# Exploring narrative inquiry as a sense-making tool for parents raising a child with autism from a family systems theory perspective

by

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## Declaration

I declare that **Exploring narrative inquiry as a sense-making tool for parents raising a child with autism from a family systems theory perspective** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references. I further declare that I submitted the thesis to originality checking software and that it falls within the accepted requirements for originality. I also declare that I have not previously submitted this work, or part of it, for examination at Unisa or another qualification at any other higher education institution.

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Date: 2024/06/22

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## Abstract

Research in the field of autism and families confirm both the challenges of families raising a child with autism, and the need for a family-focused therapy to address the systemic effect of the disorder. Despite the evidence, interventions continue to focus on the individual, and less on the family requiring much-needed support. Family therapists need empirical evidence of how family therapy can help parents of children with autism make sense of their experiences. Furthermore, such studies currently lack a common theoretical framework. Narrative therapy has proved to be effective in various contexts but there is a need for more empirical evidence to explore the possibilities of using narrative inquiry as a sense-making tool for parents raising a child with autism. The aim of this study was to explore the possibilities of using narrative inquiry as a sense-making tool for parents raising a child with autism, from a family systems theory perspective. Using a qualitative approach, the study collected primary data by means of semi-structured interviews with research participants who were recruited through a collaborative arrangement with a paediatrician based in Pretoria, South Africa. The study used purposive convenience sampling to select three couples who are raising a child who autism, and a longitudinal approach where each couple was interviewed five times over a period of five years. Using a narrative inquiry as research design backed by family systems theory, the study explored the collective experiences of the entire family, examining all inherent family relationships and subsystems. Both family systems theory and narrative inquiry are positioned within the social constructionist paradigm which revolves around the significance of meaning and understanding in human activities. Braun and Clarke’s reflexive thematic analysis was used to analyse the transcribed material. The following themes emerged from the analysis and formed part of the construction of each couple’s narrative: the characteristics of autism, diagnosis, knowledge, the marital relationship, the mother’s relationship with autism, the father’s relationship with autism, the child with autism, the siblings’ relationship with autism, the community and extended family and the future. By linking the themes to the extant literature the findings highlighted the common threads in the stories of the three couples. The construction of each couple’s narrative was discussed and narrative practices applied to highlight the meaning-making process of the participants. At a practical level, the study provides relevant empirical evidence on the effectiveness of using a narrative approach to help families raising a child with autism, make sense of their experiences. At an academic level the study advocates the use of family systems theory (FST) as a common theoretical framework.

**Keywords**: autism, family systems theory, narrative inquiry, reflexive thematic analysis, sense-making tool

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# CHAPTER I. Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that affects an estimated 1 in 100 children worldwide (Talantseva et al., 2023). The disorder, for which there is to date no cure (Neely et al., 2012; Yadav, 2020), is characterised by certain deficits in social communication and other unpredictable behaviour which make social interaction difficult for these individuals (Lindor et al., 2019; Sauer et al., 2021). The healthcare needs for people with autism are complex and require a range of integrated services which include health promotion, care and rehabilitation (World Health Organization [WHO], 2023). These special needs come at a significant cost for the families who present with higher levels of stress than parents of typically developing children (Hutton & Caron, 2005; Romney & Jones, 2020; Solomon & Chung, 2012; Twoy et al., 2007). Studies focused on the experiences of these families point to a need for support, a need to make sense of their experiences, and a need to regain control of their lives (Hartley & Schultz, 2015; Khara et al., 2020). Though treatment interventions of ASD are abound, interventions continue to focus on the child with ASD and less on the families who are equally affected (Neely et al., 2012; Parker & Molteni, 2017; Romney & Jones, 2020; Solomon & Chung, 2012; Twoy et al., 2007). The systemic effects of autism suggests a need for systemic, family-focused therapeutical approach to support these families (Cridland et al., 2013). This need has been recognised more than two decades ago. Still, the literature continue to lack a common theoretical framework to better understand the impact of the disorder and to inform clinical support services to these families (Cridland et al., 2013). Family systems theory presents the family as an organised whole with the individuals (the parts) all being viewed in relationship (interconnected) with each other (Cox & Paley, 1997; Wright & Benigno, 2019). Situated in FST, narrative therapy has been gaining traction since the 1980s as a possible intervention to help families raising a child with autism make sense of their experiences (White & Epston, 1990, 1992). However, four decades later, empirical evidence confirming its possibilities remains lacking (Goepfert et al., 2015; Romney & Jones, 2020; Sutherland et al., 2023).

## Background to the Research Problem

Autism, or autism spectrum disorder (ASD), is a neurodevelopmental disorder that is estimated to affect 1 in 100 children worldwide (Talantseva et al., 2023). According to the DSM-5, ASD across and outside of the United States affects 1% of the local population (APA, 2013). However, it remains unclear whether higher rates reflect an expansion of the diagnostic criteria to include subthreshold cases, increased awareness, differences in methodology, or a true increase in the frequency of ASD. In Africa, autism remains understudied with limited data on the prevalence of the condition. Yet, studies suggest that the prevalence of autism in Africa is similar to other parts of the world (Aderinto et al., 2023).

The disorder, for which there is to date no cure (Neely et al., 2012; Yadav, 2020), is characterised by difficulties in the social use of verbal and nonverbal communication (criterion A), and restricted and repetitive patterns of behaviour (criterion B), which manifest during the developmental phase of the child (American Psychiatric Association [APA], 2022). According to the new DSM-5-TR,[1] to be diagnosed, individuals must simultaneously display all the diagnostic criteria under the first criterion, and at least two of the criteria under the second (First et al., 2022).

Although children with autism present with disparate symptom profiles, they typically present with secondary symptoms such as aggression, hyperactivity, impulsivity, anxiety and depression, certain unpredictable behaviour and even self-harming behaviour in some individuals (Lindor et al., 2019; Sauer et al., 2021). A range of psychological comorbidities such as attention-deficit/hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), and intellectual disability (Baio et al., 2018; Hatch et al.,

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[1] Over the course of the study, the definition of autism as per DSM-5 (American Psychiatric Association, 2013) has been updated by a newer definition in the DSM-5-TR (American Psychiatric Association, 2022) to improve the reliability and validity of the diagnosis of ASD. While the DSM-5 allowed for the presence of any of the listed criteria to meet the diagnostic threshold, the DSM-5-TR revised the wording to 'as manifested by all of the following'. To be diagnosed, an individual must therefore experience differences in all the listed areas, not only some. The present study adhered to the criteria set forth in the DSM-5, as it constituted the prevailing diagnostic framework during the time the research was conducted, specifically before 2022. In this study, the terms autism and ASD will be used interchangeably.

2023; Kerns et al., 2021; Martin et al., 2020; Sauer et al., 2021; Sukhodolsky et al., 2019), and physiological comorbidities such as epilepsy, sleep disorders, and gastrointestinal problems (Guo et al., 2023; Madra et al., 2020; Sauer et al., 2021; Tse et al., 2020), are also common. In addition, immune system dysfunction has been noted as a comorbidity, with studies indicating elevated cytokine levels and inflammation (Careaga et al., 2010). These symptoms cause clinically significant impairment in social, occupational, or other critical areas, which affect their daily executive functioning and planning abilities, learning abilities, and their ability to socially interact (Robinson et al., 2009).

Because of these symptom profiles, healthcare needs for individuals diagnosed with ASD are complex and require a range of integrated services including health promotion, care and rehabilitation (World Health Organisation [WHO], 2023). That is because people with ASD tend to rely on family members, including parents and siblings, well into adulthood (Spain et al., 2017). These special needs make caring for a child with ASD challenging and extremely demanding in many aspects. Apart from having to cope with the general demands of parenting, parents often lack the confidence to manage the child’s behaviour, lack support from the wider community, lack access to supportive, therapeutic, and educational services, have to have to balance work and family, and manage additional financial strain (Hutton & Caron, 2005; Romney & Jones, 2020; Solomon & Chung, 2012; Twoy et al., 2007).

It is evident that raising a child with autism is as challenging for the entire family system as it is for the child who is living with the disorder. In a study by Papadopoulos (2021), mothers indicated how having a child with autism affected their relationship with their other children while the financial strain forced the family to make lifestyle adjustments. Studies on the effect on parents’ marital relationship pointed to added stress and pressure within the relationship (Hock et al., 2012; Woodgate et al., 2008). Yet, there are examples where couples experienced autism to strengthen the relationship with their partner (Blair et al., 1996; Myers et al., 2009). A study on sibling relationships showed that, as a result of their sibling having autism, some typically developing siblings had to take on more responsibilities than expected during their developmental years, while others faced disapproving comments from their peers (Watson et al., 2021). Grandparents in a study by Hillman, Wentzel and Anderson (2017) expressed a desire to connect with their grandchildren, but for them, inappropriate autism behaviour kept them at a distance. Whether negative or positive, the need for support to make sense of their experiences and restore order in their lives runs like a golden thread (Hartley & Schultz, 2015; Khara et al., 2020). In a more detailed account in Chapter 2, family members highlight the profound impact that raising a child with autism can have on the dynamics of spousal, sibling, and parent-child relationships, underscoring the complex interplay of emotions and challenges faced by couples in such circumstances.

The reviewed studies confirmed both (a) the manifold challenges families face when raising a child with autism and (b) the need for a family-focused therapy to address the systemic effect of autism. Despite the evidence, however, interventions continue to focus on the individual, and less on the family requiring much needed support (Neely et al., 2012; Parker & Molteni, 2017; Romney & Jones, 2020; Solomon & Chung, 2012; Twoy et al., 2007). Meanwhile, the disorder leaves these families drained, both socially and emotionally, leading to families reporting high levels of stress (Hock et al., 2012; Manono & Clasquin-Johnson, 2023; Papadopoulos, 2021), marital problems (Higgins et al., 2005; Shtayermman, 2013) and isolation within their communities (Rfat et al., 2023; Watson et al., 2021; Woodgate et al., 2008).

Family-focused research on autism is critical for understanding the impact of these disorders and informing clinical support services for these families (Cridland et al., 2013). Despite increased research interest in the field however, this type of research is still considered relatively recent with limitations abound and the research lacking a common theoretical framework (Cridland et al., 2013).

One way of providing support services for these families is through family-systems interventions or family therapy (Dallos & Draper, 2005; Goepfert et al., 2015; Helps, 2016; Spain et al., 2017). Family therapy is designed to help members of a family make sense of difficult situations, and help them work together to improve the functioning of the family system. It does so by targeting the interactions between family members and the beliefs that they hold (Dallos & Draper, 2005). In the process they develop new ways of thinking about and managing these difficulties (Spain et al., 2017). In a review article, Goepfert et al. (2015) identify a lack in therapeutic studies on children diagnosed with ASD and their families. Still, the evidence shows that families raising a child with ASD can indeed benefit from family therapy or from care informed by FST. Although family therapy does not cure ASD or eliminate its presence, it may improve relationships and the strength of the system living with ASD. It does so by decentralising the child with autism as the problem and instead, reframing the problem as ‘a pattern of interactions between people’. However, this ‘reframing’ must be unanimously true for all the involved family members, therefore, multiple family members are involved in the problem and share responsibility for changing it (Goepfert et al., 2015).

The central idea of family-systems interventions draws on FST, which views the family as a complex, organised whole or system composed of interrelated parts (family members) that influence one another (Cox & Paley, 1997; Wright & Benigno, 2019). Inside the system, families are conceptualised as hierarchically structured, consisting of internal subsystems such as a spousal/couple subsystem, parental subsystem and sibling subsystem (Bavelas & Segal, 1982; Cox & Paley, 1997; Cridland et al., 2013; Pam, 1993). Family systems cannot be understood by examining only individual members or subsystems in isolation from each other because the idea of holism states that the family as a whole is greater than the sum of its parts. This concept implies that any significant change or event in one family member will affect all other family members. This means that a problem for any member of a family has an effect on all others, and changes in any member result in adaptations among all other family members (Wright & Leahey, 2005). A final important concept in FST is the family’s ability to create homeostasis: a control mechanism which enables the family to create balance between change and stability (Bavelas & Segal, 1982; Priest, 2021). The application of FST to this study is elaborated on in Chapter 3.

Family systems theory emanated from systems theory which developed around the same time as family therapy in the 1950s and which ‘seeks to understand the dynamic behavior of complex systems, including how components of a system interact to affect the behavior of the system in often unexpected, nonlinear ways’ (Watson, 2012, p. 184). Not one but various theorists contribututed to the development of systems theory. However, the contributions of only some of these theorists like anthropologist Gregory Bateson, found particular application to FST. Bateson, whose epistemology meant the rules one uses to make sense of the world (Minuchin, 1985), is also credited as one of he main influences behind family therapists Michael White and David Epston, the developers of narrative therapy (Watson, 2012).

A narrative can be defined as an organised interpretation of a sequence of events. It is through narrative that we bring a sense of order to the seeming disorder in our world (Bruner, 1987; Murray, 2003). For White and Epston the story analogy provided useful direction for their work, based on the notion that it is through the stories we hear and tell about our lives, that we derive at meaning (White & Epston, 1990, 1992). Consequently narrative therapy developed as a form of psychotherapy that is used to help people who present with problem-saturated narratives (Cashin et al., 2013; Erbes et al., 2014). Central to narrative research is a focus on the role of narratives as a sense-making tool with the capacity to produce, challenge and change the identities of individuals as well as collectives (Holstein & Gubrium, 2012; Kerby, 1991).

Narrative therapy has long been successfully applied to a range of mental health conditions (Erbes et al., 2014; Monteiro, 2021; Rajaei & Jensen, 2020; Vromans & Schweitzer, 2011; Weber et al., 2006). Studies on the effectiveness of narrative therapy in the context of ASD are fewer but also show positive results (Cashin, 2008; Cashin et al., 2013; Goepfert et al., 2015; Tilsen et al., 2005). The small number of empirical studies exploring the possibilities of narrative therapy as a systems intervention for families raising a child with autism (Chao & Chen, 2023; Gao et al., 2023; Olinger, 2010; Romney & Jones, 2020; Solomon & Chung, 2012) stresses the need for more evidence in this regard (Romney & Jones, 2020).

## Problem Statement

Family therapists need updated information on autism and how family therapy can help parents of children with autism. Where narrative therapy has been used in various contexts the feedback has been positive, but there are few studied applications of narrative therapy in the context of ASD. More specifically, there is a need for more empirical evidence to explore the possibilities of using narrative inquiry as a sense-making tool for parents raising a child with autism (Goepfert et al., 2015; Romney & Jones, 2020; Sutherland et al., 2023).

## Aim

The aim of this study is to explore the possibilities of using narrative inquiry as a sense-making tool for parents raising a child with autism, from an FST perspective.

## Research Question

The study was guided by the following main research question:

What are the possibilities of using narrative inquiry as a sense-making tool for parents raising a child with autism, from an FST perspective?

Three sub-research questions followed from the main research question:

1. What are parents' experiences of raising a child with autism?
2. How do families make sense of their experience of raising a child with autism, from the moment of the diagnosis of autism and the years to follow?
3. How can these narratives be used as a framework (alternative lens) for healthcare professionals while in consultation with these families?

## Research Objectives

The following objectives were identified to achieve the research aim:

1. To explore and describe parents’ experiences of raising a child with autism;
2. To understand how parents make sense of their experiences of raising a child with autism, from the moment of the diagnosis of autism and the years to follow; and
3. To explore how these narratives can be used as a framework (alternative lens) for healthcare professionals while in consultation with these families.

## Research Paradigm and Theoretical Framework

Both FST and narrative inquiry are situated in the social constructionist, postmodern, poststructuralist discourses that challenge structuralist or modernist theories about the ‘true self’ and identity, humanism, and traditional psychological and counselling discourses (Besley, 2002). Chapter 3 motivates why social constructionism and family system theory not only suitable but also the logic choice for situating this study.

## Research Design

This qualitative, empirical study used a narrative inquiry to explore how three couples, who all reside in Pretoria, South Africa, make sense of their experiences while raising a child with autism. The study employed a longitudinal approach over a period of five years, from the moment of diagnosis of autism and the years to follow. The qualitative approach allowed the study to explore individuals' experiences, behaviours, and the meanings they attribute to these experiences. Primary data were collected by means of semi-structured interviews of the three couples, who were sampled using a convenience sampling technique. This selection of three couples allowed an in-depth understanding of the social and cultural context as meaning is derived from the experiences shared by the specific participants (White, 2000). Narrative conversations provides individuals the ability to evaluate past ideas or beliefs connected to their personal identity and to empower them with future opportunities for change. The collected data were analysed through a detailed and interpretive analysis which is grounded in the rich, contextual insights obtained from participants' narratives, using a reflexive thematic analysis as per Braun and Clarke (2020). The focus of this kind of analysis is about (a) how people experience and make sense of a particular phenomenon over a period of time (Angus & McLeod, 2004), and (b) how people create order out of their disordered lives by creating a narrative reality (Murray, 2008). During the analysis, the different familial relationships were explored as subsystems within the larger family system as explained by FST, for example, the relationships of the father as part of the parent-child subsystem but also as part of the husband-wife subsystem. Chapter 4 gives a detailed account of the research design process.

## Contribution

The study contributes to the discipline at both a practical and an academic level.

At a practical level, the study provides much needed empirical evidence on the effectiveness of using a narrative approach to help families raising a child with autism, make sense of their experiences. In this regard, it responds to calls made by Romney and Jones (2020), Goepfert et al. (2015), Neely et al. (2012) and Helps (2016).

Cridland et al. (2013) identified the lack of a common theoretical framework in the literature on autism and the family to better understand the impact of the disorder and to inform clinical support services to these families. At an academic level, the study joins the discourse that argues for a family-focused therapy approach situated in FST which presents the family as an organised whole with the individuals (the parts) all being viewed in relationship (interconnected) with each other (for example, Karpa, 2021).

In this study the role of the researcher is inherently interconnected with the broader context and cannot exist in isolation. Throughout the study, I maintained a consciousness of how the findings could coherently integrate into a larger process, fostering meaningful dialogues between practitioners and individuals or families from the moment of diagnosis. On a personal level, I acknowledge that engagement with the narratives of others has indelibly shaped my own identity, underscoring the transformative influence of these shared stories.

## Outline of the Study

The remainder of the study is structured as follows. The literature review that follows in Chapter 2 describes the unique characteristics of autism as having a systemic effect on the family, causing a need for family-focused therapy that helps them make sense of their experiences. Narrative therapy is presented as a possible sense-making tool. In Chapter 3 narrative inquiry, the selected research design for this study, is paradigmatically analysed in terms of ontology and epistemology. Both narrative inquiry and FST, the selected theoretical framework for this study, are situated in social constructionism. Chapter 4 defends the choice of a narrative inquiry as research design and reflexive thematic analysis to answer the study's research question and objectives. Chapter 5 reports back on the analysis of the three objectives after which Chapter 6 will conclude.

## Conclusion

Chapter 1 provided a background to the research problem of the study. Families raising a child with autism require much needed family-focused support to make sense of their experiences but treatment options continue to focus on the individual with the disorder. Narrative therapy, situated in FST, has been identified as a possible sense-making tool. Although feedback of its effectiveness in autism and the families are positive, there is a shortage of substantial empirical evidence. The chapter further identified the selected research paradigm and theoretical framework and summarised the research design that was employed before outlining the rest of the study.

# CHAPTER II. Literature Review

The chapter sets out by describing the unique characteristics of autism, to argue that autism's systemic effects affect not only the individual with the disorder, but the entire family as a system. These effects are visible through the countless recollections of family members who have shared their experiences of raising a child with autism. But to date, these studies have mainly captured the experiences of a particular family member, and not that of the collective. To support families raising a child with autism, family-focused therapy that adopts a holistic approach is proposed to examine all inherent family relationships and subsystems. A review of studies confirm how family members expressed a need for making sense of their experiences. The final section of this chapter reviews the possibility of using narrative therapy as such a sense-making tool.

