, enhanced support to them and better guidance in terms of therapeutic interventions.

The researcher found the interaction with the mothers engaging and informative. The mothers willingly shared their experiences and stories, and very little prompting or encouragement was necessary. According to the researcher, the mothers immediately felt safe within the context of the interview as some of them shared intimate details of their lives, their relationships and their struggles. Most of the mothers also became emotional when describing their journey, indicating the hardships, struggles and challenges but also the joys, accomplishments and rewards. It was clear that the mothers wanted to participate in this research as they felt that they could make a difference to the lives of other mothers, and perhaps also provide insight to guide professionals who support mothers throughout this process. The mothers' journeys were experienced by the researcher as touching and inspirational. Although all of the mothers endured tremendous struggles, they all showed remarkable strength and resilience. The mothers all believed, beyond any doubt, in their child's potential and ability to progress, and seemed to have come out of this journey stronger and wiser.

The researcher does have a subjective experience regarding the research topic, but took great care to limit preconceived ideas about information that would emerge and to allow the research to take on its own the direction. Hence, the process of bracketing was applied. The researcher kept a reflective journal throughout the research process and did member-checking to verify the data. However, the reflective journaling revealed significant similarities between the researcher's own journey with her ASD-diagnosed son and the mothers in the research study's journeys with their ASD children.

5. LIMITATIONS OF THE STUDY

While the findings of this study led to an increased understanding of the mothers' experience of receiving their child's ASD diagnosis, some limitations should also be noted. This study used a phenomenological approach as framework which allowed for the use of a small sample (seven) of the population of mothers with ASD children. Although the small sample size is not a limitation in this context, it should be noted that the small sample size cannot guarantee transferability to other settings.

An educational psychologist specialising in autism acted as intermediary in recruiting participants from her caseload. The sample demographics (white South African mothers who were married and who formed part of middle-income to high-income households) were overrepresented in this sample as these families either claimed for the assessments through medical insurance or they paid cash. Furthermore, respondent characteristics such as age, level of education and the child's specific diagnosis may have had an impact on the experiences of the mothers. Therefore, the results may not be representative of all mothers with ASD children.

6. IN CLOSING

This study provided important knowledge about mothers' experiences when receiving their child's diagnosis with an autism spectrum disorder. Naturally, this is a critical and stressful time for such families. The mothers were overwhelmed by the ASD diagnosis, the resultant loss of their dreams for the child and the challenge of coping with a situation that they were mostly ignorant about.

The research findings from this study can offer insight that can assist professionals to improve services to mothers of ASD-diagnosed children and to angle their support or therapeutic services accordingly. It can also provide insight to other mothers with disabled children. This insight can also help to reduce the anxiety, stress and feelings of inadequacy that so many mothers have endured in taking up the challenge of raising their ASD-diagnosed children. Overall, this can improve the outcomes for ASD-impacted families as a whole.

SECTION D: ANNEXURES

Annexure 1: Consent form for research

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September 2014

Mother's experiences of their child's diagnosis with an autism spectrum disorder (ASD)

CONSENT TO BE A RESEARCH PARTICIPANT

I am Melinda Wiese from the North-West University, a student completing my Master's Degree in Social Work, working on gaining insight into mothers' experiences of their child's diagnosis with an ASD. I would like to invite you to give consent and participate in this study. To follow is information about the study so that you can make an informed decision.

1. PURPOSE OF THE STUDY

The purpose of this study is to explore and describe mothers' experiences of their child's diagnosis with an ASD. You are being asked to participate in this study because your experience with your child's diagnosis is valuable and can contribute to this study, and you fall within the scope of the following criteria:

1.1 Your child have received an ASD diagnosis within the past 5 years,
1.2 you can speak either Afrikaans or English
1.3 you reside within the Northern Suburbs of Cape Town
1.4 you give permission for the interview to be voice recorded and
1.5 you indicate that you volunteer to participate.

2. PROCEDURE

If you agree to be in this study you will expected to do the following:

- One interview with the researcher where you will share your experiences of your child's diagnosis with an ASD. This interview is expected to last approximately 1 hour, and with your permission, will also be voice recorded. This interview will be conducted at a venue where it is most convenient for you, but also allows for the necessary privacy.

- If the researcher feels that a second interview will be of value and could bring new information to the fore, this will be arranged with you at your convenience.
- The information obtained from the above mentioned interviews, will then be checked and confirmed with you, either by telephone, via email or in person, and will aim to verify the correctness of the data gathered.

3. RISKS/DISCOMFORTS

Every effort will be made by the researcher to minimize possible discomfort. If any emotional discomfort is experienced, the researcher will arrange for support from an objective and suitably qualified psychologist. The psychologist will pre-determine during the first session how many sessions are needed. The costs involved will be for the researcher's account.

During this study, your name will never be made known and your data will be handled confidentially. No information that could identify you will be used in any publications resulting from this study. All information will be protected by locking it up and storing it on a password protected computer. Transcriptions will be made of digital recordings. These recordings and transcriptions will be stored for 5 years at the North-West University in a safe place, after which it will be destroyed.

4. BENEFITS

There is no guarantee that you will benefit directly from the study, but the process might prove to be reflective and insightful in nature, creating a better understanding for your own lived experiences.

You might also feel that doing something altruistic for the broader population of families with an ASD child can be of value. The findings might also be helpful to other mothers of children who have received an ASD diagnosis, and will also inform professionals to ultimately render better services and support to the mothers that they work with.

5. COSTS

There will be no cost to you as a result of your participation in this study.

6. PAYMENT

You will receive no payment for participation. You may however claim for transport costs involved if you have to travel to attend to your interview. The process of claiming will be explained during the interview, and you will be reimbursed by the researcher for all costs pertaining to your travelling for the purpose of attending the interview.

7. WITHDRAWAL

Participation is voluntary, and you can withdraw from the study until such time that the interview is transcribed, without leading to any negative sanction or prejudice.

8. QUESTIONS

You are welcome to ask any questions to a member of the research team before you decide to give consent. You are also welcome to contact the following people if you have any further questions concerning you consent:

Melinda Wiese (the researcher):

083 701 2329 or via e-mail: wiese.melinda@gmail.com

Dr Carlien van Wyk (researcher's study leader):

e-mail: Carlien.VanWyk@nwu.ac.za

Ms Carolien van Zyl (Health Research Ethics Committee of the Faculty of Health Sciences):

018 299 2094 or via e-mail: Carolien.VanZyl@nwu.ac.za

9. FEEDBACK OF FINDINGS

The findings of the research will be shared with you via telephone and in writing via email, as soon as it is available.

CONSENT FORM

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY.

You are free to decline to be in this study, or to withdraw at any point even after you have signed the form to give consent without any consequences.

Should you be willing to participate you are requested to sign below:

I _____ hereby voluntarily consent to participate in the above mentioned study. I am not coerced in any way to participate and I understand that I can withdraw at any time should I feel uncomfortable during the study. I also understand that my name will not be disclosed to anybody who is not part of the study and that the information will be kept confidential and not linked to my name at any stage. I also understand what I might benefit from participation as well as what might be the possible risks and should I need further discussions someone will be available. I also agree to the interview being voice recorded.

_____	_____
Date	Signature of the participant
_____	_____
Date	Signature of the person obtaining consent

Annexure 2: Declaration of confidentiality by transcribe

E A BARLÉ
TYPING SERVICES
52 Le Roux Road, Reebok, Mossel Bay, 6506
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TO WHOM IT MAY CONCERN

I hereby declare that I was responsible for transcribing all audio recordings for the interviews conducted by Melinda Wiese as part of her research for her Masters Degree in Social Work at the Potchefstroom Campus of the North-West University.

Transcriptionist Confidentiality Statement

I, Elizabeth Ann (Annelene) Barlé, agree to hold all information contained in any audio recording/document relating to this research by Melinda Wiese, a student conducting her research as part of her Masters degree at the Potchefstroom Campus of the North-West University, in confidence, as well as regarding individuals and institutions involved in the research study. I understand that to violate this agreement would constitute a serious and unethical infringement on the informant's right to privacy.

Mrs. E A BARLÉ (Annelene)

DATE: 30/10/2014

Annexure 3: Example of transcription

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CERTIFICATE OF VERACITY

I, the undersigned, hereby certify that ***in as far as it is audible***, the aforegoing is a true and correct transcription of the interview/s recorded by means of a digital recorder.

TRANSCRIBER	:	Annelene Barlé
DATE COMPLETED	:	20.04.2015
TOTAL NO. OF PAGES	:	19

NOTES:

1. **It was a good and clear audio.**
2. **Some words/names were typed/spelled as it was heard (phonetically).**

ONDERHOUDVOERDER: Dankie dat jy jou tyd vir my afstaan.

RESPONDENT: Dis ‘n plesier.