## The Unique Characteristics of Autism

### *The Origin of Autism*

In the 1940s, Dr Leo Kanner, a paediatric psychiatrist, and Dr Hans Asperger, a paediatrician, adopted the term 'autism' to describe a syndrome in children presenting with behavioural challenges in social interaction and communication, alongside restricted and repetitive interests (Whitman, 2004). In 1944, Asperger documented a disorder akin to autism, subsequently named Asperger syndrome (Asperger, 1944). His publication detailing the condition's symptoms, led to the creation of a school to support children with autism post-World War II. Sadly the school was destroyed by bombing, which resulted in the loss of much of his preliminary work (Gallo, 2010; Whitman, 2004; Zager, 2005). Following the war, autism started to be recognised within the context of psychiatric disorders (Aitken, 2010).

Expanding on the work of Kanner, Bettelheim (1967) emphasised the significance of the social environment in the development of autism. Controversially, he attributed the condition to the emotional coldness of 'refrigerator mothers'. Since then, his hypothesis has been thoroughly discredited by scholars such as Rimland (1964), who posited a biological basis for autism.

Inspired by political activism and social movements, and improvements in services for children with developmental delays, the 1950s marked a considerable expansion in research into the origins and development of autism. Still, autism was only formally categorised as a diagnostic condition with the publication of the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) in 1980 (APA, 1980).

### *Autism Defined*

At present, ASD is used to describe a clinically heterogeneous group of neurodevelopmental disorders (Sauer et al., 2021). These disorders share behavioural core features that affect social communication and are characterised by restrictive and repetitive stereotypic behavioural patterns and interests. The DSM-5 (APA, 2013) introduced the concept of a 'spectrum' into the ASD diagnosis, combining the DSM-IV's (APA, 1994) separate pervasive developmental disorder (PDD) classifications – autistic disorder, Asperger syndrome, pervasive developmental disorder; not otherwise specified (PDD-NOS), childhood disintegrative disorder, and Rett syndrome – under one unifying umbrella term, ASD (APA, 2013; Hodges et al., 2020). In this thesis, the terms ASD and autism are used interchangeably.

### *The Prevalence of Autism*

Autism is more commonly diagnosed in males. Yet, a recent meta-analysis by Loomes et al. (2017) suggests that the true male-to-female ratio may be approximately closer to 3:1 rather than the previously assumed 4:1. The authors propose that females who meet the criteria for ASD have a heightened risk of not receiving a clinical diagnosis.

According to the DSM-5, ASD across United States and non-United States countries affect 1% of the local population (APA, 2013). However, it remains unclear whether higher rates reflect an expansion of the diagnostic criteria to include subthreshold cases, increased awareness, differences in methodology, or a true increase in the frequency of ASD. In Africa, autism remains understudied with limited data on the prevalence of the condition. Yet, studies suggest that the prevalence of autism in Africa is similar to other parts of the world (Aderinto et al., 2023).

### ***Symptoms and Diagnosis of Autism***

Symptoms typically start to appear in early childhood and are often diagnosed by the age of three. Early indicators of ASD in infancy and toddlerhood, before reaching three years of age, include a lack of response to one's name and an aversion to maintaining eye contact (Masi et al., 2017). Individuals with ASD experience secondary symptoms, comorbidities associated with the disorder, and other challenges that affect their daily functioning and planning abilities. These secondary symptoms manifest as aggression, hyperactivity, impulsivity, anxiety and depression, and even self-harming behaviour in some individuals. Notably there is co-occurrence of ADHD and ASD with both conditions exhibiting similar behavioural and neurological characteristics. The DSM-5 (APA, 2013) has taken this co-occurrence into account and now allows for a dual diagnosis of ADHD and autism (Leitner, 2014).

Autism is also associated with a range of comorbidities, both psychological and physiological. Psychological comorbidities accompanying ASD include ADHD (Hatch et al., 2023), OCD (Martin et al., 2020; Sauer et al., 2021), anxiety (Kerns et al., 2021; Sukhodolsky et al., 2019), and intellectual disability (Baio et al., 2018; Sauer et al., 2021). Physiological comorbidities of ASD include epilepsy (Guo et al., 2023; Sauer et al., 2021), sleep disorders (Sauer et al., 2021; Tse et al., 2020) and gastrointestinal (GI) problems (Madra et al., 2020; Sauer et al., 2021). In addition, immune system dysfunction has been noted as a comorbidity, with studies indicating elevated cytokine levels and inflammation (Careaga et al., 2010).

Research suggests that the brains of people with autism show pervasive network underconnectivity that limits response flexibility (Minshew & Williams, 2007 cited in Solomon & Chung, 2012, p. 253). While children with autism can have average or above average static abilities such as categorising, organising, imitating, and computing; they tend to have severe impairments in dynamic intelligence such as anticipating, inferring, reflecting, and expanding (Gutstein, 2009). Individuals with autism is constantly exposed to novel situations and finds themselves with an expectation of the need to perform but no knowledge of how to proceed. This causes high degrees of anxiety and depression in the individual (Cashin et al., 2013, p. 34).

The symptoms mentioned above cause clinically significant impairment in social, occupational, or other critical areas, which affect their daily executive functioning and planning abilities (Robinson et al., 2009), learning abilities, and their ability to socially interact. Consequently, these individuals tend to not initiate social interactions. They often experience difficulty to process stimuli and to plan steps of an activity. An observed difficulty is their reluctance to perform independent behaviours and initiate tasks (Sauer et al., 2021). Moreover, individuals with ASD may find it challenging to generalise skills across different settings and adapt to new environments, potentially due to an oversensitivity to specific stimuli (De Marchena et al., 2015).

To be diagnosed with ASD, symptoms must present themselves in the early developmental period, although these may not fully manifest until social demands exceed limited abilities or may even be masked by learned strategies later in life (First et al., 2022).

### *The Aetiology of Autism*

The aetiology of autism is complex and can be categorised into three primary domains: (1) medical causes, which include genetic mutations and metabolic conditions; (2) neurobiological causes, encompassing brain structure and functional connectivity; and (3) environmental causes, such as prenatal exposure to certain substances. To understand the aetiology of autism, it is not sufficient to consider these causes in isolation. Instead, one needs a holistic approach that integrates medical, neurobiological, and environmental aspects, and acknowledges how these aspects interplay to develop the condition.

**Medical Causes.** The medical causes of autism are twofold: genetic or metabolic. The following subsections discuss these causes.

***Genetic Mutations.*** There are two types of genetic mutations related to autism: genetic associations and genetic medical conditions.

Genetic Associations. Autism is highly heritable (Genovese & Butler, 2023; Hodges et al., 2020). Kainer et al. (2023) and Sandin et al. (2014) estimate this heritability between 50% and 80%. Evidence for a genetic predisposition comes from studies of twins. Rosenberg et al. (2009) and Lathe (2006) indicate a greater ASD concordance in monozygotic twins than in dizygotic twins. Despite this high heritability, research has yet to identify a single gene or group of genes that accounts for autism's aetiology (Genovese & Butler, 2023; Yoon et al., 2020). It is believed that a combination of genes and other independently sufficient factors play a role in the aetiology of autism. It seems as if autism is a multiple gene disorder with several interacting genes moderating the effect on different chromosomes (Genovese & Butler, 2023). Several studies probed for a chromosome or genetic link that explains autism's genetic base. Gavril et al. (2023) identified chromosome 2q37 deletion associated with ASD. Falk and Casas (2007) agree that a diagnosis of autism is present in 24–35% of cases with a deletion on chromosome 2q37. Auranen et al. (2002) found significant evidence for linking chromosome 3q25–27 with autism. More et al. (2023) identified genes SETD2 and MACF1 with high autistic traits. Gene SETD2 is on chromosome 3 and MACF1 gene is involved in various neural processes during development. Ryan and Heron (2023) support the 7q32.1–32.2 chromosomal regions related to ASD. Sanders et al. (2011) found a significant association between ASD and duplications of chromosome 7q11.23. Arghir et al. (2021) mention that a chromosome 8p21.2p11.21 deletion is implicated in individuals with autism. Marshall et al. (2008) and Ozgen et al. (2009) in Fisch et al. (2011) support this and add that DLGAP2, MCPHI and NEF3 could be possible candidate genes for autism on this chromosome. Kantojärvi et al. (2010) found a strong association between the JMJD2C gene at chromosome 9p24.1 and autism.

Shinawi et al. (2011) found a link with autism and a deletion on chromosome 11p14.1. Liu et al. (2011) also highlighted an association between the genes on chromosome 11q23.1–q23.3 and autism. Genovese and Butler (2023) and Lu et al. (2020) associate chromosome 15q11–q13 duplications and deletions with developmental delay in ASD. Genovese and Butler (2023) claims that chromosome 15q11.2, 15q13.3 and 16p11.2 are implicated in 50% of individuals diagnosed with ASD. Shehi et al. (2022) confirm the high comorbidity between Dup15q (15q11–q13 duplication syndrome) and ASD. Stefanyshyn et al. (2024) maintain that deletions in chromosome 15q24 are associated with autism. Čiuladaitė et al. (2011) state that common features for chromosome 16p11.2 deletion are language impairment, motor delay and behavioural problems. Chung et al. (2021) claims chromosome 16p11.2 deletions as one of the most frequent aetiologies of ASD. Horev et al. (2011) support this finding. Pagnamenta et al. (2011) state that chromosome 16q21 microdeletions implicate CDH8 susceptibility to autism. Clissold et al. (2016) and Roberts et al. (2014) confirm that a deletion of chromosome 17q12 has been associated with an increased high risk for ASD. Strom et al. (2010) also associated chromosome 17q11–-q21 with autism. Liu et al. (2011) showed a link between autism and the genes on chromosome 19q13.32–q13.33. Alhazmi et al.(2022) suggested that a duplication and deletion of many genes in chromosome 22 may have a strong association with ASD. Clements et al. (2017) added that children with deletions of 22q11.2 may be at greater risk of ASD if the region includes LCR-A to B. The synthesis of the findings suggests that a number of chromosomes—specifically chromosomes 2, 3, 7, 8, 9, 11, 15, 16, 17, 19, and 22—have been implicated in the genetic underpinnings of autism. While evidence underscores a genetic association with autism on chromosomes 8, 9, 16, and 22, it is apparent that different loci within these chromosomes are involved. This points to a complex genetic framework with multiple chromosomal regions contributing to the condition's aetiology.

Genetic Medical Conditions. Several genetic conditions have been implicated to cause autism, such as neurofibromatosis, Smith-Lemli-Opitz, phenylketonuria (PKU), tuberous sclerosis, and fragile X syndrome (Freitag et al., 2020; Genovese & Butler, 2020). Neurofibromatosis is a neurogenetic condition which mainly affects the growth of neural tissue cells. It is associated with cognitive dysfunction and learning disabilities (Harchaoui et al., 2021; Payne et al., 2010). Bilder et al. (2016), Chisholm et al. (2022), and Harchaoui et al. (2021) provide support for the association between neurofibromatosis type 1 and ASD. Smith-Lemli-Opitz syndrome (SLOS) is recognised as an autosomal recessive inborn error of cholesterol metabolism that presents with neurocognitive effects (2016). From their research, the authors have drawn the inference that while autism ASD seems to be a prevalent diagnosis among individuals with SLOS, the generally lower level of functioning in SLOS patients may lead to disproportionately high scores on standardised autism assessments, which could skew the interpretation of autism prevalence in this population. Furthermore, Saskin et al. (2017) have verified the connection between SLOS and ASD, affirming the pattern of comorbidity observed in these individuals. Phenylketonuria (PKU) is a genetic disorder. Research conducted by Kareem et al. (2017) revealed that 26% of individuals with PKU also presented with autism, indicating a notable prevalence of autistic characteristics within this cohort. In addition, Kumar (2014) documented a case report where a patient with PKU exhibited behaviours akin to ASD, further highlighting the potential overlap in the behavioural phenotype between these two conditions. These studies suggest a correlation that merits further investigation into the potential genetic and metabolic interplay between PKU and ASD, to better understand the shared pathways that might contribute to the development of ASD-like behaviours in individuals with PKU. Tuberous sclerosis is an autosomal dominant, multisystem disorder, commonly affecting the brain, heart, lungs, skin, kidneys and eyes (Uysal & Şahin, 2020). Mitchell et al. (2022) and Capal et al. (2021) support the association between tuberous sclerosis and ASD. Fragile X syndrome is an X-linked neurodevelopmental disorder and the leading heritable form of intellectual disability (Hagerman & Hagerman, 2021). Abbeduto et al. (2014), Haebig et al. (2020), and Hagerman and Hagerman (2021) confirm the co-occurrence of ASD and fragile X syndrome.

**Neurobiological Causes**. Neurobiological causes related to brain structure (neuroanatomy) and functional connectivity (neurochemistry) have also undergone scientific scrutiny. Yet, definitive conclusions remain elusive regarding any particular brain structure or structures, whether impaired or underdeveloped that consistently underlie autism, remain elusive (Yapko, 2003).

***Brain Structure (Neuroanatomy)***. Research indicates neuroanatomical differences between individuals with ASD and neurotypical controls. Carper and Courchesne (2000) and Sydnor and Aldinger (2022) confirmed an increase in the frontal lobe cortex volume in patients with ASD. This increase correlates with abnormalities in the cerebellum. The cerebellum acts as a sensorimotor regulator and affects changes in executive and limbic processing. Rowland (2020) explained that a dysfunctional cingulate gyrus means that the person with autism is left brain exclusive. This is the probable cause of hyperfocus in individuals with ASD, which in turn can lead to various kinds of sensory overloads. Donovan and Basson (2017) highlighted that an early overgrow in the prefrontal cortex is a common feature of ASD and Allely et al. (2014) implicated abnormalities of the temporal cortex during language processing. A study by Habata et al. (2021) pointed to associations between the lateral orbitofrontal cortical thickness, lingual cortical thickness and the hippocampal volume and sensory characteristics. Several brainstem structures (Baizer, 2021) and the amygdala (Allely et al., 2014) have been implicated in ASD. Chandran et al. (2021) and Godel et al. (2021) associated ASD with early alterations of the grey-white matter in the brain.

***Functional Connectivity (Neurochemistry)***. Many neurochemical pathways engage in the aetiology of ASD (Marotta et al., 2020). Jiang et al. (2022) and Zhao et al. (2022) suggest a disruption in the serotonergic mechanisms during development in individuals with autism. According to Kosillo and Bateup (2021) and Mandic-Maravic et al. (2022), the neurotransmitter dopamine is also implicated in the occurrence of autism. A study by Jiang et al. (2022) links the neurotransmitters glutamate and gamma aminobutyric acid (GABA) to the aetiology of autism.

**Environmental Causes**. The literature explains how prenatal exposure to certain substances as an environmental cause for autism. These include metabolic conditions (non-genetic causes) such as infections, mitochondrial dysfunction, pregnancy, and toxins.

***Infections.*** Al-Beltagi et al. (2023) posited evidence that viral infections during pregnancy and early life—specifically those caused by herpes simplex virus, influenza viruses, rubella, cytomegalovirus, SARS-CoV-2, and Zika virus—may act as environmental triggers for the development of autism. This conclusion underscores the potential impact of maternal and early postnatal viral exposures on the neurodevelopmental trajectory of offspring. Al-Beltagi et al. (2023) also noted that children diagnosed with autism are at a heightened risk for various infections, including viral ones. There is also a positive correlation between autoimmune encephalitis and autism (Whiteley et al., 2021). There is compelling evidence suggesting no link between the development of ASD and immunisations (Gabis et al., 2022; Mohammed et al., 2022).

***Mitochondrial dysfunction.*** Mitochondria are fundamental for metabolic homeostasis (Norat et al., 2020). Citrigno et al. (2020), Frye (2020) and Siddiqui et al. (2016) confirmed that mitochondrial bioenergetics and mitochondrial fragmentation may contribute to the aetiology of autism.

***Pregnancy.*** Risk factors associated with developing autism during the perinatal period are both maternal- and child related. Maternal-related factors are mothers suffering from a disease during pregnancy and having diabetes have been linked with ASD (Mahboub et al., 2023). Medication intake during pregnancy, as examined by Grivas et al. (2021), and Hisle-Gorman et al. (2018), along with exposure to radiology, have been associated with a heightened risk of ASD, a risk that persists irrespective of the gestational stage at the time of exposure. Urinary tract infections during the first trimester and preterm delivery during the second trimester are also associated with an increased risk of ASD (Grivas et al., 2021). Advanced parental age was also implicated (Indrihapsari et al., 2020; Modabbernia et al., 2017). Child-related factors such as low birth weight, umbilical cord entanglement, infant distress during labour, and birth-related injuries have also been associated with an increased risk of ASD, as highlighted by Mahboub et al. (2023). Birth complications associated with trauma or ischaemia and hypoxia have shown strong links with ASD (Modabbernia et al., 2017). Hisle-Gorman et al. (2018) also found neonatal seizures to be associated with ASD. In their study, Indrihapsari et al. (2020) found that complications during the perinatal period and specific trimesters of prenatal development were associated with autism.

***Toxins.*** Modabbernia et al. (2017) indicated that the association between some heavy metals (inorganic mercury and lead) and ASD requires further investigation. Furthermore, Rossignol et al. (2014) validated the role of heavy metals in ASD and expanded these findings by identifying additional toxins implicated in ASD, including pesticides, phthalates, polychlorinated biphenyls (PCBs), methylmercury exposure during gestation, and childhood exposure to water pollutants.

### ***The Treatment of Autism***

Currently, the treatment of autism includes behavioural, educational, pharmacological, and other interventions. While these strategies will be discussed individually, it is often necessary to integrate multiple approaches and deliver treatment across various levels.

**Behavioural Treatments**. Behavioural approaches such as discrete trial training (DTT), differential reinforcement of incompatible (DRI), and pivotal response training (PRT) have proved to be highly effective for the individual to either control or eliminate many of the symptoms, or to develop new skills. Aishworiya et al. (2022) argue that behavioural interventions remain the mainstay of treatment of ASD. In terms of effective behavioural approaches, Anwar et al. (2022), Azman et al. (2022), Richard (2000), and Yapko (2003) expanded on the pioneering work by Dr Ole Ivar Lovaas on applied behavioural analysis (ABA). In the 1960s, O. Ivar Lovaas (1927–2010) pioneered ABA interventions to decrease severe challenging behaviours and to facilitate communicative language. He later sought to improve outcomes by focusing on interventions for preschoolers with autism, incorporating active parental participation (Smith & Eikeseth, 2010). Their evidence underscores ABA's goal of leveraging psychological principles of behaviour to shape desired behavioural responses and ameliorate unwanted behaviours, thereby offering valuable perspectives on effective behavioural approaches for addressing ASD. The common goal of this approach is to train individuals with autism to give a new behavioural response to a specific stimulus based on positive and negative consequences, simply referred to as either reward or punishment. The only punitive methods used in the programme are social rather than physical, such as saying ‘no’ or giving ‘time outs’. Scientific evidence has lent substantial support to the use of ABA in treating individuals with autism. Results from a study from Yu et al. (2020) confirmed that socialisation, communication, and expressive language was positively addressed with ABA interventions. Brosnan and Healy (2011) found that ABA is effective in reducing or eliminating aggressive behaviour across a range of ages.

***Discrete Trial Training.*** Anwar et al. (2022), Richard (2000), Ward (2022) , and Yapko (2003) elaborate on discrete trial training (DTT), originally attributed to the research of Lovaas (Anwar et al., 2022), delineating its fundamental components. Discrete trial training entails intensive home-based instruction, spanning 30–40 hours weekly, within a one-on-one framework. This approach involves segmenting behaviours into smaller components for systematic intervention. Individuals repeat tasks until they achieve the goal, then move on to more difficult tasks, with each instance of a desired behaviour being rewarded. This type of training is most effective when consequences immediately follow the relevant response. Empirical research supports the use of DTT in treating individuals with autism (Anwar et al., 2022; Geiger et al., 2012).

***Differential Reinforcement of Incompatible Behaviour.*** Differential reinforcement of incompatible behaviour (DRI) replaces self-injurious behaviour with other forms of incompatible actions. Self-injurious behaviour can result in physical harm to the individual displaying the behaviour and reduces opportunities for the individual to interact and communicate with others. In DRI there are several antecedents of the behaviour namely, waiting, being told ‘no’ and being denied access. Head hitting are, for example, replaced by prompting the individual to clap hands to meet the sensory needs (Enemor et al., 2022). Matson (1994) elaborates that this procedure consists of furnishing praise and a favourite edible at the end of intervals where no aggression was displayed. The extant literature indicates that employing differential reinforcement proves efficacious in addressing instances of aggression and noncompliance. Nevertheless, relying solely on reinforcement may not consistently yield desired outcomes; hence, it may be judicious to complement reinforcement with punitive measures such as restraint, response cost, and overcorrection.

***Pivotal Response Training.*** Pivotal response training (PRT) is considered a behavioural treatment focused on improving communication skills in children with ASD (Van den Berk-Smeekens et al., 2022). It adopts a naturalistic approach that focuses on using several strategies to help increase children’s motivation during intervention. PRT has received support for its therapeutic gains in the use of functional social communication skills in individuals with ASD (Lei & Ventola, 2017).

**Educational Treatments.** Highly structured teaching programmes such as treatment and education of autistic and related communication-handicapped children (TEACCH) and the social communication, emotional regulation and transactional support (SCERTS) model have claimed to yield the most significant advancements for individuals with autism. Subsequently, specific educational interventions will be discussed.

***TEACCH.*** TEACCH is a widely known educational programme. ABA and TEACCH are among the most popular treatments implemented by educators, service providers and parents (Anwar et al., 2022; Choutka et al., 2004; Noni et al., 2021). TEACCH employs structured teaching methods aimed at enhancing individual independence, with reported effects on improving social skills and emotional regulation. Notably, Richard (2000), Whitman (2004), and Yapko (2003) highlight the treatment's overarching goal of enhancing adaptation by capitalising on an individual's strengths while addressing limitations through their utilisation. It aids such a child to achieve their potential and to reach minimum competency as an adult. The programme includes a systemic way of organising the environment, scheduling activities, and teaching methods. A prevalent strategy employed within the TEACCH programme involves the utilisation of visual aids. Organising a child's world visually and the sequencing of behaviours provides a structure for a child who might otherwise be stressed or highly agitated by not knowing what to expect or to do next.

***SCERTS model.*** Fiaz and Atia-ur-Rehman (2020) and Yi et al. (2020) confirm that the SCERTS model prioritises the improvement of language ability and social skills in children with ASD. It incorporates these principles in an educational treatment approach to enhance the communication and socio-emotional abilities of an individual with autism (Yapko, 2003; Zager, 2005).

**Alternative communication strategies.** Picture communication constitutes a component of augmentative and alternative communication strategies (AAC). AAC entails the utilisation of graphic symbols, manual gestures, or voice-assisted systems, serving to substitute or supplement absent or non-functional speech (Iacono et al., 2016). A study by Pereira et al. (2020) proved ACC effective in promoting the development of communication skills of individuals with ASD. In addition, Donaldson et al. (2021) concluded that the participants in their study reported AAC as a communication choice for adults.

**Pharmacological treatments.** Siafis et al. (2022) and Salloum-Asfar et al. (2024) agree that there are no approved medications to treat the core symptoms of ASD. Behavioural interventions are typically used as the first line of treatment and pharmacological drugs used to reduce associated symptoms. The discussion below covers the following pharmacological interventions: antipsychotics, selective serotonin reuptake inhibitors, opioid antagonists, stimulants, and anticonvulsants (antiepileptic drugs).

***Antipsychotics.*** D'Alò et al. (2021) found anti to be effective in children and adolescents with ASD. They confirmed its efficacy for the treatment of repetitive behaviours, hyperactivity, inattention, oppositional, disruptive behaviour, emotional dysregulation, and social communication. A study by Maneeton et al. (2018) showed a 70% overall response rate of risperidone, an atypical antipsychotic, and confirmed its efficacy in the treatment of symptoms of ASD. The authors observed that with escalating risperidone treatment, side effects (particularly weight gain) also escalated. Siafis et al. (2022) confirmed these findings and added that risperidone can improve social communication, repetitive behaviours in children and adults. According to Çakır et al. (2021) and Wink et al. (2017) the most prescribed antipsychotic medications are risperidone, quetiapine, aripiprazole.

***Selective serotonin reuptake inhibitors (SSRI).*** The change of serotonin levels has been implicated in influencing brain development and triggering ASD-like behavioural abnormalities, such as anxiety and stereotyped behaviour (Zhao et al., 2022). SSRIs are one of the most prescribed medications for individuals with autism. It treats mood issues, anxiety, and irritability. However, findings are inconsistent on the benefits of SSRI's for improving aggression and the core symptoms of ASD (Williams et al., 2013). A study by Kolevzon et al. (2006) concluded that SRRIs are effective in the treatment of ASD. These authors supported the use of citalopram when treating mood and anxiety symptoms associated with ASD. It is also said that Fluoxetine can be effective to address one core symptom in individuals with ASD (Lucchelli & Bertschy, 2018; Siafis et al., 2022).

***Opioid antagonists.*** Whitman (2004) states that elevated levels of opioids have been found in the cerebrospinal fluid of individuals with autism. It appears that opioids inhibit the feeling of pain associated with self-injurious behaviours. Naltrexone is occasionally prescribed to manage self-injurious behaviour and aggression by impeding the effects of opioids in the brain (Salloum-Asfar et al., 2024). Skoglund et al. (2022) found that opioid treatment can improve social functioning.

***Stimulants***. Given their established safety profile and prompt clinical efficacy, stimulants typically serve as the initial treatment choice for managing co-occurring ADHD. Treating co-occurring ADHD should focus on improving their daily functioning (Aishworiya et al., 2022). Cortese et al. (2017)

found that from the two main stimulant families, the amphetamines are slightly more effective than the methylphenidate. Individuals using these stimulants usually tolerate the latter better.

***Anticonvulsants (antiepileptic drugs).*** Genetic abnormalities are implicated in the association between ASD and epilepsy. Carbamazepine and lamotrigine are the most used antiepileptic drugs (Canitano et al., 2022). In a study by Limbu et al. (2022), lamotrigine showed improvement in adaptive social behaviours.

**Other interventions.** Other treatments for ASD include speech and language therapy, occupational therapy, physiotherapy, and various other therapeutic modalities.

***Speech and language therapy.*** Early intervention in terms of speech and language therapy can in general significantly improve social relationships, language development and communication skills for individuals with ASD. Speech and language therapists evaluate, diagnose and treat language abilities including expressive language, repetitive language, interaction with others, and pragmatics (the use of language in social contexts) (Kalra et al., 2023). Wood and Standen (2021) concluded that although there is limited evidence for the efficacy of speech and language interventions, some areas of speech and language practice such as AAC have demonstrated potential benefits.

***Occupational therapy.*** Kalra et al. (2023) contend that occupational therapy can provide benefits to all individuals with ASD. Occupational therapy aims to enhance or develop skills and improve overall functioning in everyday activities. Gasiewski et al. (2021) added that occupational therapists help with sensory interventions, motor skills and daily living skills for individuals with autism.

***Physiotherapy.*** Physiotherapy can serve as a valuable resource for children with ASD to manage and enhance their current or expected motoric and physical difficulties. However, it is essential to tailor physiotherapy interventions according to individual preferences and needs. This consideration is crucial because individuals with autism may exhibit sensitivity to certain tactile or sensory stimuli, presenting challenges in this therapeutic context (Kalra et al., 2023).

***Other therapies.*** Research conducted by Ke et al. (2022) and Mayer-Benarous et al. (2021) concurs that music therapy holds promise for children with ASD, showing potential for enhancing social skills. However, further investigation is warranted to explore its potential benefits for oral and written language development. Aquatic therapy may also be effective in improving social and physical competence of children with ASD (Güeita-Rodríguez et al., 2021). Research by Kaur et al. (2021) indicates an improvement through yoga for children with ASD. They noted a difference specifically in socially directed verbal communication skills, spontaneous and responsive communication, and affective states.

### *Cultural Perspectives on Autism*

One can view autism through various lenses. The following subsections will discuss Western, Eastern and African perceptions.

**Western culture**. Although the rise in the prevalence of autism in the United States sparked fears of a possible autism pandemic, experts attributed it to a growing awareness of autism and changes to the diagnostic criteria (Wright & Spectrum, 2017). Western perspectives on autism revolve a lot around the concepts of limited eye contact, imaginary play and the carer’s knowledge or socio-economic status. Uono and Hietanen’s (2015) study on Finnish (and Japanese) participants found that direct eye contact is not always highly valued in all cultures and repetitive behaviours can be considered normal. De Leeuw et al. (2020) also pointed out that caregivers thus report their child’s lack of eye contact as a strength rather than a difficulty. Smith et al. (2017) addressed how differences in cultural norms perceive imaginary play differently. De Leeuw et al. (2020) added that the lack of imaginary play may be a more salient symptom of autism in high-income Western countries than in other contexts. De Leeuw et al. (2020) also pointed to a few other cultural differences. They noted that some cultures may be more forgiving if culturally acceptable behaviour varies. A caregiver’s awareness may differ according to the degree of attention paid to the child. Parenting styles also affect whether and at what age parents recognise aspects of atypical development. The authors found affordability, availability and accessibility of mental healthcare services as significant factors in the diagnosis and support of children with ASD. Literacy in mental health and typical development and language barriers also influence the transfer of information for these families.

**Eastern culture**. A study by Jegatheesan (2011) examined the beliefs of South Asian Muslim families and found that they interpreted their child with autism as a gift from Allah and saw themselves as chosen for the task of raising the child. They also advocated for the inclusion of their children in community activities. Kim et al. (2021) reviewed perspectives of East Asian families. They found that Korean parents who identified as Christians attributed their child’s diagnosis to God’s plan. However, families also commonly reported shame and stigma around the diagnosis. Spousal support and extended family support varied as many extended families live in their countries of origin. Some parents also hesitated to reveal their child’s diagnosis to their families, fearing the support they receive. Kang-Yi et al. (2018) shared beliefs of Korean families that attributed the cause of autism to poor parenting, low parenting intelligence, poor family environment during pregnancy and a lack of love. Huang and Zhou (2016) reported the experience of Chinese families and linked their isolation and deterioration in social relationships to their fear of ‘loosing face’. Shyu et al. (2010) found that 13 parents of children with autism from a medical centre in Taiwan attribute the cause of autism to both biomedical and supernatural aetiologies. Where the participants believed the cause to be supernatural, they tried strategies suggested by a fortune-teller. Clark and Zhou’s (2005) study on autism in China indicates that treatments in Eastern cultures range from herbal medicines to acupuncture to sensory integration training. Yet, these cultures would also implement treatments based on the Western biomedical model.

**African culture**. Ruparelia et al. (2016) state that cultural beliefs towards disabilities and mental health disorders influence the diagnosis of ASD in Africa. A study by Gona (2016) investigated Kenian parents’ perceptions on autism and found that their causes of autism included evil spirits, witchcraft and curses and treatment included traditional healers, offering prayers to God and modern treatment in health facilities. Fox et al. (2017) documented perceptions of Somali parents with a child with autism. These parents were uncertain about the long-term nature of autism as lay advice from their communities sketched the picture that their child would improve and that they should not be concerned or that seeking professional help was not necessary. Witnessing developmental progress resulted in the parents thinking that their child would outgrow autism or might not have autism at all. This created tension between hope and acceptance for these parents. Hussein et al. (2019) highlighted that the lack of knowledge in the Somali community in their study resulted in criticism that the parents caused the condition. Bakare et al. (2009) conducted a study with healthcare workers in the south-east and south-south regions of Nigeria. They found that 26.9% of healthcare workers ascribed the aetiology of autism to natural, preternatural, and supernatural causes, 0.7% were uncertain of autism's aetiology, and 54.4% believed that autism is treatable. The 32.1% who thought that autism is preventable reason that autism came into being because of maternal infection, trauma to the brain from birth complications or from supernatural causes such as the lack of forgiveness of sins and cutting off links with cursed ancestral spirits.

This section captures the significant role that knowledge about autism and access to quality mental health care plays in early detection and treatment. The next section will deal with the impact a child with autism has on the family: the primary focus of this study.

## The Systemic Effect of Autism on the Familly

Research indicates that autism affects not only the child diagnosed with the disorder, but also the families living and raising the child. This research study focuses on the relationships within a family of a child with autism. It namely encompasses the experiences of the child's parents, siblings, the parents' marital relationship and the extended family. Literature on these family relationships follows.

### ***Experiences of the Mothers and Fathers***

Inquiry into autism and families covers a broad spectrum of family relationships, which each shed light on distinct aspects. An eminent study conducted by Manono and Clasquin-Johnson (2023) specifically delved into the dynamics between mothers and their children with autism. The findings of this research unveiled a multifaceted journey for these mothers, marked by initial experiences of confusion, uncertainty, and worry preceding their children's diagnosis. During this crucial phase, the mothers encountered a lack of comprehension from both their immediate families and religious communities. As the diagnostic process unfolded, a significant shift in the support dynamics emerged. Close friends and family gradually became a source of increased support, providing a crucial network for the mothers navigating the complexities of raising a child with autism. The diagnosis itself was perceived as a stressful and protracted process, eliciting a range of emotional responses from the mothers. While some found relief in finally understanding their child's condition, lingering concerns about the future persisted, underscoring the nuanced and challenging nature of the experiences faced by mothers in this familial context. The mothers went through an information-seeking phase to make sense of autism. De Aguiar and Pondé (2020) described how the mothers in their study expressed feelings of sadness, anguish, hopelessness, and despair when made aware of the diagnosis. In a study conducted by Papadopoulos (2021), mothers reported experiencing emotional responses such as depression, distress, and guilt upon receiving their child's diagnosis. The demanding nature of daily childcare responsibilities contributed to feelings of helplessness and frustration. Mothers expressed concerns and uncertainty about their child's future, education, and ability to transition to adulthood. Additionally, financial strain compelled families to adjust their lifestyle. The mothers described social stigma like negative social stereotypes and embarrassment about their child’s behaviour. They also experienced a decrease in social relationships because of the stigmatisation and limited time. Mothers in a study by Hirsch and

Paquin (2019) also blamed themselves for their child's symptoms and experienced emotions of guilt and depression.

Research by Burrell et al. (2017) explored the relationship between the father and the child with autism. The participants in the study realised that something was wrong prior to the diagnosis of autism. The fathers experienced frustration, guilt and embarrassment but eventually felt a sense of acceptance. The diagnosis provided an understanding, although it was difficult to process. Information on autism allowed the fathers a sense of control over their circumstances. The fathers acknowledged the significance of fostering independence in their children with autism, particularly concerning employment opportunities. However, they were acutely aware of the delicate balance required in managing both their own aspirations and the expectations placed upon their children. The challenge lay in navigating this intricate balance, considering the unique needs and capabilities of their children with autism. Moreover, participants openly acknowledged their reliance on support mechanisms, be it through an informal social support network or support from their spouses. Fathers recognised the indispensability of these resources, underscoring the understanding that, when confronted with the intricacies of raising children with autism and facilitating their transition towards independence and employment, a strong support system is crucial in assisting fathers to effectively navigate these hurdles. In the study conducted by De Aguiar and Pondé (2020), most fathers described the diagnosis as challenging, saddening, and shocking.

### ***The Parents' Marital Relationship***

Studies on the marital relationship of parents with a child with autism delve into various aspects of the parental marital dynamic, offering insights into the complex nature of relationships when confronted with the challenges associated with raising a child with autism. On one hand, the presence of a child with autism introduces added stress and pressure into the relationships of participants, as indicated by studies conducted by Hock et al. (2012) and Woodgate et al. (2008). This heightened strain is recognised to potentially contribute to an increased likelihood of divorce, as observed in the findings reported by Hartley et al. (2010). Also, the impact extends to lower levels of marital satisfaction, as evidenced by studies conducted by Lee (2009) and Shtayermman (2013), along with diminished levels of marital intimacy, as highlighted in the work of Fisman et al. (1989), and reduced levels of overall marital happiness, as suggested by the research of Higgins et al. (2005). These findings collectively underscore the significant challenges that having a child with autism can pose to the well-being and stability of marital relationships. The mothers in the study by Papadopoulos (2021) indicated that autism changed their relationship with their spouse. These participants expressed an affecting sense of neglect towards the needs of their spouses, resulting in emotional distance within the marital relationship. The revelation of a disparity in their spouse's behaviour after the autism diagnosis was a common theme, with some characterising their partners as becoming more aggressive and emotionally distant. One participant explicitly noted an escalation in conflicts, which eventually culminated in divorce. The mothers and fathers in a study by Hirsch and Paquin (2019) agreed to the negative effect of autism on their relationship and found three different effects of autism on their relationship which included not enough alone time, not enough intimacy and frequent conflict. On the one hand, these first-hand accounts highlight the profound impact that raising a child with autism can have on the dynamics of spousal relationships, underscoring the complex interplay of emotions and challenges faced by couples in such circumstances. On the other hand, having a child with autism can also enrich or strengthen a relationship (Blair et al., 1996; Myers et al., 2009). Hock et al. (2012) reported that if parents adapt to living with a child with autism, they can find deeper intimacy and greater commitment.

### ***Experiences of Siblings***

A study by Watson et al. (2021) integrated the experience of siblings of a child with autism. The research indicated that the presence of a sibling diagnosed with ASD exerts a multifaceted influence on the personal development of the typically developing sibling. This encompasses an enhancement in both empathy and comprehension, as well as an advancement in coping mechanisms. Numerous siblings have reported assuming responsibilities that surpass the expectations for their developmental age and phase. They have also expressed apprehensions concerning both their future and that of their sibling with autism. Interactions with their autistic sibling have yielded a spectrum of experiences: on the positive side, there is a sense of pride and companionship, yet on the negative, they have encountered challenges such as managing problematic behaviours and navigating feelings of embarrassment, anger, social isolation, and fear. For some, their sibling with autism affected their social life as they were subject to disapproving comments from others, however, others were grateful for support offered by friends and extended family. Mothers in the study by Papadopoulos (2021) indicated that having a child with autism influenced their relationship with their other children as their child with autism demanded more of their time and were therefore less able to spend time with their typically developing children.

### ***Experiences of the Grandparents***

A study by Hillman et al. (2017) identified four themes in the relationship between the grandparents and the child with autism. Firstly, the grandparents had a desire to connect with their grandchildren. They longed for physical affection and admitted that the presence or absence of verbal communication presented both challenges and joys. Inappropriate autism behaviour resulted in a barrier to connect. Despite these difficulties they shared an intrinsic bond with their grandchildren. Secondly, grandparents experienced obstacles to their grandchild's care such as the family's denial of their diagnosis, living far, or financial challenges and poor systemic support (e.g., from paediatricians and schools). Thirdly, these grandparents celebrated all progress: effort by the parents and grandchild and developmental milestones. Lastly, they admitted that autism affects everyone, and they experienced emotions of concern, despair, extreme highs and lows. They also advocated resilience through advocacy. A study by Prendeville and Kinsella (2019) explored the role of grandparents in supporting families of children with ASD. All the grandparents' roles changed to meet the needs of the child with ASD. Although they experienced social isolation, they played a strengthening role in the family systems. In all eight families, the role of the grandfathers was overwhelmingly positive.

The first part of this chapter discussed various treatment options available to individuals diagnosed with ASD. Yet, the first-hand accounts by family members in this part highlight the profound impact that raising a child with autism can have on the dynamics of spousal relationships, underscoring the complex interplay of emotions and challenges faced by couples in such circumstances. These recollections confirm (a) the manifold challenges families face when raising a child with autism, (b) the systemic effect of autism, (i.e., that autism affects the entire family as a system) and (c) the need for family-focused therapy. Still, the reviewed studies points to a lack in knowledge on ASD research in at least two respects. Firstly. Despite numerous studies on the treatment of ASD, interventions continue to focus primarily on the individual diagnosed with ASD, failing to recognise how the individual's diagnosis of ASD influences both the parental and the sibling subsystems (Parker & Molteni, 2017). Secondly. The second part of this chapter summarises recollections from individual family members' experiences. These studies do not consider the collective experiences of the family as a unit. Chapter 3 will motivate the use FST as theoretical underpinning for this and other studies that explore family system interventions for families raising a child with autism for the simple reason that the dynamic nature of the disorder cannot really be understood in isolation. This study consequently propose that family-focused therapy which adopts a holistic approach will prove useful to examine all inherent family relationships and subsystems.