ONDERHOUDVOERDER: Ek gaan nou sommer begin, want jy gaan nou regtig net lekker kan gesels. So die vraag wat ek nou vir jou eerste net wil vra is, vertel vir my van jou ervarings rondom jou seuntjie se ASD diagnose.

RESPONDENT: Vertel...van die begin af?

ONDERHOUDVOERDER: Ja, so bietjie...waar jy nou...as dit vir jou moeilik is om so te dink, kom ons sê begin by die begin. Wanneer jy begin bekommerd raak het, wat jy...spesifiek rondom jou ervarings en die dinge wat jou hart aangeraak het.

RESPONDENT: Ja. Net na [redacted] se geboorte...hy was ‘n verskriklike fussy baba gewees. Baie

moeilik, gesukkel om te latch, hy't min geëet, reflux...he was a very difficult child, en ek..ek kon hom net nie happy hou nie. Dit was vir my verskriklik moeilik gewees. En...as ek nou terugkyk, sien ek 'n paar tekens. Hy't nie terug ge-smile en daai goo-goo-ga-ga taal gedoen en...maar ek het niemand geken met kinders of babas nie, so ek was maar baie onervare gewees, en ja, toe op so...hy het woordjies begin. Hy't trein, ta-ta...hy't 'n paar woordjies gebruik. En toe het dit net weggegaan. En...

ONDERHOUDVOERDER: Hoe oud was hy toe dit net weggegaan het?

RESPONDENT: Dit was rondom agtien maande. En hy't net toe..I mean, he was never very social of connected met 'n mens nie, maar toe't hy letterlik obsessief met goed geraak, met karre in sy hande rondgeloop en vir niemand gekyk nie. Jy't hom geroep...hy't glad nie respond nie. Toe't ons hom na 'n spraakterapeut toe gevat, toe't hy van twee het drie keer 'n week spraakterapie al...sy't eers gedink dis appraksie, maar wat concerning was dat hy niks verstaan het nie. En jy weet, kinders met appraksie kan verstaan, hulle kan net nie...en toe't ek 'n sielkundige gesien, want sy gedrag was ongelooflik moeilik vir my gewees. Toe't ek 'n kindersielkundige gesien en vir haar gesê, luister, I'm either not equipped for this...of iets...ek het hulp nodig hierso. En toe't ons bietjie ge-chat en sy't toe ingesit saam met die spraakterapeut. Toe vra ek nog spesifiek vir haar, dink sy hy't autism, toe sê sy vir my nee. En ja, so het ons aangegaan by haar vir...met die spraakterapeut. En toe...die een dag sê die spraak...o, en toe het ons...toe't hulle ons gestuur na die audioloog toe hierso in die Kaap. Ons moes hom laat sedeer want hy't histeries geraak. Jy kan nie naby hom stil sit...toe't hulle al daai toetse gedoen en als was normaal gewees. En toe na dit het die spraakterapeut vir my gesê hulle het 'n case study...ons was in [redacted] gewees...toe sê sy waar hulle een keer 'n maand die pediater, die twee OT's, sy die spraakterapeut en 'n sielkundige bymekaar kom...and they chat about cases, waar hulle mekaar miskien kan...toe vra sy kan sy vir [redacted] as 'n case study gebruik, toe sê ek asseblief. Enige iets. En daai volgende dag het sy net vir my gesê ek moet 'n afspraak met die pediater maak, [redacted]. Want as [redacted] siek geword het...hy was toe na haar toe gewees 'n paar keer, maar as hy siek geword het, het ek hom sommer na ons huisdokter toe gevat, and he didn't notice anything. Ek onthou net spesifiek hy't eendag vir my

gesê, is hy altyd so stil...toe ek jonger was en ek het nie want jy weet, hy't nie daai...jy weet hoe kindertjies goo-goo en ga-ga jy weet, hulle so aangaan, en [redacted] was net 'n stil kind gewees. Toe kom ek by die pediater en ek vertel haar alles, want hy't...jy weet, hy't karretjies gevat en in rye gepak en hy't...sy behaviour...he was just out of control gewees, en hy't obvously verstaan wat mens vir hom sê nie, hy't...dit was net..dit was...iets was fout. Ek het net geweet. En ja...ek meen, sy kon hom nie eens examine nie, en hy was soos 'n neut aan my gewees, vas aan my. En sy't toe nou alles neergeskryf, toe sê sy vir my [redacted]..hoe [redacted] is, is baie..sy het 'n meisiekind gesien wat so was so 'n paar jaar terug en sy's nog steeds in die dorp. Ek moet miskien met haar mamma gaan praat. Maar toe sê sy...nou sit ek daar op die vloer met [redacted] op my skoot en sy sê vir my [redacted] is op die ASD spectrum. Ek sê vir haar, wat's dit? Jy weet, hy sal waarskynlik die PDD diagnose kry. Ek sê vir haar, wat's dit? En jy weet, hulle try verduidelik, try en verduidelik, toe sê ek vir haar, het hy autism, toe sê sy vir my ja.

ONDERHOUDVOERDER: Is dit die opvoedkundige sielkundige?

RESPONDENT: Nee, dit was die pediater.

ONDERHOUDVOERDER: [redacted]?

RESPONDENT: Nee, [redacted] van [redacted]. Toe sê sy vir my sy gaan nou 'n brief skryf vir [redacted]...she just wants a second opinion. En toe moes ons twee maande wag voor ek 'n afspraak kon kry vir die tweede opinie. En ja...toe't sy dit gediagnoseer.

ONDERHOUDVOERDER: Kan ek jou gou terugvat. Jy't vroeër gesê die eerste keer wat jy die pediater gesien het...die spraakterapeut, het jy gesê jy't haar gevra, does he have autism?

RESPONDENT: Hmm.

ONDERHOUDVOERDER: So jy't op daai stadium, het jy al opgelees daaroor?

RESPONDENT: Ek het nie opgelees nie. Ek het 'n paar artikels en goeters in magazines gelees. Ek onthou spesifiek voor een van [redacted] se inoculations..ek dink dit was voor sy agtien maande een, het ons gesit en wag en ek lees toe 'n tydskrif, toe is dit oor autism en die vaccines. En ek het toe die suster gevra en sy't gesê nee, jy weet, alles is fine. En hy't sy inspuitings gekry, en jy weet, op daai stadium was Previnar nie 'n moet nie, maar ek het alles...jy weet, dokter sê doen

dit, dit gaan jou kind veilig hou, en ek het als gedoen moontlik. En ja...maar gepraat van die sielkundige. Ek het geweet iets is fout. Die spraakterapeut het van apraksie gepraat. Ek het gaan oplees oor appraksie en ek het een dag vir [redacted]..ons was by kindermusiek gewees en daar was ‘n meisietjie wat..hy was twee, sy was agtien maande...toe sê die mamma vir haar, go and get your shoes. Ek meen, daai kind is klein, en die kind het opgestaan en vir haar die skoene gebring. Dit was vir my...ek het geweet daar is groot fout because he doesn’t respond to his name. Sulke klein goedjies weet hy nie. Dit kan nie wees dat hy weet wat ons sê en hy kan net nie die motor [onduidelik]. Ek het geweet dit kan nie dit wees nie. En [redacted], ek het een keer vir hom genoem, and he just flipped. Glad nie...jy’t nie die woord autism gesê nie.

ONDERHOUDVOERDER: Het hy verstaan wat dit beteken?

RESPONDENT: Ek dink nie een van ons het verstaan wat dit beteken nie. But just bloot die woord autism...I think the stigma that goes with autism. Dis hoe mens daaraan dink. En ek meen, daai tyd toe die pediater, [redacted] hom gediagnoseer het, vir daai twee maande wat ek moes wag om vir [redacted] te sien, [redacted] was nie by my nie en ek het hom nie eens gesê sy’t hom klaar gediagnoseer nie, en hierdie is ‘n tweede opinie nie. He just couldn’t handle it.

ONDERHOUDVOERDER: Vertel my meer daarvan.

RESPONDENT: Nee, hy was net...en die ding is dis moeilik want [redacted] was, hy was baie gedrags-moeilik en [redacted] het verskriklik pressure by die werk gehad en hy raak kwaad vir my oor ek [redacted] nie kan hanteer nie en hoekom ek hom nie kan hanteer nie, en jy weet, ons huwelik het deur moeilike goed gegaan.

ONDERHOUDVOERDER: Het jy gewerk op daai stadium?

RESPONDENT: Ek het gewerk en toe hou ek op werk om by hom te wees, en ja...dit was net...ja dit was net als baie...ek weet nie, mens wou dit nie aanvaar nie.

ONDERHOUDVOERDER: Hmm. So hy’s toe nou gediagnoseer. Op daai stadium was jy nou amper half, as ek dit reg verstaan, alleen deur die proses. [redacted] was half op die kantlyn. Op watter stadium het jy dan nou die inligting met hom gedeel?