## A Need for Family-Systems Interventions to help Families Raising a Child with Autism make Sense of their Experiences

In the reviewed studies, the need of parents to make sense of their experiences of raising a child with autism runs like a golden thread. The mothers went through an information-seeking phase to make sense of autism. The fathers experienced frustration, guilt and embarrassment but eventually felt a sense of acceptance. The diagnosis provided an understanding, although it was difficult to process. Information on autism allowed the fathers a sense of control over their circumstances. These participants expressed an affecting sense of neglect towards the needs of their spouses, resulting in emotional distance within the marital relationship.

Cantarero et al. (2019) describes how people inherently have a need for meaning, similar to Chater and Loewenstein (2016, p. 138), who argue that an individual's behaviour is driven by the need to 'construe our lives in a way that makes sense (sense-making)'. Sense-making is therefore a central aspect of human behaviour (Weick et al., 2005). People tend to find comfort or come to grips with complex situations or events in their lives, through the process of sense-making. Through sense-making, people turn circumstances into situations that are understood explicitly in words and that serve as catalyst for action.  That is because sense-making serves as the space in which meanings develop that inform and constrain identity and action (Weick et al., 2005).

Family therapy can be defined as a formal, psychotherapeutic intervention, which seeks to understand and enhance relationships, communication, and functioning between members of a family (Dallos & Draper, 2005). While there are several types of family therapy, they are predominantly underpinned by systemic theories and share central tenets (Hayes, 1991).

Few empirical family therapy studies have been conducted about children diagnosed with ASD and their families (Goepfert et al., 2015). Despite the lack of a rigorous evidence base, families with ASD can benefit from family therapy or from care informed by FST. Although family therapy cannot alter ASD or eliminate its presence, it may improve relationships and the strength of the system living with ASD. Family therapy can repair and strengthen relationships, and can help family members to better collaborate with one another and providers in supporting the child, thus positively affecting child outcomes (Goepfert et al., 2015). The effectiveness of family-systems interventions. Given the multifactorial nature of the aetiology of ASCs it is suggested that systemic interventions have the potential to influence changes at multiple levels of functioning for the child and the family (Helps, 2016).

Clinical approaches like the psychodynamic school of thought (Stolorow et al. 1994), humanistic psychology (Hermans & Hermans-Jansen, 2001) and narrative inquiry (Santos et al., 2009) all share a meta-theoretical perspective that views psychotherapy as an intersubjective dynamics of sense-making aimed at changing the individual's way of interpreting his or her experience (Gennaro et al., 2010). In this type of psychotherapy process the exchange between therapist and client is a 'transformative dialogue' (Gergen, 1999, p. 250), where new meanings are constructed through narrative (Christopher & Bickhard, 2007).

## Narrative Therapy as a Sense-Making Family-Systems Intervention

A narrative can be defined as an organised interpretation of a sequence of events (Murray, 2003). Philosophers such as Sartre, Ricoeur and MacIntyre proposed that the way in which humans narratively make sense of their lives also determine how they navigate the future (Andersen et al., 2020). Therefore, it is through narrative that we bring a sense of order to the seeming disorder in our world (Murray, 2003). Philosophically, this idea is rooted in the notion that life and stories imitate each other in the same way that life imitates art and art imitates life in the Aristotelian sense (Bruner, 1987).

The idea that meaning is derived from the stories we tell and hear about our lives, drew the attention of family therapists Michael White and David Epston in the 1980s. Both White and Epston were followers of anthropologist Gregory Bateson (1972), who is considered the pioneer of FST and whose epistemology meant the rules one uses to make sense of the world (Minuchin, 1985). Working in collaboration, White and Epston (1990, 1992) found that the 'story analogy' offered a useful direction for their work which developed into what is now known as narrative therapy. Narrative therapy as a form of psychotherapy, is a postmodern, flexible, and individualised approach that is used to help people who present with problem-saturated narratives by focusing on the individual construction of meaning (Cashin et al., 2013; Erbes et al., 2014). Initially, narrative therapy has been proposed as a treatment approach for working with survivors of trauma (White, 2004, 2005).

In developing narrative therapy, both White and Epston clearly stated that they were influenced by the philosophical ideas of French theorist Michael Foucault (1980, 1985), and specifically his ideas around knowledge and power. Narrative therapy is therefore situated in the social constructionist, postmodern, poststructuralist discourses that challenges structuralist or modernist theories about the 'true self' and identity, humanism, and traditional psychological and counselling discourses (Besley, 2002). Through his examination of the concepts of madness (1965), illness (1975), criminality (1977), and sexuality (1985), Foucault studied the various ways in which Western society has depicted people within certain marginalised societies as the 'other' by labelling these individuals as 'insane', 'sick', 'criminal', or 'perverted' (Freedman & Combs, 2002).[2] According to Foucault, the power that people hold in society is directly proportionate to their ability to drive and engage in the dominant discourse that shapes society (Freedman & Combs, 2002). In the modernist, structuralist society this discourse was the idea of a 'true self': that there is a core set of structural beliefs that 'drive' our sense of self and lies beneath all our actions and experiences. In other words, beneath all the complex layers of our daily lives, there is a consistent, unchanging essence that makes us who we are (Walther & Carey, 2009). The postmodernist discourse questions these principles, including the idea of the 'true self', and the idea that there is a single, unifying truth or identity beneath the complexities of life. Instead, postmodernism suggests that identity is not fixed or singular but rather fragmented and constructed through our social relationships and through the stories that we tell, and that are told, about who we are. It is in our social and relational contexts that these stories take shape. It is when events are linked together over time according to a plot or theme, that we constantly arrive at meaning (Walther & Carey, 2009).

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[2] It is for this precise reason to avoid labelling that this study does not refer to children diagnosed with autism as 'autistic', but rather as 'children with autism'.

Poststructuralism's questioning of modernism's view of identity and the 'true self' holds implications for the idea of the nature of knowledge, how knowledge is created, and who the creators of knowledge are. This explains why therapists using White and Epston's narrative metaphor experienced a large shift in their worldview (Freedman & Combs, 2002). Narrative therapy challenges the idea that expert knowledge belongs to the world of therapists and the medical model. It furthermore challenges the truths and alleged objectivity of these disciplines (Weber et al., 2006). Instead, it takes up the ethic of collaboration and engaging in the practice of what Epston (1999) calls 'co-research'. Instead of merely solving a problem, the narrative therapists started collaborating with people to change their lives, by enriching the narratives these people and others tell about their lives.

In narrative therapy, a central belief is that the family understand their own system and have a range of resources and skills that can be harnessed to create a system of problem-solvers (Baum, 2007). The narrative approach values externalising conversations as it does not locate problems within people (Swart, 2013). Externalising conversations makes it possible for people to separate their sense of identity from problem-saturated accounts of who they are to rich descriptions of alternative accounts of their lives, relationships and identities (White, 2000). This manner of engaging in questions invite storytellers to experience themselves as agents in this world. Storytellers are able to speak in a powerful way about their narrative and identity as they realise how their narratives are constructed, how they influence their lives and how they are informed by other ideas and beliefs (Swart, 2013).

Narrative therapy has a long been applied to a range of mental health conditions (Monteiro, 2021), for example in the treatment of individuals with PTSD (Erbes et al., 2014), eating disorders (Weber et al., 2006) and major depressive symptoms (Vromans & Schweitzer, 2011). In their research, Rajaei and Jensen (2020) encourage the use of narrative therapy as an empowering, non-pathologising approach for medical family therapists and health practitioners to better help patients and families. The authors point out that being mindful of patients from different backgrounds do not only help family therapists provide more effective treatment, but also facilitate patients to be able to richly describe and meaningfully experience their new empowering stories.

In general, the use of narrative therapy in contexts other than ASD proved to be positive. However, there seems to be fewer studied applications of narrative therapy in the context of ASD (Goepfert et al., 2015). Of these, studies by both Cashin (2008) and Tilsen et al. (2005) found the externalisation techniques in narrative therapy to be helpful in treating adolescents with Asperger's disorder. In another study by Cashin et al. (2013) the authors examined if narrative therapy can help young people with autism overcome their emotional and behavioural problems. Young people with autism often present with problem-saturated narratives that are accompanied by anxiety, depression and an expectation to perform without the knowledge of how to do so. The authors found narrative therapy to significantly improve psychological distress for these individuals. The use of narrative therapy in the general context of ASD therefore seems promising.

There are few empirical studies exploring the possibilities of narrative therapy as a systems intervention for families raising a child with autism. Studies by both Chao and Chen (2023) and Olinger (2010) introduced the narrative idea of outsider-witness groups to parents of children diagnosed with ASD. Both studies indicated to be effective as the participants were able to shift their perspectives, leading to self-redefinition. More specifically, Chao and Chen's (2023) findings indicated that, after including outsider witnesses, the participants (1) became aware of past narrow perspectives, (2) recalled forgotten details, (3) redefined people, events, and objects in their lives, and (4) redefined their self-identities. In a study on Chinese families of children with ASD, Gao et al. (2023) found that narrative therapy helped generate resilience in these families by (1) cultivating positive family beliefs, adjusting the family's organisational pattern, positively extending external resources, and optimising family communication. Solomon and Chung (2021) studied how family therapists can use narratives to help parents of children with autism create meaning. In a non-empirical study, Romney and Jones (2020) explored the use of narrative therapy by marriage and family therapists who are uniquely positioned to work with families of children with autism, but who find it difficult and outside their scope of work to do so. The authors explored how these therapists, in this role, can use narrative therapy to help these families in at least three ways: firstly, to co-construct a new story which would promote family unity; secondly, to externalise the effects of raising a child and helping the families find meaning and highlighting the positives; and thirdly to help these families author their own lives. This means that in contrast with normal therapy where the client is surrounded by experts telling them what to do, in narrative therapy, the client, and not the therapist is seen as the expert on the family's problems or stories (Suddeath et al., 2017).

Family therapists need updated information on autism and how family therapy can help parents of children with autism. Where narrative therapy has been used in various contexts the feedback has been positive, but there are few studied applications of narrative therapy in the context of ASD. More specifically, there is a need for more empirical evidence to explore the possibilities of using narrative inquiry as a sense-making tool for parents raising a child with autism (Goepfert et al., 2015; Romney & Jones, 2020; Sutherland et al., 2023).

## Conclusion

By describing the unique characteristics of autism, this chapter argued that autism's systemic effects affect not only the individual with the disorder, but the entire family as a system. These effects are visible through the countless recollections of family members who have shared their experiences of raising a child with autism. But to date, these studies have mainly captured the experiences of a particular family member, and not that of the collective. To support families raising a child with autism, family-focused therapy that adopts a holistic approach is proposed to examine all inherent family relationships and subsystems. A review of studies confirmed how family members expressed a need for making sense of their experiences. The final section of this chapter reviewed the possibility of using narrative therapy as such a sense-making tool.

Chapter 3 motivates the use of FST as theoretical foundation together with narrative inquiry to create a framework that can be used by health care professionals to help parents raising a child with autism make sense of their experiences. Central to narrative research is a focus on the role of narratives as a sense-making tool with the capacity to produce, challenge and change the identities of individuals as well as collectives (Holstein & Gubrium, 2012; Kerby, 1991). Such studies often use interviews to examine how people construct identities through storytelling (Presser, 2004).

# CHAPTER III. Research Paradigm and Theoretical Framework

The previous chapter argued that the systemic effect of autism creates a need for a family-focused therapy to help families raising a child with autism make sense of their experiences. It follows that the philosophical underpinnings of research where the family is the unit of analysis, as is the case in this study, should align with a family systems paradigm. In the previous chapter it was established that despite there being several types of family therapy, all of these are underpinned by the principles within systems theory. Over the course of nearly a century, various developments in psychology, communications and psychotherapy influenced developments in systems theory and therapy, with Dallos and Draper (2005) roughly grouping these developments into four phases. Both narrative therapy and FST are situated in social constructionism, which belongs to the third phase of systems theory and therapy: the period from the mid-1980s to 2000. In this chapter it will be argued why a narrative inquiry, which was selected as research design for this study and which will be elaborated on in Chapter 4, will follow suit.

This chapter is divided into four sections. The first section will define and expand on narrative inquiry in terms of its general principles. The second section will analyse narrative inquiry in terms of ontology and epistemology to position it within a social constructionist paradigm. The third section will argue for family-focused research approach grounded in FST to explore the experiences of families raising children with autism and help them make sense of these experiences. This argument is based on the principles of FST, which are discussed in the fourth section.

## Narrative inquiry

This subsection defines and looks at the purpose of a narrative inquiry; the process of narrative in research; how meaning is created through a narrative inquiry; and the functions of the different role players in a narrative inquiry (the researcher, participants, and readers of the narrative).

### Definition of a Narrative Inquiry

Narrative inquiry, as a social construction, is concerned with making sense in an ever-changing world. It is through narrative that we bring a sense of order to the seeming disorder in our world. A narrative can be defined as an organised interpretation of a sequence of events. This aim is achieved by attributing agency to the characters in the narrative and drawing causal links between the events. Narrative accounts are shaped by a specific social context (Murray, 2003).

### The Purpose of a Narrative Inquiry

Narrative inquiry aims to understand knowledge gained from the individual's narrative of their experiences and explores experiences through the dimensions of temporality, sociality and spatiality. These dimensions provide an exploratory structure for narratives surrounding autism and its impact on relationships (Haydon & Van Der Riet, 2017). For its exploratory purposes, narrative inquiry obliges the inquirer to get as close as possible to the subjectivities of participants' lived experiences and to stay 'attentive to the intersubjective, relational, embedded spaces' (Clandinin, 2013, p. 24).

### The Narrative Process in Research

In the narrative process the reader 'reads' the narrative authored by the author in relation to the author within a specific context. However, the narrative also 'reads' the reader in that the narrative impacts on the reader and allows the reader to reflect on their own life. This implies that the reader of a narrative is not only professionally involved in reading the narrative (as a researcher) (Freedman & Combs, 1996; Kelly & Howie, 2007), but also autobiographically (as a person) in that the reader needs to be willing to be personally influenced through the reading of a narrative (Lindsay, 2006). In this sense narratives have their own unique way of generalising themselves, since a narrative has the potential to influence the life of each 'open' reader.

Kearney (2002) states that the narrative, seen as a created reality emerging from the interplay between author and reader, is characterised by the elements of plot (mythos), re-creation (mimesis), release (catharsis), wisdom (phronesis) and ethics (ethos).

A narrative is characterised by a plot (mythos), created by the author, in relation to the reader, selecting experiences from the author's life. These experiences are sequenced into a coherent whole. The order in which the experiences are sequenced is determined by the purpose of the narrative (Kearney, 2002; Murray, 2008). A narrative is a re-creation (mimesis), through the interplay between 'history-future' on the one hand; and 'person-context' on the other hand. A narrative is neither seen as a 're-flection' of 'history-future' nor as a 're-flection' of 'person-context' (Kearney, 2002; Sclater, 2003).

A narrative has the possibility of establishing release (catharsis), in that creating a plot (mythos) through narrative, as well as narrative being a re-creation (mimesis) of 'history-future' and 'person-context', people can move from being bodily beings (zoe) to becoming human beings (bios). A narrative is characterised by the development of wisdom (phronesis), whereby the author can create practical wisdom to live their life, thereby empowering the author and reader of the narrative, while deconstructing academic knowledge as privileged knowledge.

A narrative also focuses on ethics (ethos), which allows bodily beings (zoe) to become human beings (bios) through narrative. This process implies creating plots (mythos) through narrative; treating narratives as re-creations (mimesis); establishing the possibility for release (catharsis) and creating practical wisdom (phronesis) through narrative (Kearney, 2002).

People live-in-the-world (cosmos) as bodily beings (zoe) and are confronted on a moment-to-moment basis with a variety of random experiences. By sequencing these experiences through narrative they create order out of disorder and become human beings (bios) (Kearney, 2002; Lindsay, 2006).

## The Creation of Meaning through a Narrative Inquiry

There are many ways through which meaning is created in a narrative inquiry: rich descriptions, co-journeyors, taken-for-granted-beliefs, unique outcomes, externalising conversations and narrative and identity formation.

### *Rich Descriptions*

Stories, ideas or beliefs that are transmitted through cultural and societal channels may exhibit varying degrees of detail, ranging from rich to thin descriptions. Thin descriptions of our stories are powerful as they lead us to belief that they are the truth and that their effect on us is not up for questioning. Rich descriptions of our stories or ideas include their history, influence and power and open possibilities of being questioned. Rich descriptions allow for the possibility of choice, the identification of the absent but implicit, for meaning making, uniqueness and actions of individuals that include one another (Swart, 2013; White, 2000). This study allows parents to richly describe, through storytelling, their experience of living with a child with autism in their families.

### *Co-Journeyers*

The narrative approach acknowledges human beings as being experts in their life and the stories they tell. The role of the practitioner or researcher is to create a space for the individuals to bring their wisdom (explained as phronesis above) and knowledge to the table. The role of the practitioner or researcher is to come alongside individuals with curiosity, respect and transformational questions to allow for possibilities to be opened. The individuals (the participants in this study) are given a voice as experts in their life (Swart, 2013).

### *Taken-for-Granted-Beliefs*

Taken-for-granted beliefs are ideas in society and cultures we grow up with and people in positions of authority tell us that they are a fixed reality, the way things are. These ideas become the lens through which we see life and our own identities (Swart, 2013). Taken-for-granted ideas create problem-saturated stories because they measure individuals against the ‘normal’ other - but it never really exists. Internalised conversations become the way people compare and judge themselves. Contrary to this taken-for-granted-beliefs, narrative practitioners strive to move into a reflective space where knowledges, expertise and wisdom can be shared without judgement. It is this shift from the isolation of the problem to a community of co-journeyers who are now authorised to engage with the alternative preferred story (Swart, 2013).

### ***Unique Outcomes***

Unique outcomes are the unpacking of the dominant problem narrative (the problem-saturated story) that unveiling latent insights which are the seeds of the alternative narrative (the new narrative). An alternative narrative can be a thinly described story or a story that has gone unnoticed that is being unpacked and thickened. Unique outcomes speak of the not-yet-told stories, the different kinds of knowledges (Swart, 2013). According to White and Epston (1990), the construction of change occurs from the expansion of unique outcomes. The research process can draw upon the power of unique outcomes to create opportunities to facilitate conversations, recruit lived experiences and examine alternative stories.

### ***Externalising Conversations***

The narrative approach places a premium on externalising conversations, recognising them as a methodology wherein transformative dialogue emerges from a linguistic shift. Since problems are linguistically constructed, it is through a modification in language that the narrative of the problem is reconfigured. This technique facilitates a detachment from the prevailing problem narrative by refraining from attributing issues directly to individuals (Swart, 2013). Externalising conversations enable individuals to separate their sense of identity from narratives that are oversaturated with problems, guiding them towards rich descriptions of alternative accounts of their lives, relationships, and identities (White, 2000). Externalising conversations counteracts the effects of labelling, it reduces guilt and blame, it enables people to work together and it allows for the development of the alternative story to emerge (Swart, 2013).

Narrative is fluid, not fixed, as narrative (and identity) is subject to change. Although narrative work identifies problems, it aims to recognise the relationship between the person and the problem in its cause in the surrounding context. Narrative practitioners or researchers speak in ways to not locate the problem in the person but as separate from the storytellers (the participants) (Swart, 2013). I was cognisant of the manner in which I spoke about autism throughout the interviews with the participants.

This approach to inquiry encourages storytellers to perceive themselves as active participants within the world. It empowers storytellers to articulate their narratives and identities with conviction as they gain insight into the construction of their stories, understand their impact on personal lives, and recognise the influence of external ideas and beliefs (Swart, 2013).

In this study autism is externalised to allow for the construction of the participants' narratives in a meaningful way. The externalisation of autism was established early on in conversations with the participants. It was evident early on how the participants constructed autism as the problem and explaining the narrative principle of 'the problem is the problem' to them allowed them a different lens with possibilities. This allowed us to speak in ways to not locate the problem in the person but as separate from the participants (Swart, 2013).

### ***Narrative and Identity Formation***

Central to the exploration of self and identity within the psychological domain, narrative identity represents the complex interplay of memory, experience, and aspiration. Narrative identity constitutes an individual's internalised and continuously developing life narrative, which the individual constructs to rationalise their evolution into the person they are in the process of becoming. Integrating the selective reconstruction of the past with an imagined future, narrative identity provides human lives with a sense of unity, moral purpose and temporal coherence (McAdams, 2019; McAdams & McLean, 2013).