RESPONDENT: Ek het so slowly but surely het ek vir hom gesê...ek het die woord PDD gebruik. So ek het half...en hy’t basies die diagnose aanvaar toe [redacted] dit vir hom gee. I wouldn’t say,

aanvaar, hy't dit...

ONDERHOUDVOERDER: En jy? Waar was jy in terme van jou emosies en...belewenis van die hele proses tot daar?

RESPONDENT: Hoe bedoel jy?

ONDERHOUDVOERDER: Wat het deur jou gedagtes gegaan op daai stadium?

RESPONDENT: Ek dink 'n mens wonder hoekom jy. Het jy dalk iets verkeerd gedoen? Miskien kon jy iets anderste gedoen het, of miskien het jy...I don't know, jy try uit-figure hoekom. En op daai stadium as mens 'n diagnose kry, you don't actually know what it is. Jy't nie 'n idee nie. Jy dink die heeltyd aan jou kind is nou drie, jy dink altyd aan, o, hy moet skool toe gaan, mainstream skool toe gaan. Maar as jy nou down the line sit en kyk, dis nie die doel nie. Dis glad nie...ja, ek dink net nie...dit was vir my baie, baie moeilik gewees. En hy's die Desember het sy hom gediagnoseer...[redacted] het hom toe gesien en toe het sy vir my gesê ek moet die sielkundige gaan sien wat in [redacted] is, spesifiek die vrou, [redacted] want haar meisiekind het autism, en ek het met die een mamma gaan praat, [redacted] se ma, [redacted]. Ek het haar af en toe vir koffie ontmoet en...want jy is so alleen. Jy weet niks nie. Almal probeer vir jou goed sê. Its just very confusing. En toe was ek by [redacted] gewees vir 'n paar sessies en sy't my toe op 'n anti-depressant gesit en dit het definitief gehelp, maar net...iets wat sy vir my gesê het is, ek moet net onthou, op hierdie pad wat ek gaan loop gaan daar baie mense wees wat vir jou goed sê, baie dokters wat beter weet en almal het hulle eie opinie en hulle eie belief van hoe jy dit regmaak, en ek moet besef, there is no cure. Daar is nie 'n kuur nie, and you just got to learn to live with it. En ek as ma weet beter as die spraakterapeut, as die OT, as enige sielkundige of onderwyser. Ek ken my kind.

ONDERHOUDVOERDER: Dis wyse woorde.

RESPONDENT: En ek moet die besluite maak. En as ek nie gemaklik is met iets nie, dan doen ek dit nie. En ek dink ek het dit nogal tot hart gevat, en ja, jy weet, met die intervensies en goeters, sien ek daar's soveel goed en mens probeer alles, maar op die ou end moet jy maar doen wat vir jou werk of vir jou, jou seun, vir jouself en jou familie, want you completely give your life up om alles vir hom te doen according to A to Z wat die mense nou sê jy moet doen en,

ek meen, wat van jou? En jy weet, ek sê dit nou sonder guilt, maar ek...I wouldn't say sonder guilt, maar mens dink nie eens aan jouself nie, want jy voel so skuldig dat jou kind so is. Dit moes jy gewees het.

ONDERHOUDVOERDER: Ek hoor jou. Vertel my gou bietjie meer van net na die diagnose. Wat het toe gebeur? Wat was toe die pad wat julle toe gestap het? In terme van die intervensies, in terme van julle verhoudings in die huis, in terme van jou.

RESPONDENT: Net na dit, toe's hy gediagnoseer, toe's hy [redacted] toe. Toe't sy vir ons gesê, [redacted], ons moet [redacted] research, ons moet [redacted] doen en [redacted], en ek het toe gekyk op die Internet oor [redacted], [redacted], en...ek het nie eens na die [redacted] eers gekyk nie. En...in my mind oor dat [redacted] bo-aan gestaan het, het ek gedink, miskien het sy, die dokter daai eerste geskryf oor dat she feels that's the better thing, but she didn't actually say it. Jy weet, jy soek net 'n teken van êrens af wat jou in 'n rigting in...en so was ons [redacted] toe gewees, ons het [redacted] ontmoet en ek was so verlig gewees. Dit het vir my gevoel iemand verstaan my en iemand can actually help. En, jy weet, en toe het ons geboek vir 'n week se workshop. Maar dit sou eers die Februarie kon gebeur het. So ons het vir 'n paar one-on-one sessions van [redacted] af deurgekom elke keer. Maar dit het vir my nogal, as ek nou terug daaraan dink, want ek het..ek het iets teen [redacted] and for a long time I couldn't understand hoekom nie, want ek voel die information wat ek by hulle gekry het, het my rêrig equip en vir [redacted]...my gewys sy potensieel en alles. Maar dit was...toe ons daai week geboek het, jy weet [redacted] het nog daai aand gebel en, hoe gaan dit, want sy't my 'n paar tips gegee, doen dit en dit en dit, en toe die volgende dag weer gebel. Sodra ons daai deposito betaal het, het ek nie weer van haar gehoor nie.

ONDERHOUDVOERDER: Die deposito vir die werkswinkel?

RESPONDENT: Ja, vir daai week.

ONDERHOUDVOERDER: En toe't sy nie weer individueel met jou kontak gemaak nie?

RESPONDENT: Nee.

ONDERHOUDVOERDER: Maar julle het toe steeds vir [redacted] vir twee of drie sessies geneem?

RESPONDENT: Ja, ons het hom vir 'n paar sessies geneem, maar ons het niks met haar...ons

het haar nie eens gesien dan nie, want dit was...maar toe ons nou vir daai week daar kom, toe is sy nou obviously daar. Met die eerste werks...die dag wat [redacted]..hy't met 'n meisie, [redacted] gewerk, en ek het so skuldig gevoel daai dag, want hoe sy hom hanteer het en wat hy actually kon...hy kon nie iets sê nie, maar jy weet, hy't uitgewys...ek weet nie...net hoe sy met hom gewerk het, ek was verbaas om te sien hoe slim my kind eintlik is. That there is somebody in there en dat ek dit nooit gesien het nie. En dit was vir my absoluut amazing gewees. En toe ons vir daai week gekom het, [redacted] was ook nie saam gewees nie. Ek het dit alleen gedoen. Met die hele ding, he's very much completely into his work and he's the financial support. I've got to fix the rest. So ons is [redacted] toe alleen gewees, ek en [redacted] vir daai week, en ek meens om daai gedrag eers te breek, daai eerste twee dae se skree en se...ja.

ONDERHOUDVOERDER: Kan ek net gou terugkom na jou vorige kommentaar oor [redacted] en die deposito? Watter sin het jy daarvan gemaak?

RESPONDENT: Wat ek interpret...she's done this for many years. Haar tegniek werk. She now just needs the numbers. Verstaan jy? Ek dink, she's very good at the backstage en die hele goed run, but she doesn't have people skills. Sy's glad nie goed met mense nie. En ek is ook nie die tipe gewees wat ja en amen gesê het vir wat sy vir my gesê het nie en she doesn't like that. So ons het nie eye-to-eye gesien nie, maar...I disregarded her, want die proses werk.

ONDERHOUDVOERDER: Is julle klaar toe met [redacted] na 'n sekere tyd?

RESPONDENT: Ja, na daai week is ons klaar met [redacted] gewees. Toe't hulle vir ons 'n [onduidelik]-program gedoen. Ek het in [redacted] mense try kry wat my kon help, maar ek meen daar is niemand nie en ek het dit self try doen en...dis jou kind. Ek kon hom nie tutor nie. Its just not possible. En meen, hy was soos 'n soldaatjie gewees toe ons terugkom van [redacted] af, en na dit, it wears off. If you don't keep on it kom die gedrag terug. En you know, he started slipping again, en toe was daar 'n opportunity dat ons [redacted] toe kon trek en ons het gespring vir dit. Toe ons hier kom het ek...[redacted] was nog die heeltyd in speel-skooltjies gewees. Wat my altyd so hartseer gemaak het, dan sal ek vir die juffrou vra, hoe was [redacted] vandag...absoluut fantasties, hy't net daar doodstil gesit en speel in die hoek. En dis nie wat jy wil hê nie.

ONDERHOUDVOERDER: Op sy eie.

RESPONDENT: Ja. En, ja..maar die ding is mense weet nie van autism nie, hoe om die kinders te hanteer nie. Jy weet, hulle voel ongemaklik.

ONDERHOUDVOERDER: Hmm. Het jy sulke geleenthede gebruik om byvoorbeeld vir die creche juffrou 'n bietjie inligting te gee?