Narrative conversations allow individuals the ability to evaluate past ideas or beliefs connected to their personal identity and for empowering future opportunities of change.

In this study the rich accounts over the period of four years hoped to facilitate the development of identities. Reflective meaning making has the potential to facilitate personal growth and transformation. Equally important is that experiences provide opportunities for the development of self-understanding and personal growth (McLean, 2008).

### The Functions of Role Players in a Narrative Inquiry

The relationship between the author and the reader of a narrative is one of critical collaboration, allowing both author and reader to be agents of the research process (Lindsay, 2006; Terre Blanche et al., 2006). On the one hand, both author and reader contribute to the emerging narrative, while on the other hand both author and reader are encouraged to embrace a curious stance towards the narrative reality that is being shaped in the author-reader interplay. The positions of author and reader should not be seen as mechanistic in nature, but rather as organic as these two positions are interchangeable, where author becomes reader and vice versa. Furthermore, through the emergence of a narrative in the author-reader interplay, knowledge is created (Gergen, 1985). In this narrative process the author “authors” a narrative in relation to the reader of the narrative within a specific context. However, the authored narrative “authors” the author of the narrative, in that it shapes the life of the author. This is summarised in the words of Andrews (2000, pp. 77–78):

> Stories are not only the way in which we come to ascribe significance to experiences … they are one of the primary means through which we constitute our very selves. We become who we are through telling stories about our lives and living the stories we tell.

## Research Paradigm: Social Constructionism

An analysis of narrative inquiry in terms of ontology and epistemology positions the research design within a social constructionist paradigm.

### *Ontology: Narrative Inquiry's Collaborative Construction of Reality*

In the same way that the aim of a narrative therapist is to not 'edit' the story of the client, but instead to assist the person to co-construct their reality through their own narratives – making the person the 'co-therapist' (Cashin et al., 2013) – the narrative researcher neither attempts to unearth a single 'truth' from the realities of participants nor tries to achieve outside verification of their analysis (Ponterotto, 2005). Therefore, in a narrative inquiry, there is no single, fixed reality, but instead, multiple, flexible realities which are (a) subjective and (b) collaboratively co-constructed. The realities are subjective because it is influenced by the context of the situation, namely the individual's experience and perceptions, the social environment, and the interaction between the individual and the researcher (Clandinin, 2013; Galbin, 2014; Lock & Strong, 2010; Nightingale & Cromby, 1999; Ponterotto, 2005). Moreover, the realities are collaboratively co-constructed through the meaning and experiences that are shared between the participants and the researcher. This relational experience forges a continuous linkage across time – past, present, and future (i.e. the idea of temporality) – situated in a particular social, cultural, and environmental context (Clandinin, 2013; Galbin, 2014; Lock & Strong, 2010; Nightingale & Cromby, 1999).

This view of reality evolved from a loss of faith in 'one true story' (read: reality) which was characteristic of the modernist mindset (Dallos & Draper, 2005). Therefore, with regard to ontology, narrative inquiry instead aligns with the beliefs of postmodernism and specifically social constructionism, namely the existence of multiple, constructed realities rather than a single true reality. Against meta-narratives, postmodernism sees the word full of contending smaller narratives where people make their narratives convincing in order to put their point of view across (Lyotard, cited in Ryan & Rivkin, 2004).

### *Epistemology: Narrative Inquiry’s Challenge of the Nature of Knowledge*

In the previous chapter it was posited that poststructuralism’s questioning of modernism’s view of identity and the ‘true self’ holds implications for who the creators of knowledge are, what the nature of knowledge is, how knowledge is created, and what the relationship is between the ‘knower’ (the research participant) and the ‘would-be knower’ (the researcher).

With regard to the creators of knowledge, narrative therapy (and narrative inquiry) challenges the idea that expert knowledge belongs to the world of therapists and the medical model (or the world of academic research and theoretical models) by challenging the truths and alleged objectivity of these disciplines (Weber et al., 2006). In narrative therapy, the person is positioned as an agent in the treatment from the beginning (Cashin et al., 2013). Together with the therapist or researcher the client and participant becomes ‘co-therapist’ and ‘co-researcher’ (Epston, 1999). In doing so, the individual is given the much needed voice that Foucault was advocating for in his writings on the power and knowledge and the marginalised in society (Freedman & Combs, 2002) through intense researcher–participant interaction and discourse that last up to three hours. Chapter 4 will describe how in this study, intense researcher–participant interaction and discourse involved five, three-hour sessions with each of three couples.

With regard to the nature of knowledge and how it is created, narratives that are shared during a narrative inquiry are not repositories of pre-existing meanings waiting to be uncovered. Instead, the postmodern, social constructionist view sees knowledge as generated within communities of the ‘knowers’ (participants) and the ‘would-be knowers’ through the sharing of narratives (Freedman & Combs, 1996).

With regard to the relationship between the ‘knower’ (the research participant) and the ‘would-be knower’ (the researcher), narrative researchers situate themselves in their work, use open-ended questions during interviews, and develop close relationships with participants, allowing the participants to explain their experiences in great detail.

This view of knowledge aligns narrative inquiry with a social constructionist epistemology. Modern positivists views emphasised objectivism (minimising bias by the researcher), independence of the researcher and participant, the use of rigorous, standard procedures, and the replication of findings to arrive at a universal truth or knowledge that can be generalised (Ponterotto, 2005). In contrast, social construcionists advocate a transactional, subjective approach to knowledge creation where reality is socially constructed and the dynamic interaction between the researcher and the participant is central in capturing the experience of the participant (Ponterotto, 2005). Instead of prioritising empirical facts and universal rules that can be generalised, social constructionists privilege the particularities of specific, contextualised details by concentrating on the nuances of meaning, with the findings inevitably influenced by their own perspectives and values (Butler-Kisber, 2010; Freedman & Combs, 1996; Ponterotto, 2005).

The paradigmatic analysis positions narrative inquiry within a social constructionist paradigm, a paradigm which re-evaluated humanism and traditional psychological and counselling discourses to address issues of meaning, subjectivity, power and ethics (reference).

## A Case for Family-Focused Therapy Grounded in Family Systems Theory

Family-focused research on autism is critical for understanding the impact of these disorders and informing clinical support services for these families (Cridland et al., 2013). Despite increased research interest in the field, the field is still considered relatively recent with limitations abound. Furthermore, the field lacks a common theoretical framework.

Several limitations were found in current studies exploring the experiences of families raising a child with autism. Many of these are mainly recollections from individual family members (for example, Manono and Clasquin-Johnson (2010) studying the dynamics between mothers and their children with autism). Furthermore, the types of research design often overlook the complexity of the underlying family system (for example, the survey by Higgins et al. (2005) examined the relationship between ASD characteristics, family functioning and coping strategies using only certain predefined variables). There is also minimal understanding on the ways in which family members support each other (for example, Seligman and Darling's (2007) study results showing that mothers and fathers differ in the types of support they provide for their families). Despite some studies highlighting the contributions of extended family members' support (Blackledge & Hayes, 2006), research in this regard remains limited. There is also a lack of report on the positive impact of ASD on families like those provided by Blair et al. (1996) and Myers et al. (2009), and limited research on the impact of neurotypically developing siblings, such as the one by Watson et al. (2021).

There is also a lack of common theoretical framework in current family-focused research on autism. In Cridland et al.'s (2013) review, Cox and Paley (1997) and Klein and White (1996) found no single systems theory about families but instead various family systems (FS) approaches based on the scope of their focus (Cridland et al., 2013). Having a common theoretical framework holds several advantages. It improves the communication of findings, it ensures that research methodologies are grounded in theoretically sound concepts. A greater synthesis of individual studies' results will also make the detection of emerging patterns more apparent (Siegel, 1988; Swanson, 1988; Waterhouse, 2009).

Chapter 2 argued that the systemic effect of autism creates a need for a family-focused therapy such as narrative therapy to help families raising a child with autism, make sense of their experiences. In the first section of this chapter, the research design selected for this study, narrative inquiry, was presented as also being situated in a social constructionist paradigm. It has furthermore been stated that narrative therapy was to a large degree informed by the writings of the pioneer of family systems theory Gregory Bateson, for whom epistemology meant 'the rules one uses for making sense of the world' (Hoffman, 1985). The sections that follow will argue for a family-focused research approach grounded in FST to explore the experiences of families raising children with autism and help them make sense of these experiences, based on the principles of FST.

Priest (2021, p. 5) defines family systems theory as ‘a theory that predicts and explains how people within a family system interact and how interactions inside the family system are different from those outside of it’. Bavelas and Segal (1982, p. 90) explain a system as ‘a set of objects with relationships between the objects and their attributes’, to which Wright and Leahey (2005) agrees. A family is therefore seen as a small group of interrelated and interdependent individuals, which, through their relationships with one another, makes up the family system (Wright & Leahey, 2005). Owing to the inherent interrelatedness and interdependency within a family system, an event or condition impacting one member invariably resonates through the entire unit (Minuchin, 1985).

To find testable hypothesis of family systems can be overwhelming (Priest, 2021). The author cites Carr’s (2016) listed proposals for FST stating that:

- a family is a social system that supports the welfare of its members;
- the family system has boundaries and is organised in subsystems;
- the boundary around a family separates it from the broader social and cultural systems;
- patterns of family interaction are governed by rules;
- patterns in family relationships can be described in terms of family roles, routines and rituals;
- there are processes that prevent and promote change within a family; and
- patterns that exist in one part of the system also exist in other parts of the system.

Kerr and Bowen (1988), as cited in Priest (2021), suggests that a family system is governed by three other systems:

- *The emotional system*: A natural system that allows all organisms to receive, integrate and respond to information within itself and from the environment.
- *The feeling system*: A system in which humans experience different emotions.

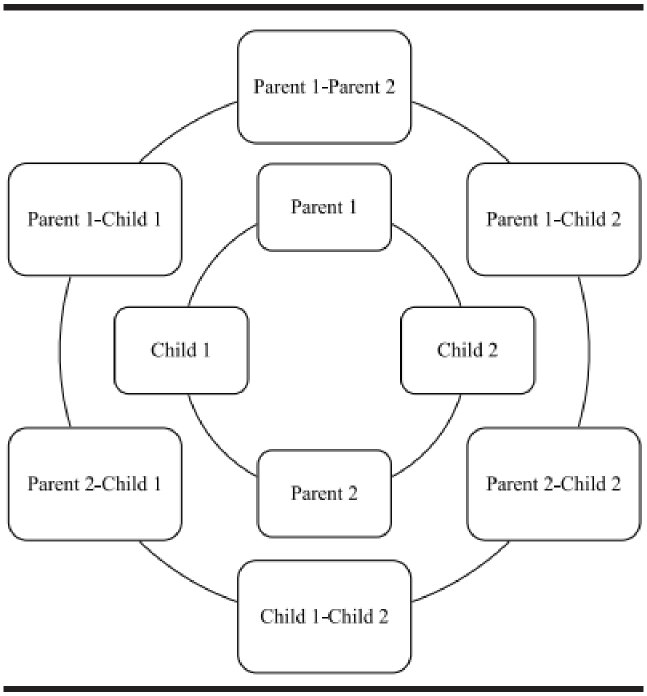
- *The intellectual system*: A system that allows humans to have the capacity to know and understand.

Family systems theory is non-pathology-orientated and focuses on identifying and interrupting repeating sequences of behavioural exchanges. The problem behaviour diminishes when the problem-saturated patterns are successfully addressed. Family systems theory posits that the contextual environment is imperative for attributing significance to behavioural interactions, thus elucidating the character of relational dynamics within the family (Johnson & Ray, 2016). The recurrence of interactional patterns within familial relationships, established over a duration, encapsulates the quintessential nature of a family system (Bavelas & Segal, 1982).

Figure 1 below depicts FST as an example of a nuclear family of four individuals. The inner circle demonstrates the interrelatedness and interdependency of everyone within the family system and the outer circle points to the dyadic relationships within the family system. Illustrations will vary depending on the family structure.

**Figure 1**

*Family Systems Theory as an Example of a Nuclear Family of Four Individuals*



Source: B. M. Wright and Benigno (2019, p.760)

## Principles of Family Systems Theory

Figure 1 on p.53 summarises FST as comprising the following principles: hierarchies and subsystems, holism, that a change in one family member affects all family members, and homeostasis.

### *Hierarchies and Subsystems*

In a hierarchy each higher-level unit consists of lower-level systems. A family system is part of a larger supra system which further comprises many subsystems (Wright & Leahey, 2005). These parts (or individuals) are connected (thus in relationship) with one another. Two or more interconnected family members can form a subsystem, for example sibling, parental or spousal subsystems. Each family member may also be part of a variety of different subsystems for example, a father is part of a parent-child subsystem as well as a husband-wife subsystem (Wright & Leahey, 2005). Relationships are affected by and have effects on other subsystems (e.g. parent-child, sibling-child) and the family as a unit (Minuchin, 1985). Having a child with autism is linked to outcomes for subsystems within the family unit, such as increased marital strain, poor parent-child relations, and adverse child-sibling relations (Tint & Weiss, 2016).

### *Holism*

Family systems theory advocates that the collective entity of the family transcends the mere aggregation of its individual members (Wright & Leahey, 2005). This theoretical perspective prioritises the family as an integrated whole, perceiving the constituent individuals primarily through their roles and interactions within this holistic framework (Bavelas & Segal, 1982; Pam, 1993). While dyadic-level processes or subsystem relationships (parent-child, marital) are important to consider, it is equally as important to recognise family-level processes as distinct proximal influences on individual outcomes

Evidence has consistently supported the notion that caring for an individual with ASD can have negative effects on members of the family and aspects of the family system as a whole. However, less is known about the opposite direction of effects: the influence of family processes on the outcomes of individuals with ASD (Greenlee et al., 2018).

### *A Change in One Family Member Affects all Family Members*

Family systems theory shifts from lineal causality (individual orientated theories) to circular causality where a family is seen as a mutually causative system. It aims at connecting the problem behaviour of one person with the surrounding behaviour of the other family members. Mutual influences create an interactional pattern. A sequence of interactions takes place between members of a family (Johnson & Ray, 2016; Pam, 1993). No individual member exists in isolation from another. Any meaningful change or event in one family member affects all the family members (Wright & Leahey, 2005). Siblings in a study by Watson et al. (2021) assumed responsibilities that surpassed the expectations for their developmental age and phase, while Hillman et al. (2017) reported on inappropriate autism behaviour which resulted in a barrier for grandparents to connect with their grandchildren.

### *Homeostasis*

A further crucial concept within FST is the capacity of a family to establish equilibrium between adaptability and constancy (Wright & Leahey, 2005). Systems can be understood in terms of feedback processes. Feedback is possible in an open system such as a family. Negative feedback aims to maintain stability (homeostasis) and to prevent change. Positive feedback will increase change over time (Bavelas & Segal, 1982). A family member’s response can either introduce change (positive feedback) or maintain the stability (negative feedback). The idea of a family continually striving to maintain homeostasis is being challenged as families are constantly changing and therefore unable to maintain a state of equilibrium (Wright & Leahey, 2005). The current study portrays how change in one individual in a family can affect the other individuals.

Systems require both autonomy and adaptation and the two also depend on each other. Family systems develop and maintain autonomy by allowing for rules and boundary-making processes that generate and maintain the family. These processes occur across time and remain relatively stable. The family is also an adaptable system as it responds to its environment (inside and outside of the system) by changing its rules and boundary-making processes. The disruption to the equilibrium in the family relationships are seen pre-diagnosis as Burrell et al. (2017) points out that the fathers in their study realised that something was wrong prior to the diagnosis of autism. The fathers experienced frustration, guilt and embarrassment but eventually felt a sense of acceptance. A restoration in the equilibrium are noted as some mothers in a study by Manono and Clasquin-Johnson (2023) found relief in finally understanding their child's condition. The aim of the adaptations is to help the family maintain autonomy (Priest, 2021).

Family systems theory incorporates principles from cybernetics, the science of regulation and information exchange in biological and mechanical systems, extending its focus to the realm of human interaction (Priest, 2021). Specifically, the theory emphasises second-order cybernetics, which acknowledges the researcher's influence within the system under study. This approach aligns with the methodological principles of narrative inquiry, which is cognisant of how the researcher’s perspectives and actions integrate with and influence the unfolding narrative (Johnson & Ray, 2016).

The family members of a child with autism are in relationship with one another. Subsystems are the interconnected relationships between the child with autism and the mother, the child with autism and the father, and the child with autism and the sibling. According to FST, a change in one family member affects all the family members. It can thus be understood that the diagnosis of a child with autism affects, not only the child with autism, but the family in its entirety. This aligns with the study by Papadopoulos (2021) which reported on the mother-child relationship that a child with autism demands more of a parent’s time and therefore leaves parents with less time to spend on their typically developing children. Hirsch and Paquin (2019) elaborated on the wife-husband relationship stating the negative effect of autism on the marital relationship and found that, as a result of autism, the husband and wife did not have enough alone time, not enough intimacy and frequent conflict. Families of children with autism are likely to face various adjustment periods over time to maintain its autonomy.

## Conclusion

Since narrative therapy as a family-systems intervention is grounded in FST, this chapter presented FST as the logic underlying theoretical framework for this study. Both FST and narrative inquiry are situated in social constructionism, which was presented as the choice of research paradigm for this study. Chapter 4 will elaborate on the use of narrative inquiry as research design and reflexive thematic analysis as the selected analytic tool to answer the research question of this study.

# CHAPTER IV. Research Design and Methodology

This chapter argues why this empirical, qualitative research study used a narrative inquiry as research design and reflexive thematic analysis as per Braun and Clarke (2020) to answer the research question stated in Chapter 1 of this study. It is divided into two main sections, the first elaborating on the research design, and the second detailing the research methodology.

## Research Design

### *Empirical Study*

In the research question: 'What are the possibilities of using narrative inquiry as a sense-making tool for parents raising a child with autism?' the unit of analysis is 'parents who are raising a child with autism'. Whenever the unit of analysis of a study is a real-life object which involves studying human behaviour (as is the case here), it means that one is dealing with empirical research (Mouton, 2013, p. 52). In contrast to non-empirical research which is suitable for studying abstract ideas, concepts, theories or methods, empirical questions address some real-life problem (Mouton, 2013, p. 52).

### *Primary Data*

To answer an empirical question, one must either collect new (primary) data or analyse existing (secondary) data from the real world (Mouton, 2013, p. 69). Primary data may give researchers more control over the data quality (Bryman, 2012) but is labour intensive and takes time to collect and analyse, which has cost implications (Javaid, 2024). But primary data leaves the researcher with unique and original insights that are directly related to the research question at hand. This may not be available from other existing sources (Bryman, 2012). For precisely this reason, this study opted to use primary data to answer the research question. In this study the primary sources were selected parents who are raising a child with autism.

### ***Qualitative Approach***

Some of the most common primary data collection methods include surveys, interviews, focus groups, observations, experiments, case studies and ethnography, but not all of these are appropriate for qualitative studies. In this study, the research question asks *what* are the possibilities, which is exploratory, and hence, qualitative in nature (Mouton, 2013, p. 52).

There are at least five reasons why a qualitative approach was appropriate for this study. First, the research question focuses on how people experience and make sense of a particular phenomenon over a period of time, which is exploratory, not explanatory, in nature (Angus & McLeod, 2004). Second, one of the purposes of the study is to understand how people create order out of disorder in their lives though creating a narrative reality (Murray, 2008). Third, in this research, literature is seen as a conversational partner, and not as objective truth that needs to be verified or falsified (Bakker et al., 2010). Fourth, in storytelling and narratives, various forms of material can be used, such as interviews, letters and pictures, through which the author-reader creates a narrative reality (Monk et al., 1997; White & Epston, 1990). And finally, the analysis focusses on the narrative as reality and how narrative identities are created in the narrative through the author-reader interplay with the aim of creating order out of disorder (Murray, 2008).

Instead of using numbers (as is the case in quantitative research), qualitative research uses words (Creswell, 2019, p. 380) as empirical material and starts from some basic theoretical assumptions where (a) the idea of reality is a social construct which is (b) created through the perspectives of participants in everyday practices using everyday knowledge and (c) these productive efforts are based on processes of meaning making (Flick, 2007).