RESPONDENT: Ja. Ek het vir haar gesê, hanteer hom so, maak so en maak so. Toe kry ek 'n...daar's 'n juffrou [redacted] wat 'n speel-skooltjie gehad het, but she was...'n kind...special need gehad het...she was inclusive. Sy't hulle ingevat en sy't vir my gesê, absoluut, bring vir [redacted], en sy was so gewees...verskriklike streng vrou. Sy kan sesstien kinders van age 3 tot 6 kan sy letterlik aan die gang hou stok siel alleen, en almal luister. Sy was baie goed met [redacted] gewees. Baie goed. En van daar af het ons [redacted] toe getrek. So ek dink daai stuk in [redacted] wat hy by haar was, tussen die diagnose en haar, was baie goed gewees, because hy het darem bietjie stability daar tussenin gekry. Jy weet, ons het goed soos kindermusiek, moms and tots en alles moontlik gedoen om hom te try socialise, maar ja, dit was net...its like fighting a losing battle.

ONDERHOUDVOERDER: As jy dit sê, bedoel jy dat jy nie, toe nou vordering gesien het nie?

RESPONDENT: Ja.

ONDERHOUDVOERDER: Is dit die losing battle?

RESPONDENT: Ja. En, toe is daar weg. Toe land ons nou hierso. Nou moet ek 'n skool soek vir [redacted]. En niemand wil jou kind hê nie. [redacted] is vier, hy dra nog 'n doek, hy was nog nie gepotty-train nie, hy kan nie praat nie, niemand wou hom in hulle skool gehad het nie. En [redacted] het toe 'n rash op sy hand gekry, toe gaan ek na 'n dermatologist toe, hier in [redacted], toe gee sy vir my die naam van 'n vrou, [redacted] plaasskool...hier. Toe't sy vir my gesê, by all means, bring hom. En toe sê ek vir haar maar hy dra doek...sy't gesê dit maak nie saak nie. Bring hom, ons maak 'n plan. En so het ek...hy't 'n attachment met een msiesie gevorm, [redacted], en so het ek later aan cue-kaartjies gemaak, een van 'n seuntjie wat op 'n potjie sit en een wat staan en piepie, en sy moes net die heeltyd na hom toe gaan en vir hom vra, wil jy...verstaan jy, en vir hom die woordjies gewys en gesê. En so het ek maar probeer om...want ek het gevoel dis baie belangrik...want hy't verskriklik gedrag opgetel soos op stories, hy't die aksies gedoen en

alles, en ek het net gevoel as hy gaan sit in ‘n special needs skool met kinders wat soos hy is, gaan hy nie vorder nie, want sy groot probleem, ja, dis sy taal, but its also his social skills. Its the unspoken communication wat hy nie gaan leer nie. En ja, hy’s nou nog by haar. Hy doen baie goed. Toe’t ek...hy was alleen daar toe gewees, en toe ek ‘n meisie van [redacted], [redacted], sy was [redacted] se program manager gewees, toe’s sy daar weg. Toe’t sy hom drie keer ‘n week kom tutor hierso.

ONDERHOUDVOERDER: By die huis of by die skool?

RESPONDENT: Hier by die huis. Toe’t sy swanger geraak, toe gaan sy. Toe kry ek [redacted] wat die workshop en die goeters by [redacted] gedoen het met [redacted], sy’t toe vir ‘n jaar voltyds vir ons kom werk, dag en nag. En say was amazing. Sy was fantasties met daai gedrag, en as jy daai gedrag onder beheer het, kan die leerproses plaasvind. En ek is by [redacted], die spraakterapeut, en [redacted] Dit was vir my ook maar moeilik gewees, ek het nie geweet wie waar, wie’s beter, wie’s goed nie en so kom ek die dag by die spraakterapeut-hulle in en [redacted] het net...ek meen, hy’s baie sku gewees vir mense, en die OT’s..pragtige klein meisietjie met sulke swart hare, en hy’t netso vir haar gesit en kyk die heeltyd, hy’t net oë vir haar gehad, en toe besluit ek sommer daar, ok, dis hulle. En...waar was ons toe gewees...o, en toe gee hulle vir my die naam van iemand...[redacted], en toe gaan ek na hom toe, want ek...ja, jy het jou speech, jou OT, jou tutor. Ek weet nie wat ek doen nie, autism-gewys al daai goeters. Ek soek iemand wat..ek wou iemand gehad het wat van die buitekant af kyk en sê, ok, XYZ moet gebeur, hy’t kom observe, ek het hom toe gekry, hy’t by die huis kom observe.

ONDERHOUDVOERDER: [redacted] nou?

RESPONDENT: Ja. [redacted]. Hy’t by die skool gaan kyk. Hy’t terwyl [redacted] terapie gedoen het, het hy gaan insit en...he specialises in autism. En hy het toe vir hulle gewys hoe om met [redacted] te werk, to actually get his attention en...dis net hoe jy met hom praat, wat jy doen, en hy’t net vir hulle daai klein tips gegee. Ek en [redacted] het hom saam gaan sien, en ek moet sê dit was goed gewees want [redacted] is a very straight-shooter tipe mens. He doesn’t sugar-coat anything en ek hou van dit, en ek dink vir [redacted] was dit ook refreshing gewees dat iemand vir jou sê, dis hoe dit is. Want jy kry niemand...as jy vir hulle vra, wat gaan gebeur, of hoe gaan dit, almal...jy weet,

prognose is, dis moeilik, mens kan nie sê nie, elke kind is anderste. Ek sê, wil nie spesifiek weet nie, I just want to know of patients that you have, hoe het dit al uitgedraai, dis al wat ek wil weet. En ja, hy's net...he's been a good support for the family.

ONDERHOUDVOERDER: Is dit die eerste keer wat [redacted] toe nou half onboard kom?

RESPONDENT: Ja. En...ja..maar ek meen, ek dink dit was vir hom baie moeilik gewees, want hy is mal oor kinders en hy is baie spelerig en al daai, en mens kry niks van [redacted] af terug nie. En dit was vir hom baie erg gewees. Kyk, vir my ook, maar ek meen, he just couldn't handle it. Glad nie. Dit was...toe [redacted] jonger was op 'n stuk het hy...hy moes of by my wees, of by [redacted] wees, die meisie wat na hom gekyk het by die huis. [redacted] kon hom nie op sy eie hanteer nie. It was just too much for him. Toe na...ek meen, nou's als anderste, want [redacted] is nou...he communicates, hy maak eye contact, hy's amper soos 'n normal little boy, as 'n mens dit so stel, but he's still different.

ONDERHOUDVOERDER: Hoe beleef jy hom nou?

RESPONDENT: Ek geniet hom oneindigbaar. Dit voek ek haal in daai cute baby...agtien maande, twee jaar...ek kry dit nou. Want jy voel, you were robbed of that, jy weet.

ONDERHOUDVOERDER: You lost out.

RESPONDENT: Ja.

ONDERHOUDVOERDER: Ek wil ook by jou weet, hoe dink jy is jou ervaring anders gewees as mamma, as wat [redacted] dit ervaar het, die hele proses?

RESPONDENT: Wel, ek meen, hy moes werk en sonder geld kan ons nie goed vir [redacted] gedoen het nie, en the responsibility, dit was my verantwoordelikheid om goeters uit te sorteer en te laat werk en uit te vind en...ek weet ook nie...ek...op 'n manier het ek...dit klink erg...het ek ook nie [redacted] se judgement getrust nie. Ek wou in beheer van dit wees en die besluite maak. Ek sou help waardeer het. Ons het baie baklei oor hoeveel ure ons wat gaan doen, hoe ons hoe gaan doen en ja, toe't [redacted] net vir my eendag gesê...wel vir ons al twee toe ons daar was, toe sê hy, you don't trust your husband. Toe sê ek vir hom, no. So daar was 'n paar moeilike goed om deur te werk, en as dit goed gaan met jou kind, gaan alles goed, want jy's...hoe ek my lewe gedink het gaan uitdraai en hoe dit het en hoe dit nou is, I would never have imagined. Nooit.

Want jy lewe nie nou vir jouself nie. Al probeer jy. Nou probeer ek. Na ses jaar.

ONDERHOUDVOERDER: Ja. Dis ‘n aanpassing.

RESPONDENT: Completely.

ONDERHOUDVOERDER: Wat is die goed wat jy mee sukkel om aan te pas?

RESPONDENT: Ek weet nie wie ek actually is nie. Sonder [redacted] se rondryery, worry oor programme, en mense manage, en research doen en alles met hom, ek weet nie wie of waar ek inpas nie.

ONDERHOUDVOERDER: Dis amper asof jy jou identiteit verloor het as mens.

RESPONDENT: Absoluut.

ONDERHOUDVOERDER: Ok. Die positiewes uit die proses, watse ervarings of oomblikke kan jy onthou wat vir jou uitgestaan het?

RESPONDENT: [redacted] was drie gewees, toe is dit die eerste keer wat hy mamma sê. Hy was amper vier gewees. En soos ek terugkyk, dan weet jy hy doen goed. (dame baie emosioneel). Soos laas Kersfees...ek en [redacted] het altyd toe [redacted] klein was, dan sê ons, die Kersfees gaan hy praat. Kersfees het gekom en niks gebeur nie. So het ons elke jaar. En laas Kersfees het hy nou lekker woordjies begin sê. Ons het dit ge-video-tape en ek het die ander dag daarna gekyk weer. Dis so amazing waar hy nou is. Maar dis hartseer om te dink waar jy was. Dis baie moeilik.

ONDERHOUDVOERDER: As jy terugkyk dan, daai besef ook dat hoe ver jy eintlik al gekom het.

RESPONDENT: Mens vergeet van alles. Ek meen, [redacted] was so moeilik, ek onthou ek moes vlieg [redacted] toe met hom een dag, ek en hy alleen, hy’t my gebyt en geskop en...he was just completely out of control. Maar ek meen alles was so understandably overwhelming vir hom maar, net die goed wat ek...tantrums by die winkels, al daai goeters. En mense het…its got to get worse before it gets better.

ONDERHOUDVOERDER: Wanneer hy dan nou so in die vliegtuig of in die winkelsentrums tantrums gegooi het, wat...hoe’t jy dit hanteer, of wat het deur jou kop gegaan?

RESPONDENT: In die begin het ek skaam gekry, want ek onthou as ek ‘n stout kind in ‘n winkel

gesien het, het ek gedink, ag, die ma kan die kind nie hanteer nie, of kyk hoe stout is daai kind, you know, you judge. En nou doen jou kind dit, en hy kan dit nie help nie, but nobody knows. En oordat hy nie ‘n physical disability het nie, word jy nie met dieselfde kam geskeer as ander mense wat special needs kinders het, as jy nie actually iets kan sien daar’s fout nie. En ek dink op daai manier kry jy nie die mense se empathy nie, en dit is moeilik. En ek kan verstaan, soos ek het al ‘n paar kinders gesien dan dra hulle hierdie ‘I am not naughty, I have autism’-shirts. Ek kan verstaan hoekom hulle ma dit doen, maar dis vir my ook maar verkeerd, because dit is ‘n selfsugtige ding. Ek voel hulle doen dit vir hulle-self, because they don’t want to be embarassed. Ek sal nie ‘n label op my kind wil sit nie. He’s different.

ONDERHOUDVOERDER: Hoe sien jy die pad vorentoe met [redacted]?

RESPONDENT: Hy vorder baie vinnig op die oomblik en dis baie exciting en...maar dis nog steeds moeilik as ek sien wanneer hy sukkel met ietsie. So spesifiek karate. Hy doen nou karate. Hy sukkel met...jy weet, sy motor-planning is vir hom moeilik, om die goeters te doen wat die kinders doen, he really...hy doen een hand, ander hand, o, het hy nou op die regte plek...verstaan jy, en hy probeer baie hard en ek kan sien, hy wou gister nie gaan nie, want die sessie voor dit, kon ek sien dit was vir hom bietjie moeilik gewees. Initially was dit als lekker maar ek dink hy begin nou besef goeters is moeiliker vir hom as vir ander kinders, op sekere aspekte.

ONDERHOUDVOERDER: Wat doen dit aan jou hart?

RESPONDENT: Dis baie erg. Ek weet nie...dis nogal iets...want ek sien vir [redacted] weekliks vir myself. Ek sien al twee jaar ‘n sielkundige. You need that emotional support somewhere. Ek wil reeds vir hom vra...sê mens vir [redacted], sê jy nie? I can’t not tell him.

ONDERHOUDVOERDER: Ja. En wanneer?

RESPONDENT: Wanneer gaan hy verstaan wat dit beteken, Jy weet, ek wil nie hê dit moet hom negatief impak of hom laat voel hy’s anderste nie.

ONDERHOUDVOERDER: Ja. En die toekoms vir hom?

RESPONDENT: Ek stuur hom nou na [redacted] toe, en I’m happy for him to be wherever goed genoeg vir hom is, want die staatskole is nie goed genoeg vir hom nie. They don’t understand

him. En ek het initially het ek altyd anderste om na dit gekyk. Ek moet vir [redacted] regkry, he needs to be able to fit in there, fit in there. Dis nie hy wat moet verander nie. Dis die skole. Die skole is net nie reg vir hom nie. En [redacted] is klein klassies, hulle verstaan, hulle probeer, they've got more knowledge van alles, en ek dink hy sal gelukkiger wees. Want vir my is sy emotional wellbeing vir my alles. Ek wil hê hy moet 'n gelukkige seuntjie wees, hy moet 'n lekker lewe hê, en ek dink as ouers over-compensate 'n mens partykeer met speelgoed en sulke goeters, maar ek dink jy kyk ook dan na jou eie childhood baie keer. You start reflecting on things that you wish you would have had of...en ek maak spesifiek punt om tyd met hom te spandeer, letterlik, dan vat ons die dag dan gaan ons Mall toe, maar as hy hier wil afdraai, I literally take myself down to his level, en...seker so 'n week terug het ons dit gedoen, en dit was vir my een van die lekkerste dae wat ek nog met hom gehad het. Dit was amazing gewees.

ONDERHOUDVOERDER: Is hierdie lekker tye...raak die frekwensie daarvan meer?

RESPONDENT: Ja, al hoe meer. Maar dit freak my ook uit op dieselfde tyd.

ONDERHOUDVOERDER: Hoe so?

RESPONDENT: Want goeters verander. Hy't nie meer so baie ABA nodig nie. Dan dink ek as ek nou dit so verander, gaan hy dan nou nie teruggaan nie, of jy weet, hierdie resep het nou gewerk, wat gebeur as ons nou iets verander en dit werk nou nie meer so uit nie, en...ek dink ek is nou al so gewoond, I'm controlling every single aspect of this child's life dat...I don't know how to let go.

ONDERHOUDVOERDER: Ja. Dit sluit amper aan by wat jy netnou gesê het rondom jou eie identiteit, dat jy amper nou alweer van vooraf jouself leer ken.

RESPONDENT: Ja. En dis moeilik. Ja, jy weet, ek het altyd gedink ek is 'n very straighforward, level headed tipe mens, jy weet waar jy gaan, hoe jou lewe gaan wees...en ek het net 'n complete curve ball gekry. En ek dink dit in self is baie moeilik. You know, you have your white picket fence and your 2 ½ kids and jou blah, blah, blah, en die realisation laat jy dit nooit sal hê nie, is ook 'n verlies. You've got to...ja...

ONDERHOUDVOERDER: Ja, die droom.

RESPONDENT: Hmm.

ONDERHOUDVOERDER: Ek het so bietjie notatjies gemaak. Ek wil gou net teruggaan na een ietsie. Toe julle by [redacted] was, jy't gesê netnou dat [redacted], dit het vir jou gevoel there's someone that can actually help. So tot op daai stadium, ek bedoel, [redacted] is toe nou al gediagnoseer, julle was al by spraakterapeute, arbeidsterapeute, yet you say, vir die eerste keer het dit vir jou gevoel daar's iemand wat actually kan help.

RESPONDENT: Die dokter gee vir jou 'n diagnose, hy skryf vir jou drie goed op 'n bladsy, en sê vir jou, sien jou in ses maande. Whereto? Waarnatoe gaan jy nou? Wat moet jy doen? Jy't geen idee nie. Dis soos iemand gooi jou in 'n land waar jy niemand ken nie, jy kan nie die taal praat nie, and you've just got to go.

ONDERHOUDVOERDER: So, ten spyte van die feit dat julle met redelik baie professionale mense te doen gehad het tot op daai punt, het dit eintlik vir jou gevoel hulle rig jou nie noodwendig in 'n rigting nie.

RESPONDENT: Because I don't think they actually know. Ek dink nie hulle weet nie. Ek dink dit is baie moeilik vir iemand wat nie 'n kind het wat op die spektrum is of wat daagliks of baie gereeld in kontak kom met so 'n kind om actually empatie te hê en te verstaan en actually te weet hoe elke dag se lewe is nie. En ek dink vir 'n dokter of 'n terapeut...I suppose they do their best, maar...hulle weet nie. Hulle weet rêrig nie.

ONDERHOUDVOERDER: Ok. Net miskien ter afsluiting, As jy nou terugkyk na jou journey, wat is dit wat jy voel jy geleer het, of wat is dit wat jy saamvat met jou as mens?

RESPONDENT: Een ding wat nogal baie opkom met mense is, hulle is altyd, as hulle nou uitvind jou kind is op die spektrum...jy weet, die Here sal nie vir jou hierdie kind gegee het as jy hom nie kan hanteer nie. Dan ek raak ek so kwaad hier binne-in my want op stukke het ek duidelik gedink daar is fout, because I can't handle this child. En ja, dis net...sulke goedjies...

ONDERHOUDVOERDER: Wat maak jy daarvan dat mense dit vir jou gesê het?