Qualitative research makes sense of a social phenomenon by interpreting the meaning people make of their lives. A phenomenon is studied in its natural setting using the accounts of small groups. The researcher cannot be separated from the process. In qualitative research the analysis of the material establishes patterns or themes, and the written account includes the voices of the participants (Beck, 1993; Creswell, 2013; Payne & Payne, 2004).

This study explored individuals' experiences, behaviours, and the meanings they attribute to these experiences through a detailed and interpretive analysis which is grounded in the rich, contextual insights obtained from participants' narratives. It is about (a) how people experience and make sense of a particular phenomenon over a period of time (Angus & McLeod, 2004), and (b) how people create order out of their disordered lives by creating a narrative reality (Murray, 2008).

### ***Narrative Inquiry***

This subsection discusses the implications of using a narrative inquiry as a research design; and describes how a narrative inquiry was used in this study.

#### **The Implications of Using a Narrative Inquiry as a Research Design**

Narrative inquiry is one of the most common research designs used in qualitative research and refers to ‘a spoken or written text that gives an account of an event or action or series of events or actions, [that are] chronologically connected’ (Czarniawska, 2004, p. 17). It is a postmodern approach which opens up space for the client’s perspective to be heard (Johnson et al., 2019). Narrative inquiry allows the researcher an opportunity to explore ways in which humans experience the world (Connelly & Clandinin, 1990), and is concerned with making sense in an ever-changing world. It is through narrative that we bring a sense of order to the seeming disorder in our world (Murray, 2003).

Although the use of narrative inquiry in interventions with families raising a child with autism is not new (Parker & Molteni, 2017; Solomon & Chung, 2012), there is a need for more empirical evidence on the use of narrative inquiry as a tool for parents to make sense of their experiences of raising a child with autism (Romney & Jones, 2020; Sutherland et al., 2023). For that reason, I selected a narrative inquiry as the most appropriate research design to create knowledge that would answer the research question. By using narrative inquiry, it was possible to understand the underlying dynamics of the different subsystems in the family system, for example, father-mother, father-child with autism, siblings, etc. Through the personal recollections of parents who are raising a child with autism, I was able to collect rich, qualitative, primary data. Narrative inquiry as a sense-making tool therefore proved to be an appropriate research design to explore and describe parents' experiences raising a child with autism and to understand how families make sense of their experience from the moment of the diagnosis of autism and the years to follow.

#### The Use of Narrative Inquiry in this Study

With further reference to the study by Romney and Jones (2020), the current research study also applies narrative inquiry within the context of the family system. This study, however, expands on the findings by Romney and Jones by exploring how narrative assumptions can specifically aid the parents of children diagnosed with ASD, to make sense of their own experiences within the family. In the field of narrative inquiry, this research study provides valuable insights for families in the South African context. By facilitating the sense-making process of parents raising a child with autism, the researcher beliefs that a narrative inquiry may empower these parents to shift their perspectives and see their family in charge of authoring their story.

### ***Longitudinal Time Frame***

Stories happen over time and have a start, a middle and an end (De Shazer, 1991). To understand the stories (narratives) of parents raising a child with autism, I decided to use a longitudinal approach over a period of five years. Longitudinal studies are appropriate for qualitative studies that consist of repeated data collection focusing on the temporality (time and change) of a phenomenon (Audulv et al., 2022) while cross-sectional studies are appropriate for observational studies analysing data from a population at a single point in time (Wang & Cheng, 2020). Ployhart and Vandenberg (2010, p. 97) concluded longitudinal research as 'the study of change and containing at minimum three (more than three is better) repeated observations on at least one of the substantive constructs of interest'.

Audulv et al. (2022) explains qualitative longitudinal research as qualitative studies that consist of repeated data collection focusing on the temporality (time and change) of a phenomenon. Longitudinal narrative research builds on the foundation of this study that stories are told to organise experiences in a meaningful way, knowing that stories are not stable because meaning making is not static. The continuity and discontinuity of narratives present new opportunities for understanding how the past, present and future play a role in the constructing and deconstructing identity and the meaning people make of their experiences (McKibben & Breheny, 2023). Henderson, Holland, McGrellis, Sharpe and Thomson (2012) state that second interviews are fundamentally positioned in relationship to the first interview. Ryan, Rodriguez & Trevena (2016) began their second interview by briefly addressing the previous interview. This investigation required qualitative data from human participants through the documentation of verbal stories by parents. Reflections on previous interviews afforded both myself and participants the opportunity to position ourselves in the new narrative in relation to what happened before.

### *Reflexive Thematic Analysis*

Reflexive thematic analysis is a constructionist method of analysis which examines ways in which events, realities, meanings and experiences are the effects of discourses in society (Braun & Clarke, 2006). Social constructionism has specific implications with regards to reflexive thematic analysis. In addition to the reoccurrence of essential information, the construction of meaning plays a vital role in the development and interpretation of codes and themes. Therefore, themes that present themselves repeatedly, are on their own not necessarily meaningful to the analysis. It only becomes meaningful once the researcher has analysed the themes with the research question and the participants' responses in mind (Byrne, 2022). Braun and Clarke's reflexive thematic analysis is both descriptive and interpretative in nature (Braun & Clarke, 2022). These qualities correlated well with the narrative focus on the understanding and construction of personal stories in the meaning-making process. An illustration of the research design that was followed by this study is depicted in the diagram in Figure 2 on p.64.

## Research Methodology

The research was underpinned by a qualitative framework that sought to deeply understand individuals' experiences, behaviours, and the meanings they attribute to these experiences through a detailed and interpretive analysis. This methodological foundation facilitated a thorough exploration of the research questions, grounded in the rich, contextual insights gleaned from participants' narratives.

### *Participant Recruitment*

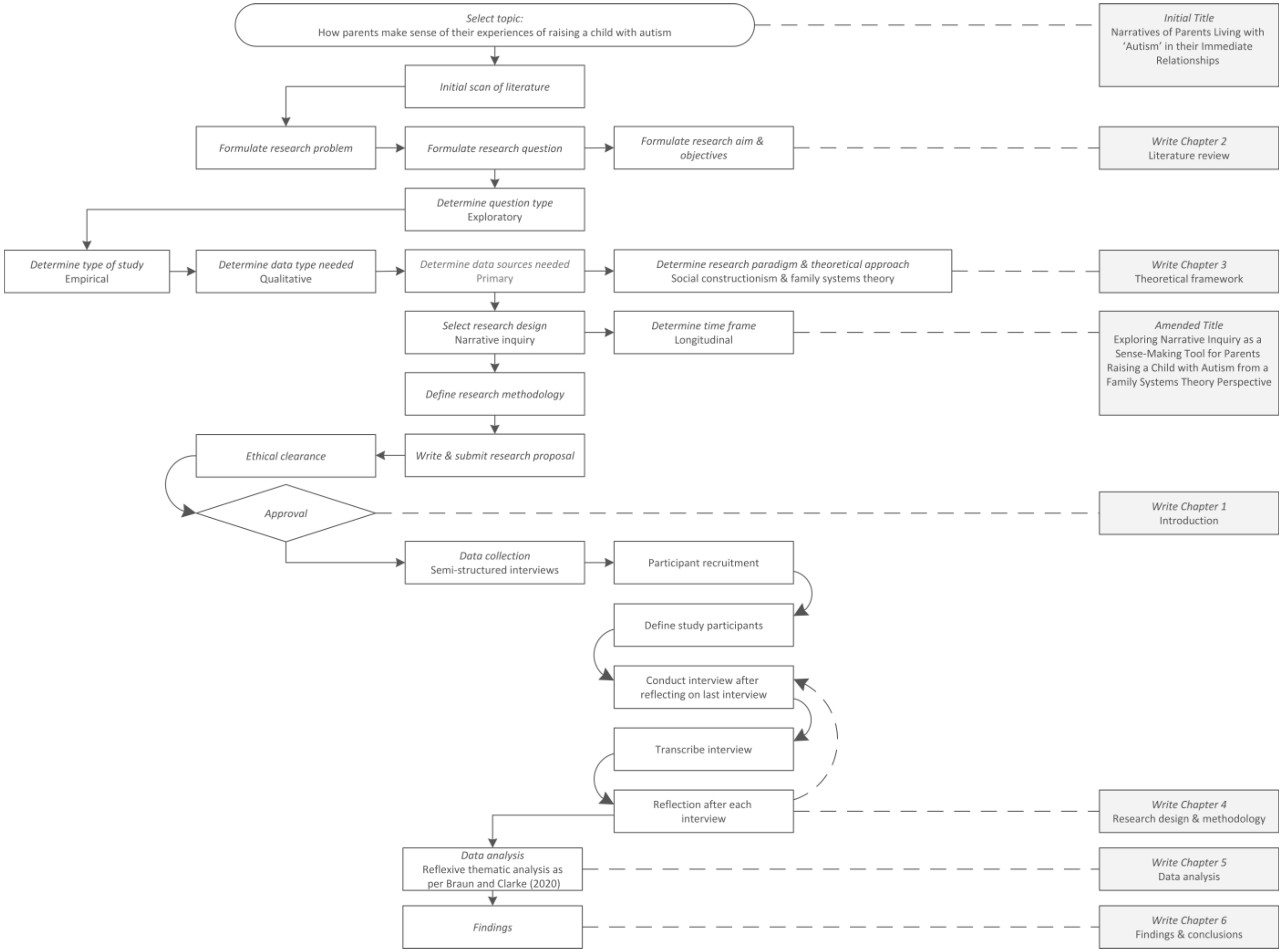
#### Participant Selection (Sampling)

Qualitative sampling practices focus on collecting material from a specific group or subgroup in the population (Golafshani, 2003). Because of the time-consuming and in-depth nature of the analytical process, qualitative research makes use of a small number of participants (Langdridge, 2007). This study used purposive convenience sampling. This sampling method aims to search for participants who fit the criteria set for the research project (Langdridge, 2007). Osborne (1994, p. 180) states "the researcher seeks out those who have experienced the phenomenon in question and can communicate their experiences". In this study, the research material comprised the narratives of three couples raising a child with autism.

I contacted all potential participants who requested more information on the study. However, some did not follow through or, because of personal reasons, decided not to partake in the study. As the study is grounded in meaning making, the sampling process had to be carefully considered. Because narrative inquiries aim at understanding the narrator's culture, identity and history, the emphasis is not on large sample sizes (Haydon & Van Der Riet, 2017). Instead, a narrative inquiry provides a rich, vibrant narrative presentation of findings which allows a deep understanding of the investigate phenomena

**Figure 2**

*Research Design Process Followed in this Study*



(Haydon & Van Der Riet, 2017; Josselson, 2006). According to Subedi (2021), narrative inquiry uses a small number of participants in comparison to other qualitative inquiry approaches. Subedi (2021) referenced a narrative study by Wise (2020) who chose to interview three participants. Similarly,

Thomas-Stark (2016) conducted a narrative study and interviewed only six participants. Saturation in qualitative research refers to the stage when data collection is thorough without any additional themes emerging (Naeem et al., 2024). Hennink and Kaiser (2022) describe the principle of data or thematic saturation as the point in data collection when more data may not lead to more information to achieve the research aim. In a homogeneous population the sample size could also be smaller (Hennink et al., 2017). In this study, the concept of saturation was carefully considered and achieved through the in-depth exploration of rich personal accounts, aligning with the narrative approach's emphasis on detailed, individual experiences. Data saturation was determined as being reached when the narratives provided by three couples consistently echoed the study's themes, offering a comprehensive understanding that sufficiently addressed the research objectives. This judgement was made based on my expertise and analytical insight, indicating that additional interviews were unlikely to yield new, substantive insights relevant to the aims of the study.

### Inclusion Criteria

To participate in the study, participants had to meet the following criteria:

- The couples had to be in a legally binding marital relationship or live together in a marital relationship while parenting their biological child with autism;
- The couples had to be South African citizens as this study would be carried out in a South African context;
- The couples’ biological child had to be clinically diagnosed with autism by a paediatrician;
- Both partners in the marital relationship had to be willing to participate in the study;

- The couples had to reside in the geographical area of Tshwane to ease physical contact sessions with the researcher; and
- The couples had to be able to express themselves fluently in either Afrikaans or English.

#### Recruitment Process

The research participants were recruited through a collaborative arrangement with a paediatrician based in Pretoria, South Africa. Once the paediatrician had diagnosed a child with autism, he gave potential participants an invitation letter to participate in the research project.

#### Researcher Invitation

Once the potential participants have read the *research invitation* and signed the *research contract* forms (see Appendix D on p.211), I received the signed invitation letters from the peadiatrician. I contacted the participants telephonically and arranged a research information session with them at the practice of the paediatrician. During the information session, I explained the research in more detail using the research information and informed consent forms (see Appendix E on p.214). If the potential participants fully understood the conditions of the research as stipulated in the research information session and agreed to participate in the research project, they signed the *informed consent* form (see Appendix E on p.214). A date was then set for the first research session to take place at my private practice. This practice provided the participants with a safe and comfortable environment, away from possible distractions, where trust could be built. This first session would serve as a background interview, which happened two weeks after the research information session, and will be explained in the next section.

### *Study Participants*

#### Researcher Description

In qualitative research, the researcher becomes the instrument through which participants are studied (Rager, 2005). In narrative inquiry, the researcher plays an active role in the story being told:

they are part of the interview process, and are presented with the oral accounts as told (or reconstructed) by the participants. These accounts are situated in time and place. When sharing their lived experiences with the researcher, the participants reconstruct their past with reference to how they understand the present. Based on their personal understanding of the present, consecutive accounts are told and re-told (Bignold & Su, 2013). Therefore, the researcher becomes one of the participants in the research.

My background includes my experience in private practice and my experience as a researcher. By the date of submission, I would have been practising as a counselling psychologist for 15 years, consulting with children, adults, couples and families. I often consult families or couples with children who present with different challenges or traumas, having to make sense of major life changes or adjustments. Over the past 15 years, I have acquired significant skills in narrative work. These include listening and asking questions with focused attention, patience and curiosity while building a relationship of mutual respect and trust (Freedman & Combs, 2002). These skills are significant since it fosters a safe environment for clients to share sensitive stories in my private practice. These skills have also contributed to my building relationships with the participants.

My master’s thesis was titled: *Parents’ experiences of their marital relationships after their children have been diagnosed as having autistic disorder*, where I used a phenomenological approach to interview three couples once off. The topic for my master’s thesis was completely separate from my doctorate study; however, it sparked an interest in the field of families’ experiences of raising a child with autism. The current study is different in its methodology and its duration. While my master’s thesis focused on participants’ experiences, I wanted the doctorate study to capture how the participants’ experiences helped them make meaning over time. This was done through a narrative inquiry. The master’s thesis also shaped my interest and understanding of the complexities that families raising a child with autism have to deal with, and laid the groundwork for the current study's focus and questions.

The final chapter of this dissertation is a reflexive account of my own position and experience in undertaking this PhD on the impact of autism on families. Swart (2013) highlighted that in narrative inquiry, the role of the researcher should be alongside that of the individual: with the same curiosity, respect and transformational questions. This will create possibilities. These principles give the participants a voice as experts in their own lives.

As researcher, I was cognisant of the fact that I am not a parent of a child with autism. This allowed me to be curious and to approach the participants with the utmost respect as they are ultimately the experts of their lives. I entered the research from my role as a psychologist and a mother of two young boys. My professional capacity assisted in uplifting and freeing participants when, for example, a concept like the externalisation of autism was explained. I view therapy with my clients as a golden opportunity to discover potential, and to empower them in a way that facilitates unique outcomes. Being a mother myself, my work with families make me acutely aware of family dynamics and the impact of family dynamics on the family system. I was, therefore, able to put myself in the participants' shoes. This allowed me a deeper understanding and compassion for what the other parents had to make sense of, while maintaining a curiosity stance. My personal experience also confirmed my own identity as an individual to help people find meaning and purpose in their own lives. I met the participants who were recruited from a paediatrician's practice. The participants and I therefore entered the relationship as strangers. The relationship had to be built and trust had to be earned. I feel honoured to have met the participants and to empower and allow them a voice at this very vulnerable time in their lives.

### Research Participants

Table 1 on p.70 summarises the profile of the research participants. Fictitious names are used to protect the identity of the participants.

### Researcher–Participant Relationship

A crucial aspect of a narrative inquiry involves building a trust relationship between the researcher and the participant. For that reason a background interview was arranged with each of the participants before starting with the actual interviews.

## *Data Collection*

### Data Collection Protocol

Apart from the background interview, each of the three selected couples participated in five interviews. The first four interviews took place over a period of a year, with each interview scheduled three months apart. This was followed by a single interview with each couple, four years later. This data collection process is illustrated in the diagram in Figure 3 on p.72.

The interviews were conducted like this for the following reasons. Firstly, the process captured the dynamic and evolving nature of the participants' experiences and perceptions related to the phenomenon under investigation. Secondly, a longitudinal approach enabled me to observe changes and continuities in the participants' narratives over time, offering insights into how their experiences and understandings have developed or transformed.

The decision to spread the four interviews across three-month intervals provided a balance. On the one hand, it allowed enough time for potential developments in the participants' lives. On the other hand, it allowed the participants to stay engaged in the research process. However, flexibility was essential. I had to accommodate the participants' demanding schedules, acknowledging the importance of participant convenience and the pragmatic realities of conducting in-depth qualitative research. Such

**Table 1**

*Research Participant Profile*

| | **Couple A** | **Couple B** | **Couple C**[3] | |
|---|---|---|---|---|
| *Father* | | | | |
| Name | Thabo | Joshua | Rick | |
| Present occupation | Environmental officer | Technical and shift manager in automotive industry | Millwright in chemical industry | |
| *Mother* | | | | |
| Name | Jane | Mary | Erica | |
| Present occupation | Safety officer | Full-time mom and preacher | Full-time mom | |
| *Child with autism* | | | | |
| Name | Taki | Dumi | Cobus | |
| Date of birth | 29/04/2010 | 2008/01/21 | 2009/12/03 | |
| Date diagnosed | 13/10/2013 | 2013/05/01 | Autism: | 2013/10/03 |
| | | | Cerebral palsy: | 2015/10/10 |
| *Family history* | | | | |
| Date of marriage | 2010/06/26 | 2004/04/26 | 2009/04/04 | |
| Home language | Venda | Zulu | Afrikaans | |
| Other siblings | Brother born 2015/03/07 | Brother born 2011/12/12 | Sister born 12/12/2012 | |

---

[3] *Note on Couple C*: This child's diagnosis changed later in the study. As the study was conducted over a period of five years, the change in diagnosis can be attributed to the initial criteria being visible to the pediatrician at the time of consultation compared to a doctor's visit at a later stage. The researcher decided to keep this family in the study as the diagnosis correlated with the selection criteria in the beginning of the study and the aims and objectives of the study was still maintained throughout.

adjustments underscore the commitment to ethical research practices, where one prioritises participants' well-being and respect for their time constraints.