RESPONDENT: Stupidity. Stupidity. Hulle weet nie.

ONDERHOUDVOERDER: Ja. Dit het jy 'n paar keer gesê nou, dat mense weet nie.

RESPONDENT: Baie keer. En my skoonma self...en dit is nie net ander mense wat jou attack en judge nie. Ek meen, my skoonma het letterlik vir my een aand gesê ek spandeer nie genoeg tyd

met my kind nie, ek doen nie dit nie, ek doen nie dit nie, sy gedrag is so...en ja, ek is nie ‘n goeie ma nie. En dit...hulle het nie verstaan nie. So jy word heeldag ge-judge and you can’t do anything about it, en jy voel ook jy doen niks reg nie, want ek meen, jy sit alles in, met die proses wat so stadig is, [redacted] is nou ses, we are now seeing the benefits van al daai jare wat jy net gaan en gaan en gaan. Sy eerste spraakterapeut het vir my gesê, ek het vir haar gesê ons doen soveel spraakterapie, hoekom gebeur daar niks nie? Toe sê sy vir my ek moet dink aan ‘n groot jug, en ons gooi net in die heeltyd, heeltyd, en een dag as die jug so bo kom en hy begin so oortip, jy weet, dan drip, drip, drip die water...nog bietjie, dan gaan jy op ‘n punt kom waar dit begin vloei, en dis wanneer die taal net uitkom. En dit is hoe dit gebeur.

ONDERHOUDVOERDER: Op die oomblik is dit hoe jy dit ervaar nou met sy taal?

RESPONDENT: Ja. En hy verstaan goed. Ek en hy lê nou elke aand en boek lees en daai klein goedjies...

ONDERHOUDVOERDER: Wat hy vroeër kon doen nie...

RESPONDENT: Glad nie. He was just wild, all over the place, glad nie geconnect nie. Dit was...jy kon niks met hom doen nie. En dit was...en ook, dit was vir my verskriklik gewees, want met hom as baba, I never made that connection with him. Ek het glad nie daai goo-goo-ga-ga feeling oor hom gehad...dat dit the most amazing ding ervaar in my lewe nie, glad nie. En as mense dit sê dan...nie meer nie, maar ek het altyd gedink, ag hulle praat nonsense, hulle sê dit nou maar net. Hoe voel jy dit? Dit maak nie vir my sin nie. En as ek na [redacted] nou kyk, het ek daai gevoelens vir hom.

ONDERHOUDVOERDER: Ok.

RESPONDENT: En dis nogal...dit was vir my ook moeilik gewees, hoekom ek...my kind het nie soos myne gevoel nie. Hy was...I didn’t understand him. Nobody understood him.

ONDERHOUDVOERDER: Ja. Nobody did.

RESPONDENT: Hy’t homself nie verstaan nie.

ONDERHOUDVOERDER: En dis ook nou anders.

RESPONDENT: Ja, absoluut. Alles, ek belowe vir jou, dit is..ek dink ‘n ma wie se diagnose...wat ‘n diagnosis kry, ek wens ek het ‘n video van heirdie laaste ses jaar gehad, dat hulle kan sien

waar jy begin, alles wat mens deurgaan en jy weet, daar is...mens kan die lewe actually geniet, ‘n bietjie, na ‘n paar jaar. As jy deur daai journey gaan you don’t think it is possible.

ONDERHOUDVOERDER: That you will ever be happy again.

RESPONDENT: Ja.

ONDERHOUDVOERDER: Ek is so bly dit is waar jy is.

RESPONDENT: Ja ek ook.

ONDERHOUDVOERDER: Is daar iets ander wat jy voel ons nog nie aan geraak het nie, wat jy graag nog wil deel?

RESPONDENT: Nee, nie iets spesifieks nie. Is daar iets spesifieks wat jy nog wil weet?

ONDERHOUDVOERDER: Nie vir nou nie. Baie dankie.

RESPONDENT: Plesier.

ANNEXURE 4: Table of themes, subthemes and categories

THEMES, SUBTHEMES AND CATEGORIES

Theme	Subtheme	Category	Quote
Proximal Processes **Mothers' experience of interactions and relationships within her immediate family.**	Mother – Child	Connectedness.	"It was just the way he wasn't quite present. And I felt that almost from the day he was born. I can't hundred per cent **connect** with him. Not that I felt less for him, it just felt like there just wasn't … with [redacted] there was that instant connection." "I felt that … something I was doing wrong that I couldn't quite **connect** to him." "I never made that **connection** with him. I did not have that goo-goo-ga-ga-feeling for him, that it's the most amazing feeling … never." "… I mean, he was never very social or **connected** to a person [referring to herself] …"
		Linked emotions	"… not nice **for him**, not nice **for me** …" "If it is a bad day **for** [redacted], it is a bad day **for me**. If it is a good day **for** [redacted] it is a good day **for me**." "**If I take a dip, he takes a dip**. So we dip together … and this is bad, because he rides this roller-coaster as he is with me."
		Child's behaviour	"He was a very **difficult** child, and I just could not keep him happy. It was very difficult for me." "I mean, [redacted] was so difficult … he bit and kicked me … and he was just completely **out of control**."

			"… I later felt that I could not go anymore [social events], because I did not know how to **manage him**." "… but he is **difficult**. He is not an easy child if I have to compare him to his sister … you can talk and talk, but if he does not want to listen, he does not want to listen." "… because I did not know how to **manage my child** …"
		Child's isolation.	"He always did his **own** thing. He would go on his **own**, sit and play on his **own** …" "He always kind of did his **own** thing. He was always like…he would go off on his **own** and sit and play …" "But it was the way he **wasn't quite present**. And I felt that almost from the day he was born." "… and [redacted] would be off on his **own** mission …" "You try, you know, to play and do things and to **engage**, but he does not want to."
	Mother – Father	Fathers' response.	"He said there is **nothing wrong** with him. But that's my husband; he is very black and white." "And [redacted], I mentioned it to him once, and he just flipped. Not at all … you just did **not mention the word 'autism'**." "My husband had now educated himself … and he is **out of denial** …"

		Fathers' involvement.	"At this stage my biggest problem is that I need to **drag my husband along** … all the time." "But I was very lonely; I had to **drag him along** all the way." "I am actually mad at him. I was the one who had to fight for everything, pay for everything, and he is the **first one to take credit."** "So for a very long time **he did not educate himself** … because it was my responsibility [interventions], I must see to it, he will pay for it, whatever he [the child] needs." "My husband and I…we are an absolute **winning team**. He supports me 100% and he is also a wonderful support in the house, you know, he helps a lot."
		Marital relationship.	"He's behaviour was very difficult, and Shaun had a lot of pressure at work, and he would get angry at me for not being able to handle Ryan … our **marriage** went through a difficult time." "Yes we must work much harder at our **marriage**, and we need to be more punctual, how do I say … to make time and to say okay, now it is time for our **marriage**." "Our **marriage** was not ready for him, even if he would have been healthy. So yes, it did put more pressure on our **marriage**, but it could not really have gotten worse … or maybe it could have, but you see, the cracks were already there." "… to stay sane … to keep your **marriage** going, together with everything else … so yes, I can see that **marriages** can break up under this kind of pressure, because you just don't have the time."

	Mother – Other children	Challenges for other siblings.	"And you are very hard on her, suddenly … because she is the **perfect child** that does everything correctly, and then if she makes one mistake [I would say …]: 'there's nothing wrong with you, couldn't you have though to do it this way?', so things was not going too well between myself and her [sibling sister]." "… and **my daughter** did not know where to put her head [after incident where brother threw tantrum at her after-care]." "I feel very guilty about [redacted] in that respect because there's a lot of things she can't do because [redacted] can't do it and we have to at these stage still do things as a family, because of her age." "[redacted], my eldest could see I am not myself. How do you explain this [my emotional reaction to his **brother's** diagnosis] to him?" "We [**mother and daughter**] started going out alone again, just to have coffee somewhere, because previously I would have felt too guilty to do anything without [redacted]." "… and how she just embraced **her brother** from day one … it was so beautiful to see, and not embarrassed by him at all …"
Person (micro) **Mother's experience of her internal and external characteristics and resources.**	Internal strengths	Faith / Religion	"… luckily, **faith** was the biggest thing for me then. It opened doors for me that I did not think is possible." "The only thing that kept me standing was at night when everyone went to bed; I took my **Bible** and locked myself in the car. When I came out of there, I felt I could continue." "So it is difficult, but one pulls through. And **your faith** … so it's … I think other people would have cracked."

			"**God** told me. I went to Him, and then I knew what I needed to do." "So I said to my husband, **God** is with us in this thing [fight against autism], we do not have to fight it alone."
		Following their own instinct or 'gut'.	"But I knew **something was not right**." "… he was just out of control, and he obviously understood what I told him … it was just … something was wrong. **I just knew**." "I don't know, I was there and I just felt I cannot put him here [special school], **I know who he is."** "You must do what will work for you … because … **I followed my heart** and until today I know that not taking [redacted] out of his school, was the right thing for him." "It is the most stupid things you listen to, instead of **following your own gut**."
		Informing themselves.	"I **Googled** so many things, because I just wanted to … and I gotten onto a lot of blogs of parents with discussing their kids with autism. I found that helped quite a lot." "So this mother started **investigating** the internet." "I realised that I have to walk the road with this woman [expert on-, advocate for-, and mother of autistic children], because I will learn from her … and information. I **need information**, because I know so little." "I think the most important thing is **informing yourself** as much as possible regarding the diagnosis … it helps you to understand your child better and helps you

			to cope better with the diagnosis."
	Internal challenges	Feelings that the cause of ASD might be their fault.	"So you start thinking, oh my gosh, it's **something I did**, I influenced his environment to the point that he became autistic." "I think one wonders why me. **Did I do something wrong**? Maybe I should have done something different, or maybe … you know, you try to figure it out." "But you don't think of yourself, because you **feel so guilty** that your child is this way. It must have been you." "**Was it something I did during pregnancy**, you know, that is the type of questions you have that you cannot answer or read up on."
		Feeling uninformed.	"And at that stage when you get the diagnosis you don't actually know what it is. **You have no clue**." "… and she told us that he is definitely on the ASD spectrum. And yes, you sit there … and you don't know, you really don't know. I had **no clue** what it was." "At that stage 'autism' **was just a word for me**. I just knew it was something that you don't want your child to have." "I think I kind of … ja … just the day he was diagnosed, thinking how overwhelming it felt, because I **didn't have a clue** of what to do." "Then I went to the doctor, and the doctor told me maybe we should have him tested … evaluated for autism. And this was literally **the first time ever that I heard about autism."** "At first I felt very lost. I did not know anybody with autistic children, and I did not

			know with whom I should talk … **so I was very lost**." "Whereto? Whereto from here? [after diagnosis] What must you do? You have **no idea**. It is like you are thrown into a country where you do not know anyone, and you can't speak their language, and you've just got to go."
	Internal characteristics	Personality/Temperament	"Luckily I have a **strong personality** and I am used to fighting on my own." "I am a very **focused person**, I have goals, and I need to do the correct thing, you know …" "And I think what makes it very difficult, is that I am a **control freak**." "… with me, I like to be **in control** of something and I need to know exactly what is happening."
	External resources	Finances.	"You know, every therapy route you want to take with your child is **expensive**, and when you don't have a big disposable income, you kind of have to pick which one is the best one, which route do I take now first, and which do I leave for later when there's more money in the pocket." "And you could do it if you've got **buckets of money**, but you can't do it if you don't." "Luckily the medical aid covers that, because now **finances** are also starting to become an issue." "… luckily he [husband] has his own business, if it wasn't for him, because I also have a good job and all, but **budget is budget** … I often ask myself how other people do what they need to do if they are not as fortunate?" "… it is unaffordable, [redacted] … I could not afford [redacted]."

Context **Mothers' experience of her environement**	Micro	Life-changing decisions for the family.	"We **moved** to [redacted] [suburb closes to intervention programme] to be closer to [redacted] [ABA intervention programme]." "We just **bought a new home** to accommodate our son, because we lived in a very small house … and we also bought another car, because we now have two children." "I worked, and then **I stopped working** to be with him … and yes … it was very difficult." "And he does not talk Afrikaans, he prefers English, and so we **changed our whole home language to English."** "This is why I literally moved off the farm [because we were isolated], I took [redacted] and we came to live in the city, because I felt something was not right. So this is what I did and then I would visit my husband over weekends."
		Mothers fulfilling multiple roles within her immediate family.	"Because you are you're child's doctor, he's psychologist, you are you're child's … You don't have a cooking clue what you are doing, but **you are everything**, and you have to, and you have to … quickly." "Without doing [redacted]'s **driving** [to therapies], worries about programmes, **managing of people** [therapeutic team], **doing research** [about autism and interventions], and everything for him … I do not know where and how I fit in." • "… I have struggled with the fact that I need to work full time, with so many **other responsibilities** …" "… we both **work**, we do the GAPS diet [intervention], we do the protocol [**intervention**], I must do my own home [**cleaning, cooking**], I must do my own

			children [**homework and looking after**], so the pressure is overwhelming, and it does not stop." "I had to fight for him all the time, and I needed to **do everything**. I had to … the diet was my responsibility. Until today, everything is my responsibility. The tutors … everything. I do it … all by myself …" "We must stand up, we must speak for our children. And this is the **role that I took, I am my child's advocate."**
	Meso	Support received from: Family	"… but they [my parents] love my children very much, and they are in fact **the only people with whom I will leave my children** …" "My parents moved to Cape Town 8 years ago, and I told her that God knew she had to move closer, because **I would not have been able to do this alone**." "Our circle of friends became much smaller, but our **family ties were strengthened."** "Even in my own family, until they did not experience one of his meltdowns, they never accepted how severe his needs are. And this was sad, that it had to come to that, that they had to see how severe it is before they started **supporting us."** "My sister lives in Cape Town. I think … she was my rock through it all … my parents as well, but they live far." "And even my mother-in-law … it is not just other people that attack and judge you. I mean, my mother-in-law literally told me one evening that she thinks I do not spend enough time with my child, and this is the reason for his behaviour … and yes, that I am not a good mother."

		Friends	"After a while people [**friends]** stop inviting you, you know, because you can't go to those kinds of things." "Ja, so a lot of the **friendships** aren't there anymore, because we can't do everything that they want to do." "So, I lost all my **friends**, because not one of them understood." "… very very **good friends** of ours just could not handle Francois anymore because their child was this perfect child, and this hurt me as friend and parent, because I felt rejected …"
		Colleagues	"I mean my **co-workers** now, they're fantastic and they celebrate the little highs with me and the good times with me, and then … ja, my work's been absolutely amazing." "I had a **boss** that is fantastic. She is really … out of this world. Fantastic. She just said: "[redacted] as long as your work is up to date, you do what you need to do, as many hours as is needed." "My other saving grace was my work. Not the work that I did, the **people at my work**. In the past I wanted to move to another department, but today I know why I had to stay. The colleague that previously irritated me literally became my psychologist."
		Medical professionals	"So she touches base a lot [**professional**], but you kind of feel like you're on your own little island, you know. How can they possibly know what I'm going through?" "It was bizarre, but I felt very alone, because everyone [**medical professionals**] has a different opinion, and everybody sends you to different people …" "I blame **doctors and specialists** that they did not tell me about [Western Cape

			Autism Foundation] them earlier." "Ja, [redacted] … he specialises in autism … he just gave them those small tips. Myself and my husband went to go see him together, and I must say, this was very positive as [redacted] is a very straight-shooter type person. He doesn't sugar-coat anything **and I liked that**, and I think it was very refreshing for my husband as well." "Because I don't think they actually know [medical professionals]. I think it is very difficult for someone who does not have a child on the spectrum or that is in daily contact with such a child to have total empathy and to really understand the daily life of such a parent. And I think for a doctor or a therapist … I suppose they do their best, but … **they don't really know."** "… it is incredibly confusing, and I think one of the other big things is … **doctors should talk to one another**. They are so focussed on their patients and their referrals and in fact they only confuse their patients …"
	Macro	Society's perceptions of ASD.	"So socially it is very difficult to adapt, because **society** does not make room for children like him." "The guy at this table [in the restaurant] just kept giving me this look like, what are you doing? Get your kid under control." "And because he does not have a physical disability, you are not judged in the same way as others with special needs, where you can actually see something is wrong. And I think, in this way, you do not get the empathy, and it's difficult." "… and people, when they find out you have a child with ASD … they are like … you know, God would not have given you this child if you cannot handle him. Then I get so angry … because I actually cannot handle this child. Stupidity. Stupidity. They don't know."

			"And the thing is, people just do not know about autism, or how to handle these children. You know, they feel uncomfortable."
		Society's perspective of delayed development in boys.	"Everybody tells you, **boys take longer, don't worry**." "And everybody was going, **he's a boy, he's lazy**, you know that sort of thing." "Now these things are pronounced, where in the past I accepted, ok, **he is a boy**, they are busy and active…" "Yes. And everybody kept telling me, **he's a boy, don't worry, boys take longer** …"
Time **Mothers' experience of the journey through time**	Before diagnosis	First signs and symptoms	"I died inside, I was totally alone, and as I spoke to people everybody told me there is nothing wrong with him, boys do that, boys don't talk, and everybody laughed at the things he did, so did I, but as he grew older his differences became more pronounced." "And [redacted] would be off on his own mission, and he wouldn't really be focused on what they were doing, wouldn't be mimicking what they're doing, which the younger sibling often do. So that was a cue for me that something was off." "… he never wanted to play with other children. He always went off on his own. He would … which was also challenging, for instance, if we went out to a place he would just walk away. He would get lost …" "It is as if you start moving outside of yourself, things that used to be important, now means nothing."
	Diagnosis	Moment of diagnosis	"The **diagnosis** is devastating, as you know it is permanent." "Even though you knew [the diagnosis], **it is still a shock** when you are told."