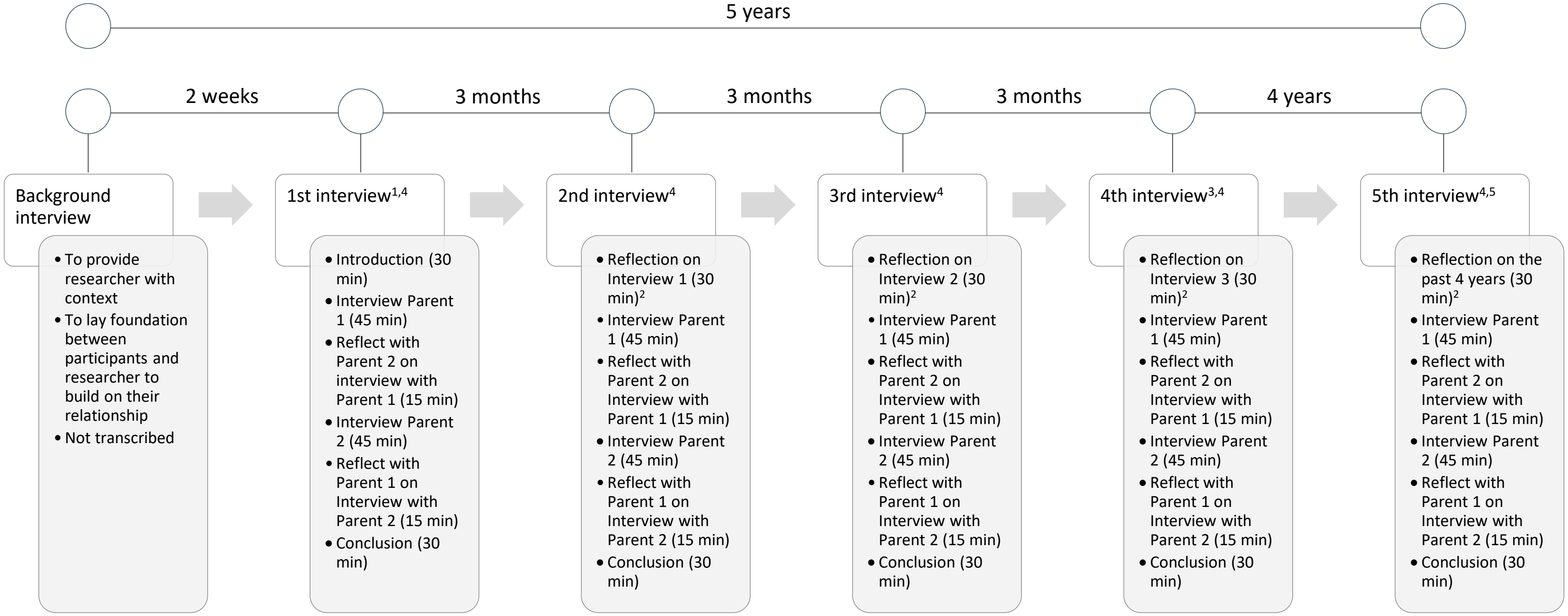
The decision to conduct four interviews per couple were based on the principle of data saturation. This approach ensured that the collected data was sufficient to thoroughly explore the research questions, with the narratives reaching a point where additional data would not likely introduce new themes or significantly enhance the understanding of the studied phenomenon. This careful consideration ensured that the research was both comprehensive and respectful of participants' contributions, aligning with qualitative research's emphasis on depth and richness of data over breadth.

In hindsight, the scheduling of the four interviews on three-month intervals proved meaningful. It captured the fluidity of participants' experiences over time and ensured a thorough exploration of the phenomenon under real-world conditions. The approach demonstrates a balance between theoretical rigour and pragmatic flexibility, characteristic of qualitative research excellence.

The four-year interval marks a period of reflection on my part as a researcher. Apart from personal circumstances, I had to consolidate and reflect on the direction that the study was taking. Upon resuming the study, I conducted a follow-up interview with each couple. This follow-up interview mirrored the structure of the initial interviews. The additional engagement provided a unique opportunity to capture the evolving dynamics of living with a child with autism, offering insights into how families adapt, create meaning, and navigate their experiences over an extended period. This methodological adaptation underscores the narrative inquiry's principle that views participants as experts of their own stories, enriching the study with a longitudinal dimension that highlights the changing nature of personal narratives (Swart, 2013). At the end of the 5th interview each couple had to name how they perceived autism at that point in their lives. At this point in time, all three couples found it easier to agree on their experience of autism, so they also found it easy to agree on naming it as well. This was significant for two reasons. Firstly, it provided the couple with an opportunity for identity

**Figure 3**

*Data Collection Process*



*Note:*

[1] This interview commenced with the following three questions:

i. Desribe how you experienced the diagnosis of autism.
ii. Describe how you experience the interplay between autism and your family.
iii. Describe how you experience the interplay between autism and your relationship.

[2] Before each interview commenced, a reflection was done on the previous interview.

[3] The transcription of the 4th interview was e-mailed to the parents to reflect on.

[4] All interviews (from the first to the fifth interviews) were audiotaped.

[5] The 5th interview was conducted 4 years after the last interview. As a result of this lapse in time in the research, the researcher again gained consent from the participants. They were all on board and again understood the research process. This interview lasted 90 minutes and each parent was interviewed individually in the presence of the other. This interview was conducted at the residence of each couple. From a narrative point of view, it afforded the researcher the opportunity to experience the participants' life worlds within their contexts. The researcher felt honoured as she could have had brief encounters with their children.

construction. Secondly, it provided me with empirical evidence of the effectiveness of using a narrative inquiry in helping families raising a child with autism to make sense of their experiences, responding to the call by Romney and Jones (2020). The following three subsections elaborate on the content of the background interview, the 1st to 4th interviews, and the 5th and final interview (to be read together with Figure 3 on p.72).

### Background Interview

The main purpose of this interview was to lay the foundation of the researcher-participant relationship, in other words, to get to know each other. This relationship is a crucial element in narrative inquiry (Swart, 2013). The interview took place at my practice and was not transcribed. The aim was to create an environment where each participant could independently construct and articulate their personal understanding of autism, both in the context of their own lives and within the familial dynamic. The interview therefore explored the history and the various stages of the couple's life together. The interview began with the following question: 'Can you describe your relationship from the day you met, how it evolved over time, till where you are today?' This interview therefore provided the researcher with a context before the first interview was conducted, two weeks later.

### Interviewing the Participants: 1st to 4th Interviews

These interviews also took place at my private practice. The practice was located within a reasonable distance from where the participants reside and was a quiet space, free from distractions. The participants were all comfortable with the arrangement. Each parent was interviewed individually in the presence of the other. This allowed each participant to construct his or her own meaning of autism in his or her life as well as within the family. It also provided the participants with an opportunity for self-reflection. The meanings created by each participant was seen as important. The interviews were semi-structured in nature. Each interview commenced with a reflection on the previous interview. A transcription of each interview was e-mailed to each participant, three weeks prior to the following interview. This afforded the participants with the opportunity to re-read the conversation and make it easier to reflect on the time that has passed since the last conversation. It also became clear that this way of looking back and focusing on the present assisted the participants in identifying their growth and thus narrating their new identities. Each interview lasted for three hours.

#### Interviewing the Participants: 5th Interview

This interview was conducted four years after the last interview. Because of this time lapse in the research, I had to again obtain consent from all the participants. They were all on board and again understood the research process. This interview lasted 90 minutes and was recorded. Each parent was interviewed individually in the presence of the other. This time, however, the interview was conducted at each couple's residence. From a narrative point of view, it afforded the researcher the opportunity to experience the participants' life worlds within their contexts. I felt honoured as it enabled me to have some brief encounters with their children.

### *Data Analysis*

#### Transcribing the Interviews

The interviews were transcribed by an independent person who signed a confidentiality statement (see Appendix F on p.217). The transcriber, who is self-employed, qualified herself at Kelly Greenoaks Business College. Once the transcriptions were completed, the recordings were returned to the researcher.

#### Reflexive Thematic Analysis

Braun and Clarke's reflexive thematic analysis (2020) was used to analyse the transcribed material. This type of approach captures the values and subjective skills that a researcher brings to the process and their reflexive engagement with theory, data and interpretation (Braun & Clarke, 2020).

Thematic analysis focuses on identifying, analysing and reporting patterns (themes) within material (Boyatzis, 1998). This method is mainly concerned with content, in other words, "what" is said

(Riessman, 2008). Braun and Clarke's reflexive thematic analysis is both descriptive and interpretative in nature (Braun & Clarke, 2020). These descriptive and interpretative facets of the analysis correlated well with the narrative focus on the understanding and construction of personal stories in the meaning-making process.

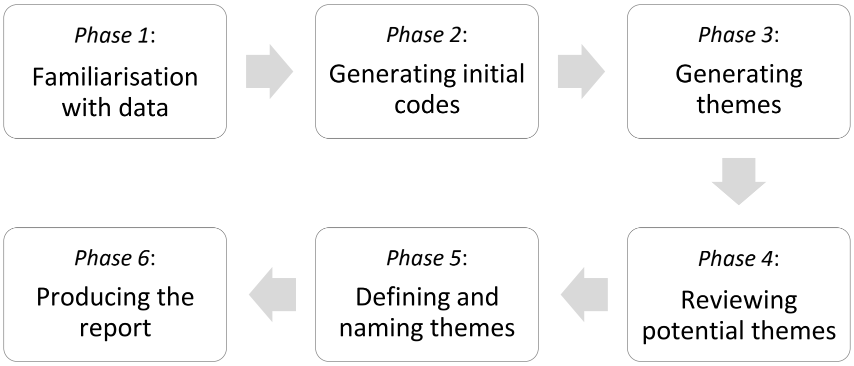
Reflexive thematic analysis is a constructionist method which examines ways in which events, realities, meanings and experiences are the effects of discourses in society (Braun & Clarke, 2006). Social constructionism has specific implications with regards to reflexive thematic analysis. In addition to the reoccurrence of important information, the construction of meaning plays a vital role in the development and interpretation of codes and themes. Therefore, themes that present themselves repeatedly, are on their own not necessarily meaningful to the analysis. It only becomes meaningful once the researcher has analysed the themes with the research question and the participants' responses in mind (Byrne, 2022).

This type of analysis highlights the researcher's active role in knowledge production as the researcher reads data through a lens of their social, cultural, political and historical positions (Braun & Clarke, 2020). It reflects the researcher's interpretative analysis as they bring forth the participants' voices but ultimately tell their story about the data. Braun and Clarke's reflexive thematic analysis, which acknowledges the positions of both the participants and the researcher, is therefore ideal to use as an analytical tool in a narrative inquiry. Byrne (2022) points out that it is anticipated that no two researchers will overlap in their criteria in the same way and that there should be no expectation (although it can be possible) that codes or themes interpreted by one researcher may be reproduced by another. For this reason, I also decided not to make use of a co-coder.

Therefore, using Braun and Clarke's reflexive thematic analysis' six phases (see Figure 4 on p. 76), I analysed the material in this study. Each of these six phases was repeated after each interview. Each interview was digitally recorded with the participants' permission.

**Figure 4**

*Braun & Clarke's Reflexive Thematic Analysis' Six Phases*



*Note*. Adapted from Braun & Clarke (2020)

### *Phase 1: Familiarisation with Data*

In this phase the researcher reads and re-reads the entire dataset to familiarise themselves with the data (Byrne, 2022). In this study, each interview was transcribed by an independent person soon after the interview was conducted. The transcriptions documented the interviews with the participants verbatim. As researcher, I then read the transcriptions numerous times to become familiar with the data. I also took notes of any casual observations in the text. This is in accordance with Byrne (2022) advising that the researcher should, throughout the process, take notes of her thoughts regarding the data and the analysis.

### *Phase 2: Generating Initial Codes*

Codes are building blocks for what will later become themes. Coding entails the production of short descriptive notes of relevant information. Through repetitions of codes, the researcher identify the codes that are beneficial to interpreting themes and those that can be discarded. Also, when a dataset is fully coded and codes are arranged, there should be sufficient depth to examine the patterns (Byrne, 2022). Codes are seen as entities that capture (at least) one observation. The coding process is integral to theme development as the themes are the outcome of the coding and theme development process (Braun & Clarke, 2020, 2022). For this task, I performed the coding manually by generating codes and making notes in the text and using coloured pens to organise the material relevant to the research question.

### ***Phase 3: Generating Themes***

This phase can commence when all the relevant data items have been coded. The focus has now moved away from the interpretation of individual data items to the interpretation of combined meaning across the datasets (Byrne, 2022). At times more than one code was assigned to a phrase and other segments to ‘miscellaneous’. At this point I connected codes to develop themes. At certain points narratives were constructed as sub-themes.

### ***Phase 4: Reviewing Potential Themes***

Byrne (2022) explains that this phase involves two levels of review. Firstly, one should be attentive to the relationship between the codes that inform each theme and sub-theme; if the codes form a consistent pattern, it can be concluded that the themes or sub-themes make a logical argument that contributes to the overall storyline. Secondly, the themes are assessed on how well they provide the best interpretation in relation to the research question(s). Throughout this process I took notes and revised the themes to conclude a meaningful interpretation. This aligns with Braun and Clarke (2020) who encourage researchers to actively and creatively generate themes to which they as the researchers are central to.

### ***Phase 5: Defining and Naming Themes***

In this phase a detailed analysis of the thematic framework is provided. The sub-themes and themes are described in relation to both the dataset and the research question(s). During this phase the researcher identified extracts from the text to provide accounts of the arguments made in a specific theme (Byrne, 2022). Names was also assigned to the themes. Byrne (2022) recommends that names should be concise, informative and memorable. In this study the participants assigned their own names to the last interviews. This was significant in their identity formation process.

### ***Phase 6: Producing the Report***

This is the completion and final inspection phase of the analysis, portraying the themes in a logical and meaningful manner. However, the write-up can change throughout the process just as the codes and themes can change (Byrne, 2022). In synthesising the approaches advocated by Byrne (2022) and Braun and Clarke (2013) into the concluding phase of the analysis, it becomes evident that the traditional separation of 'results' and 'discussion' may be re-envisioned to integrate synthesis and contextualisation directly within the results section. Byrne (2022) highlights the dynamic nature of reflexive thematic analysis, where the articulation of analysis may evolve alongside the development of codes and themes. Similarly, Braun and Clarke (2013) advocate for an approach where synthesising and contextualising the data are integral to presenting the results, suggesting a more integrated and cohesive narrative. This study embraced these perspectives by weaving the themes together in a coherent, insightful manner in Chapters 5 and 6, ensuring that the findings were not only presented but also critically examined within their broader context, which would reflect the fluid and iterative process of reflexive thematic analysis. This method acknowledged the evolving nature of the write-up, mirroring the adaptability required in the analytical process itself.

### **Reflecting on the Narratives**

Once the interviews had been transcribed, they were e-mailed to the participants to reflect on, three weeks before the next interview. The participants were asked to reflect on the transcriptions using the following questions as guidelines:

- Who is autism in your narrative?
- What relationship does autism have with you in your narrative?
- What relationship does autism have with your spouse in your narrative?
- What relationship does autism have with your relationship in your narrative?
- What relationship does autism have with your child/children in your narrative?

- What relationship does autism have on the extended family in your narrative?

Each interview started by a reflection of the previous interview. After the four-year lapse, the final interview with the participants started by reflecting on the journey over the past four years. Based on the analysis of the narratives throughout the process, I also participated in all of these reflections. However, my analysis should not be seen as superior to the participants' reflections, but as *a* reflection.

## ***Trustworthiness/Methodological Integrity***

### **Quality and Rigour**

The quality of qualitative research rests on a process of evaluating research. Within qualitative research, trustworthiness refers to the degree of confidence in the data and methods used to ensure the quality of the study (Connelly, 2016). In narrative research, trustworthy research echoes the principles of ethical research as described above (Josselson, 2007). When formulating the data, the researcher is actively involved and influences the process of generating, collecting and shaping the data within the study. In qualitative research, and particularly in narrative research, the researcher is an integral part of the data collection and analysis process (Connelly & Clandinin, 2006; Josselson, 2007). The researcher's role accentuates key aspects to enhance the trustworthiness of qualitative research including interpretation and sense-making, interaction with participants, data construction, reflexivity, credibility, dependability, confirmability, transferability, and authenticity.

#### ***Interaction with Participants***

The way in which researchers interact with participants, the questions they choose to ask and how they engage in the research process can have a significant impact on the data collected. The researcher's ability to create a comfortable and trusting environment can affect the depth and authenticity of the narratives shared (Connelly & Clandinin, 2006; Josselson, 2007).

#### *Data Construction*

In narrative research, both the researcher and participants construct the data through a dialogical process. The researcher's role in formulating the data includes selecting which stories or excerpts to focus on, how to code the data or allocate the themes and deciding how to present the narrative (Connelly & Clandinin, 2006; Josselson, 2007).

#### *Interpretation and Sense-Making*

The researcher's understanding and interpretation of the data plays a crucial role in formulating data into coherent themes or narratives. Researchers interpret the data through their lens which is influenced by their background, theoretical perspectives and personal experiences (Connelly & Clandinin, 2006; Josselson, 2007).

### Reflexivity

Recognising the researcher's role in formulating the data asks for a reflexive approach. The researcher must continually reflect on their influence on the research process and outcomes. This is achieved by being aware of and transparent about their own biases and decisions throughout a study (Connelly & Clandinin, 2006; Josselson, 2007).

### Credibility

Credibility of research demands that the selected methodology should be well explained and justified (Stenfors et al., 2020). Connely (2016, p. 435) suggests checking with the following question: "was the study conducted using standard procedures typically used in the indicated qualitative approach or was an adequate justification provided for variations?" In this study, credibility was enhanced by member checking and prolonged engagement. Member checking was done by allowing the participants to read the transcriptions of the interviews before each interview giving them an opportunity to reflect on these. Prolonged engagement was also used as the longitudinal study gave me as the researcher an opportunity to build a trusting relationship with the participants over time (Connelly, 2016; Loh, 2013; Stenfors et al., 2020).

### Dependability

Dependability refers to the extent to which the research findings and the study as a whole could be replicated under similar conditions (i.e. supporting the consistency of research findings over time). This aligns with the definition by Stenfors et al. (2020). In this study it involved detailing the approach to narrative inquiry, the process of engaging with families, the analytical strategies employed, and the steps taken to ensure ethical considerations. Through this study I hope to provide a document others can follow by using narratives in different contexts. Families undergoing major adjustments can benefit from such a research framework.

### Transferability

Transferability in qualitative research pertains to the degree to which the findings from one context can be applied or adapted to other settings, contexts, or groups (Stenfors et al., 2020). Connelly (2016) clarifies that qualitative researchers concentrate on the rich, detailed accounts of participants, acknowledging that these stories are representative of specific experiences rather than universal truths. In this study, the potential for transferability is rooted in the detailed descriptions and interpretative processes of the narratives, offering insights that may resonate with or be relevant to different contexts and settings. This approach enables other researchers or practitioners to assess the applicability of the findings to their own unique situations.

### Confirmability

Confirmability refers to a clear link between the data and the findings (Loh, 2013; Stenfors et al., 2020). In this study, I indicated how I arrived at the findings by combining detailed descriptions with quotations.

#### Authenticity

In authenticity, the principles of fairness and genuineness is important. This includes attempts to respect the participants' values (Amin et al., 2020). Throughout this study, I checked that participants were comfortable in all areas of the conversations and processes. Ontological authenticity refers to the extent that participants' personal constructions enhance through their participation in the research (McLaughlin, 2001). In this study, identity formation was visible through the process of meaning making.

### *Axiology*

Narrative researchers recognise their biases and expectations; reflecting a constructionist perspective. Social constructionists argue that the researcher's values and lived experiences are inseparable from the research process. Researchers should acknowledge and describe, their values, but not eliminate them. A constructionist epistemology requires close, prolonged interaction with the participants to understand their lived experiences. This makes it impossible to eliminate value biases in such interactions (Ponterotto, 2005).

### *Rhetorical Structure*

Narrative inquiry studies are usually written in the first person and usually include the extensive 'voice' of participants by means of quotations. The rhetoric inherent in a narrative inquiry aligns with a constructionist paradigm which acknowledges the subjective and interactive role of the researcher. Researchers comprehensively detail their own experiences, expectations, biases, and values and openly discuss the emotional and intellectual impact of the research process on themselves (Ponterotto, 2005).

### *Ethical Considerations*

I received ethical approval for this study from Unisa in October 2017 (reference number PERC-17030, see Appendix C on p.209) the time, I had to address the following aspects of research ethics during the initial meeting with the participants: research permission, consent, professional conduct, privacy, anonymity, protection from harm, and material storage.

### Research Permission

#### *The Paediatrician*

I obtained permission from a paediatrician in Pretoria that once he diagnosed a child with autism, they would give potential participants an invitation letter to participate in the research project (see Appendix D on p.211).

#### *University of South Africa*

I obtained permission from the Postgraduate and Ethics Committees in the College of Human Sciences at the Unisa to conduct the research (reference number PERC-17030, see Appendix C on p.209).

### Principle of Consent

I gave the potential participants information regarding the research project during the research information session, which took place at the paediatrician's practice. Based on this information they were able to make an informed decision and gave informed consent regarding their participation in this study. Participation was completely voluntarily. Wang and Geale (2015) reiterates that narrative research implies a responsibility towards the dignity, privacy and well-being of the participants and that participants should sign informed consent only after the information about the study was obtained. The participants in this study signed informed consent at the start of the study and again 4 years later, before the final interview.