			"The day he was **diagnosed**, thinking how overwhelming it felt, because I didn't have a clue of what to do." "I was totally **in shock**. I was in tears, and my husband was not there when I got the message, and then you immediately ask yourself is this something like Down syndrome that the child will stay in your house for the rest of his life …" "The [redacted] is like switching on a light. Now at least you know what you are facing."
	After diagnosis	Interventions	"I cannot cope. I am not made for this." "… this is a road that I do not want to travel on. You do not want to walk it. You did not choose it. It chooses you. You don't want it." "You know, we tried everything like Kindermuzik, Moms & Tots and everything possible to get him to socialize, but yes … it was like fighting a losing battle." "At that stage I still had my crying moments, but it started getting better. It was not daily anymore. It was not constant. And I think by that time I already buried my boy. He was dead. I had a new boy … a problem child that I need to help." "… just when she worked with him, I was surprised to see how clever my child really is. There is somebody in there and I never saw it. And this was absolutely amazing for me."
		Child's development during interventions.	"We have him back." "It made a huge difference to his behaviour."

			"So you get judged all the time, and you feel like you cannot do anything right, you give everything, but the process is just so slow … [redacted] is now six, we are now seeing the benefits of all those years that you just go and go and go [to interventions]." "Suddenly he started repeating words: 'Thanks, mommy', and the PECS file was introduced, fantastic." "He gets so excited when he sees [redacted] [tutor], and he gives wonderful cooperation."
	Current	Mothers' awareness regarding her child at present.	"He tries. You can see he tries, and this is already positive, as previously we had nothing." "I enjoy him endlessly. It feels like I am catching up on that cute … eighteen months, two years … now I get my chance. Because you feel, you were robbed of that, you know."
	Future	Mothers' hopes, dreams and visions for her child's future.	"I have found peace that he might be my responsibility for the rest of my life. But it's ok, because I know he will grow up and be happy. Will he be able to cope on his own? That nobody can tell me." "I believe, until today, that he will come out of this. I believe that this is temporary. I will not stop believing this." "I am scared. What if he does not recover? What if something happens to me, would my husband be able to look after him?" "I try not to think too far into the future. I have thought, hopefully he will be able to go to a mainstream school."

			"I try not to get too excited. One needs to stay humble, but for now, the future, I don't think too far ahead. For me, the future is tomorrow. How will his day be tomorrow? Will he have a good day at school, will he listen … will he wait his turn?" "I haven't built dreams for him yet." "I want him to be a happy boy, he must have a good life." "Is he gonna cope when we're not there one day anymore. Is he ever gonna reach a point where he's self-sufficient?" "It does scare me a little bit. Am I gonna be able to understand his needs and be able to help him meet his goals and things like that. Is he going to be enough of a dreamer to realise how intelligent he is and what he can do with it?"
	Throughout the process	Growth and/or journey.	"I think the whole process was more of a blessing to me than a curse." "And then also … Just teaches you to really focus on the little things, which I think I would never have probably done to this extent if we didn't have [redacted]." "I went through all the phases. Phase one was, I cannot accept this, phase two … he must rather not be here. I prayed that God should take him. The third phase was, ok … maybe I shouldn't be here." "I always thought I am a very straightforward, level headed type of person, you know where you are going and how your life is going to be … and I just got thrown a complete curve ball. And I think this is difficult. You know, you have your white picket fence and your two and a half kids and your blah, blah, blah, and then the realisation that you will never have this, this is a loss." "While you're going through the journey, you don't think it's possible."

Annexure 5: Technical guidelines for journal

HAMMILL INSTITUTE ON DISABILITIES

Focus on Autism and Other Developmental Disabilities Author Guidelines

Published in association with the Division on Autism and Developmental Disabilities. *Focus* addresses issues concerning individuals with developmental disabilities (DD) such as autism, mental retardation, and cerebral palsy. Manuscripts reflect a wide range of disciplines, including education, speech–language pathology, physical therapy, occupational therapy, psychology, medicine, and social work. *Focus* strives to be responsive to professionals and families of individuals with DD. Because the intent is improving the lives of these individuals, the editorial staff seeks manuscripts that disseminate the results of empirical research and strive to provide a forum for professional discussions from diverse philosophical and theoretical perspectives. Published quarterly.

Types of Manuscripts

Published are 3 types of full-length manuscripts (**15–30 double-spaced pages**): (1) original research reports; (2) reviews and interpretations of professional literature; and (3) theoretical papers, conceptual statements, and position papers; and 2 types of short manuscripts (**2–10 double-spaced pages**): (1) replication of prior research findings and controlled data-based case studies, and (2) book reviews.

Original Research Reports describe investigations related to an aspect of understanding and meeting the needs of individuals with autism and other developmental disabilities. Diverse research methodologies (e.g., single-subject designs, group designs, qualitative investigations) are encouraged. Criteria include research question relevance, design quality, sound implementation procedures, thorough outcome analysis of research findings, and implications for practice and policy.

Reviews and Interpretations of Professional Literature: qualitative or quantitative syntheses of current literature and integrations of research findings and implications that offer substantive implications for practice and policy.

Theoretical Papers, Conceptual Statements, and Position Papers: advance new models for understanding, analyzing, and solving problems related to developmental disabilities; innovations for practice or policy that are new to the research literature; discussions of issues and problems in the field; or other descriptions, interpretations, and discussions with implications for the field.

Replication of Prior Research offers value by providing depth and generalization to the professional literature. Short manuscripts such as abbreviated formats of traditional manuscripts, descriptive studies, or data-based case studies usually are appropriate.

Book Notes: reviews of recently published books/other publications of interest to individuals involved with persons with autism and other developmental disabilities. Before submitting a review, contact the editors to verify that the product being reviewed is an appropriate match for the journal. **(2–4 pages)**

Acceptance Criteria

Authors are encouraged to write in a manner that is maximally communicative, interesting, and informative and to communicate that an individual with a disability is a person first. Manuscripts should should not be considered for publication elsewhere, nor should they have been previously published. Consideration may be given to material that has previously had limited circulation elsewhere. If an article appeared before in any form, authors must clearly indicate this in their cover letter, should include copies of potentially duplicative material that has been previously published, and should provide links to duplicative material on the Internet. Failure to disclose the existence of duplicate material may represent a violation of copyright.

Manuscript Preparation

Guidelines specified in the *Publication Manual of the American Psychological Association* (6th edition, 2010) should be followed. Pay particular attention to the sections concerning guidelines for nonsexist language, avoiding ethnic bias, and disabilities. ***NOTE. Authors for Whom English Is a Second Language:*** It is highly recommended to have a colleague or copyeditor who is fluent in English review the manuscript before submission.

General

1. Authors must submit a **SEPARATE TITLE PAGE FILE** with **(1)** article title; **(2)** first name, middle initial, and last name of each author, with highest academic degrees; **(3)** names of institutions to which each author is affiliated, along with complete addresses AND e-mail addresses; and **(4)** any acknowledgments, financial disclosure information, author notes, and/or other text that could identify the authors to reviewers.
2. **Format:** 8½ × 11 in. document; 1-in. margins; double spacing, left alignment, Times New Roman 12-pt. type. Include title and abstract.
3. **Heads:** Do not use small capital letters.
4. Place figures in separate files. Tables may appear at end of main text file. Please use Word's table functions. All tables and figures must be cited in text.
5. Use tab key and centering functions for head alignment, paragraph indents, etc. DO NOT USE THE SPACE BAR.
6. Use endnotes sparingly. Number with Arabic numerals starting with 1 and continuing through the article. **Example:** (see Note 1). NO footnotes.

Artwork

Must be production-ready. Because most art will be reduced to fit, use bold type that is large enough to be reduced and still be readable, and make sure rules/tick marks are at least 1 pt. Acceptable electronic formats for art: TIFF, EPS, Word, or Excel. For scans/photos, download the SAGE **Image Resolution Guidelines** from the Instructions & Forms link at **http://mc.manuscriptcentral.com/focus**. If you have trouble when loading Excel files, copy and paste them into a Word document.

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Manuscript Submission

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Log in, or click the "Register Here" option if you are a first-time user. Once logged in, click on Author Center. Have the following available before starting submission: manuscript files, including separate title page; all coauthors' full names and e-mail addresses; # of figures, # of tables, # of manuscript pages. Click the "Submit a Manuscript" link and follow the submission steps. A guide is available on the main page under "Resources," User Tutorials.

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