### Professional Conduct

As the researcher, I ensured that the study did not become a therapeutic study by doing the following. Firstly, I made it clear to the participants in the *research invitation letter*, and in the *research information and consent letter* that the study is an exploratory study and not a therapeutic study. I also did not employ any therapeutic interventions during the research process. Secondly, I adhered to the research process as depicted in my research proposal and approved by the Postgraduate Research

Committee of Unisa. Lastly, participants had the right to voice their reservations at any point during the research should they wish to not explore an aspect or aspects that surfaced during the research. Should the participants wish to explore such aspects further, I would refer them to a registered counselling psychologist for this purpose. Such consultation(s) would be made available free of charge.

### Principle of Personal Privacy

Assuring participants of their confidentiality and privacy is central in narrative research. Researchers should do everything to safeguard the participants' privacy. Only when they trust that the researcher will ensure their anonymity would they tell us their deeply personal stories (Josselson, 2007). Personal privacy comprises the right to confidentiality and the right against intrusion. The former means that the participants have the right to maintain control over the information they choose to share. The latter means that participants are not compelled to share everything about their experience as they have the right to decide what to share and what to withhold (Allan, 2001; Human et al., 2009). Throughout this study, the participants maintained the right to personal privacy.

### Participant Anonymity

In narrative inquiry, a distinction needs to be made between personal identity as the author of the narrative, and the narrated identity as the actors in the narrative (Sclater, 2003). In both instances anonymity was upheld. Josselson (2007) explains that the researcher must protect the integrity of participants' ongoing relationships with those who feature in their stories. It is necessary to change all names in the texts. In this study, codes were used for the personal identity of the participants as the authors of the narratives with reference to the 'narrated identity' of the actors in the narrative. Fictitious names were used to protect the identity of the participants. The researcher kept a codebook should it be necessary to reconstruct the original. In addition, each couple constructed their own name or theme for how they experienced autism at the time of the final interview. In this way, the narrative of their identity was explored and built upon. This was significant as it added to the co-creation of the research process. In this way the participants' voices added to the analysis of the study. The power of analysis and reflecting on narrative to build identity became central to this study.

### Principle to Protect from Harm

During narrative research, data about significant and meaningful aspects in the participants' life is obtained from an empathetic and respectful relationship with the participant (Josselson, 2007). If participants at any time during or after the research process felt overwhelmed by sharing their experiences, they had the option to contact a registered counselling psychologist, to be debriefed or for therapy. Such consultation(s) were available to the participants free of charge. Participants also had the right to withdraw at any stage during the research processes without incurring any negative consequences. There were no specific anticipated harmful effects of this research.

### Material Storage

The research narratives and the recorded interviews is stored in a secure cabinet in my office for a 3-year period upon completion of the study, after which all material will be destroyed.

## Conclusion

This chapter argued why this empirical, qualitative research study used a narrative inquiry as research design and reflexive thematic analysis as per Braun and Clarke (2020) to answer the research question stated in Chapter 1 of this study. The next chapter will report on the findings of the reflexive thematic analysis as per Braun and Clarke (2020) as it relates to the three objectives set out in Chapter 1 of this study.

# CHAPTER V. Analysis and Discussion

This chapter delineates the presentation of the research findings into two distinct sections. The initial section provides an analysis of the emergent themes as discerned through Braun and Clarke's reflexive thematic analysis (Braun & Clarke, 2006). These themes, which became apparent in the narratives of couples discussing their experiences of living with autism within their relationships, include: characteristics of autism; diagnosis; knowledge; the marital relationship; the mother's relationship with autism; the father's relationship with autism; the child with autism; the sibling's relationship with autism; the community and extended family; and the future. This section will further incorporate an integrative review of both historical and contemporary research on autism, aiming to contextualise and deepen the understanding of the broad themes identified in the narratives of the three couples involved in this study.

The second section of this chapter shifts focus to the construction of each couple's narrative, integrating the findings with narrative inquiry and narrative practices. This approach not only aligns with, but also substantively informs the conceptual framework of this study, facilitating a comprehensive understanding of the lived experiences of the couples as they navigate life with autism.

## Findings related to Objective 1: Parents' Experiences

The first objective was to explore and describe parent's experiences of raising a child with autism. Using Braun and Clarke's reflexive thematic analysis, the following ten themes emerged from each couple's experiences over the period of five years. Each theme is discussed to show the progression from the first interview to the fifth and final interview.

### *Theme 1: Characteristics of Autism*

#### Couple A

In the first interview, couple A's story about their journey with autism began by being very aware of the symptoms of autism in their child. Thabo expressed specific concern about Taki's speech when he said, ‘My main worry was not the behaviour at first, it was that he couldn’t speak.’ Jane added that she was grateful that Taki loved contact and concluded that ‘maybe my son has got a milder version of it [autism]’.

In the second interview, Jane mentioned that ‘the only symptom of autism that I experience more often is the screaming, especially if he is in a place where he does not want to be’. She was aware that his speech could improve over time. She added that a symptom like beating had improved.

In the third interview, both Jane and Thabo said that autism’s symptoms like ‘crying and screaming has decreased’ and Thabo added that Taki’s ‘speech is improving, and he can communicate his needs.’ However, both parents also spoke about a downside to autism, with Thabo saying that ‘autism demands attention’ and Jane agreeing: ‘Autism is selfish; it doesn’t just take away your money, it also takes away your time and it affects your peace. It really pushes you.’

In the fourth interview, Jane reflected on the character of autism and their stance towards it when she said, ‘The selfishness of autism hasn’t disappeared, but I think we get better at it.’

In the final interview four years later, the couple were in agreement that autism kept challenging them as Jane said that ‘autism is sneaky; it doesn’t stop the challenges.’ However, according to Jane, ‘his speech has improved a lot and also his comprehension.’

### Couple B

In the first interview, this couple were in agreement that they were stuck with autism for life. Mary said that autism ‘is something I cannot avoid’. She sounded helpless when she said that ‘autism is alive, there is nothing we can do’ and Joshua added that ‘you can live with it for the rest of your life’.

In the second interview, Joshua experienced autism as ‘financially draining’.

In the third interview, Joshua explained how their perspective on autism had changed: ‘It [autism] used to consume time; now we can channel our time not on the worries but to something we can do.’ He also stressed that ‘we cannot remove it [autism]; we are trying to live with it’.

In the fourth interview, autism had become something that Mary felt they could live with. She explained: ‘I am not as worried as I used to be. I see improvement and it [autism] is not as bad as it was from the start and I am managing now.’ Joshua said how his definition of autism had changed for the better: ‘We sometimes are starting to ask ourselves the definition of autism. Comparing what the doctor said to what we see really. The doctor said he would not improve in his speech, the doctor did not give us any hope.’

In the final interview four years later, the couple spoke about immense improvements concerning autism. Joshua said: ‘Dumi understands much better than before. We can now talk to him. We can now see his feelings. It is not as much as we would want to, but at least we get to see how he feels about certain things.’ Joshua mentioned that they did not have hope before, whereas now, ‘we hardly speak about it [autism] in relation to our family. I would say we are trying to get to know Dumi, not really autism.’ Mary agreed about the improvements and said: ‘Before, we thought he would be one of those children needing constant attention. We never thought that there will be a time that we would leave him and his brother alone in the house.’

### Couple C

In the first interview, Erica explained how autism presented itself as ‘pretty normal’ in Cobus. She described the characteristics of autism by saying that ‘autism does not make eye contact and does not want to be touched’ [‘outisme maak nie oogkontak met jou nie, outisme laat ander mense nie aan hulle vat nie’]. However, she said the contrary applied to Cobus as he made eye contact and was very loving. Rick was very realistic in saying that ‘a child with autism stays on the spectrum for the rest of his life’ [‘’n kind met outisme gaan op die outisme spektrum bly vir die res van sy lewe’], but added that autism does not only have to be negative as it can also be positive.

In the second interview, the focus of autism was now more on its symptoms: ‘We should not work on Cobus; we must begin to work with the symptoms. Give that extra attention. That brings a bit of relief'[' 'n Mens moet nie aan Cobus werk nie, maar ons moet aan die simptoom begin werk. Daai ekstra aandag gee. Dit bring bietjie verligting']. Erica added that her son had a speech developmental disorder but was making progress.

In the third interview, Erica spoke about how autism was perceived when she said: 'People see autism as something ugly; they don't realise it can be something beautiful. Not everyone with autism is ugly.' ['Mense sien outisme as 'n lelike ding, en hulle besef nie dit kan 'n mooi ding wees nie. Nie almal se outisme is lelik nie.']. Rick added that there had been some relief:

> … since we last spoke to the therapists about Cobus's progress. It just shows that the massive a mountain we had to climb is no longer there. [ … vandat ons die laaste keer met die terapeute gepraat het oor Cobus se vordering. Dit wys net daai massiewe berg wat mens moet uitklim is nie meer daar nie].

In the fourth interview, Erica spoke about how their focus had changed: 'Nowadays we don't really talk about autism. We talk mostly about progress, moving forward.' ['Deesdae praat ons nie werklik van outisme nie. Ons praat meeste van die tyd oor vordering, vorentoe gaan.'].

### Characteristics of Autism: What does the literature say?

The accounts by participants on the characteristics of autism agrees with those described in the literature. Autism remains a disorder for which there is, to date, no cure, confirming that parents are indeed stuck with autism, for life, with the doctors often giving no hope (Neely et al., 2012; Yadav, 2020). The described symptoms also align with those in the literature regarding: lack of eye contact (Masi et al., 2017), speech impairment (APA, 2013), screaming, beating, and anxiety when they are in a place they do not want to be (Kerns et al., 2021; Sukhodolsky et al., 2019). Healthcare needs for individuals diagnosed with ASD are complex and require a range of integrated services including health promotion, care and rehabilitation (WHO, 2023) because people with ASD tend to rely on family members, including parents and siblings, well into adulthood (Spain et al., 2017). Apart from having to cope with the general demands of parenting, parents often lack the confidence to manage the child's behaviour, lack support from the wider community, lack access to supportive, therapeutic, and educational services, have to have to balance work and family, and manage additional financial strain (Hutton & Caron, 2005; Romney & Jones, 2020; Solomon & Chung, 2012; Twoy et al., 2007). Despite the toll on these families, couples report a strengthening in their relationship over time (Blair et al., 1996; Myers et al., 2009), in the same way that the participants in this study admitted: 'selfishness about autism doesn't get better, but [we are] getting better at it, now now we can channel our time not on the worries but to something we can do'; 'we cannot remove it [autism], [so instead] we are trying to live with it', as they realise that '[autism] does not only have to be negative as it can also be positive' and 'can be something beautiful'.

### ***Theme 2: Diagnosis***

#### **Couple A**

In the first interview, Jane experienced the diagnoses as hurtful and confusing when she stated that 'It [the diagnosis] was a very bad knock and I was kind of confused and had a lot of questions'. However, she felt that it was 'very liberating that there is a condition for it' and that she could identify it [autism] and read up on it. In the second interview, Jane referred to the diagnosis of autism and said that 'when I found out about it [autism] everything was just autism'. She indicated that a lot had changed: 'This condition humbles you. It is not all bad, there is something good that comes from it.'

#### **Couple B**

In the first interview, Joshua said the diagnosis 'was shattering'. It was not what Joshua had expected from the doctor: 'I thought it would be something that they can do something about. I wanted to find out if there is a way to overcome it, but I couldn't find it with the doctor. The doctor did not give me hope; he said that there was nothing we can do.' Mary was left confused by the diagnosis.

In the final interview four years later, Mary was reminded how frustrating the initial diagnosis had been and explained, ‘I could not even understand it myself.’ However, she now spoke with relief about the diagnosis as ‘they actually have a name to identify it and say it is autism’. She spoke with relief about improvements such as ‘Dumi is no longer isolating himself and he is more social’.

**Couple C**

In the first interview, the couple described a roller-coaster of emotions at the time of the diagnosis. Referring to the beginning of their journey, Rick said, ‘We knew there was something.’ [‘Ons het geweet daar was iets.’] Both parents experienced great sadness and Erica said, ‘In the beginning autism was a very big shock.’ [‘Dit [outisme] was aan die begin ‘n baie groot skok.’] Erica added that they went for a second opinion: ‘I can’t look at autism because I don’t see it; I won’t understand it.’ [‘Ek kan nie na outisme kyk nie want ek sien dit nie; ek sal dit nie verstaan nie.’] The second opinion attributed Cobus’s condition to a hearing loss.

In the second interview, Rick referred to the diagnosis as ‘an extreme disappointment: the doctor said that Cobus will never be able to talk properly and never thus and that … ’ [’n verskriklike teleurstelling: die dokter het gesê dat Cobus nooit reg sal praat en nooit dit en dat nie … ’]. The couple commented on Cobus’s progress since the diagnosis and Erica gave his communication ability as an example:

> Lately there are a lot of things that show he is moving forward. For example, Cobus said, ‘I love you’ [Deesdae is daar baie goeie goed wat wys dat hy vorentoe beweeg. Cobus sê byvoorbeeld, ‘I love you’].

In the third interview, Rick spoke about how devasted he was by the initial diagnosis: ‘then my whole world collapsed’ [‘toe het my hele wêreld inmekaar gestort’]. Erica remembered the doctor’s description of autism, saying that autism ‘looks like this ugly thing for which there is no hope’ [‘lyk soos hierdie lelike ding waarvoor daar geen hoop is nie’].

In the final interview four years later, Rick said that they visited another doctor who changed Cobus's diagnosis to cerebral palsy and apraxia. Erica explained that she experienced several complications during pregnancy, and traumas with the baby at birth. She added that 'the new diagnosis made us more positive about everything' ['Die nuwe diagnose het ons meer positief oor alles gemaak']. Rick spoke positively about the new diagnosis: 'The diagnosis made me "forward thinking". My outlook changed. I am no longer unsure; I am much more confident about it' ['Die diagnose het my "forward thinking". My visie het baie verander. Ek is nie meer onseker nie; ek is baie meer versekerd daaroor'].

### Diagnosis of Autism: What does the literature say?

A study by Girli (2018) describing the initial reactions of shock and disbelief by parents, highlight just how traumatic the diagnosis can be. Similarly, the mothers in a study by De Aguiar and Pondé (2020) expressed feelings of sadness, anguish, hopelessness and despair when made aware of the diagnosis. In a study by Papadopoulos (2021), mothers experienced emotional responses such as depression, distress, helplessness, frustration and guilt upon receiving their child's diagnosis. A study by Manono and Clasquin-Johnson (2023) portrayed mothers' experience of the diagnosis as a stressful and drawn-out process, eliciting a range of emotional responses from these individuals. While some found relief in finally understanding their child's condition, lingering concerns about the future persisted. The findings of a quantitative study by Rogers et al. (2016) using questionnaire also agreed with the stressful nature associated with the diagnostic process.

The findings in this study align with those in the literature. Both Jane and Mary experienced the diagnosis as confusing and Joshua felt that the diagnosis was 'shattering'. Joshua expressed powerlessness as the doctor 'did not give me hope; he said that there was nothing we can do'. Couple C described the diagnosis as a 'roller-coaster of emotions' filled with shock, sadness and disappointment. Erica said that the doctor 'made autism look like something ugly without any hope'. This research study added an extra dimension to the experience of the diagnosis as it also provided the participants with a name and thus answers to questions. This may well be as this study was conducted over a period of five years and the participants had time to construct the diagnosis in different ways. Jane described the diagnosis as ‘very liberating that there is a condition for it’, while Mary was relieved as they ‘actually have a name to identify it and say it is autism’. Erica also focused on the positive in the diagnosis. Although Girli’s study (2018) was also a longitudinal study, it seems that the theme of the diagnosis only portrayed the negative. A possible explanation is that later on in the study, the topic of the diagnosis was not addressed again.

### ***Theme 3: Knowledge***

#### **Couple A**

In the first interview, it became clear that knowledge is power in helping them to know and understand autism. As Thabo said, ‘Knowing this disease and the knowledge is helping me to understand the condition.’

In the second interview, couple A perceived having knowledge about autism as very important in their journey when Thabo said that it made him ‘proud of myself because it shows me that I understand autism and it brings the best out in me.’ Jane added that knowledge ‘makes you realise you are much stronger than you think you are.’

In the third interview, the couple were in agreement that having knowledge about autism was empowering as Thabo explained that ‘my wife reads a lot; she gets information for us and we discuss it’.

In the final interview four years later, both parents agreed that knowledge stayed an integral part of their journey as Jane said that knowledge was ‘continuous’ and Thabo said that hearing stories of others living with autism ‘give you hope’ to see the progress of some kids.

**Couple B**

In the first interview, knowledge provided the parents with a positive conception of autism. Joshua said that knowledge 'answers some questions, it's liberating. It now brings me close to my child more than ever'. He added that learning 'is like a light at the end of the tunnel, like a hope'.

In the third interview, Joshua also explained that new knowledge on their child's treatment directed them to change medication. In turn, 'these results are better because there is something we can do and it might steer it in a better direction.'

In the fourth interview, finding knowledge had taken a back seat. Mary explained that 'We are no longer searching. We were fighting fires. We were hungry for survival. We rather want to concentrate on trying to make him develop speech and develop the survival skill of life'.

In the final interview four years later, knowledge still played an important role for the couple. Mary concluded that 'as research keeps on happening about autism, there is hope that there will be better ways of dealing with autism from the parent's perspective to the child'.

**Couple C**

This theme was evident in the second interview, when Rick stressed that the purpose of knowledge allowed him to 'better understand a lot of uncertainties' ['verstaan baie onduidelikhede beter'].

In the final interview four years later, knowledge still played a big role in the couple's lives. Erica said:

> 'We still *google* cerebral palsy because the doctor told us that Cobus would actually be unable to walk. I see that already as a miracle' ['Ons *google* nog steeds serebrale verlamming, want wat die dokter vir ons gesê het, Cobus moes eintlik nie loop nie. Ek sien dit klaar as 'n miracle'].

### Knowledge of Autism: What does the literature say?

The literature reported a lower parenting stress and an increase in competence where education about autism was used as a form of intervention. Knowledge also increased parents' understanding of symptoms associated with autism, and strategies used to support their child with autism (Kuravackel et al., 2018; McAleese et al., 2014). The participants in a study by Papadopoulos (2021) and Navot et al. (2017) confirmed a lack of knowledge on how to effectively assist their child with autism. Mothers in a study by Manono and Clasquin-Johnson (2023) went through an information-seeking phase to make sense of autism.

Knowledge about autism was equally important for all three couples in this study. Joshua described knowledge as follows: 'Knowing this disease and the knowledge is helping me to understand the condition' and that having knowledge about autism made him 'proud of myself because it shows me that I understand autism and it brings the best out in me'. Jane added that knowledge 'makes you realise you are much stronger than you think you are'.

## *Theme 4: The Marital Relationship*

### Couple A

In the first interview the marital relationship was addressed when Thabo said that 'it [autism] brought us closer than before' as he explained that his wife initially cried a lot and he supported her. Jane supported her husband by providing him with information regarding autism. She was also firm that 'autism were never allowed into our marital relationship'. Jane said 'It [autism] made us realise that we need each other in our lives'.

In the second interview there was a slight difference in the discussion about their marital relationship: both Thabo and Jane agreed that as a result of autism they were much closer than before. Both also commented on how they made an effort to get to know each other again: Jane said that [her husband] 'took it upon himself to get to know me all over again. I have also tried to improve. I was too independent, but I am learning to accommodate him'. Thabo added 'One other thing is that I started to sort of learn about her [my wife] again'.

The third interview focused on the agreement between the couple that autism strengthened their marital relationship, as Thabo said, 'It [autism] brought us together because we are supporting each other emotionally. In the beginning she (his wife) was strong and I was not at that level. Now we are almost at the same level.' Jane agreed, 'It [autism] made us stronger, more appreciative with one another. It has also made us realise that we need each other in order to go through this journey.'

In the fourth interview, both Jane and Thabo were in agreement that autism strengthened their marital relationship. Jane said: 'I told myself that we got married way before autism … it cannot now come and dictate us how to live our lives.'

In the final interview four years later, the couple were in agreement that autism strengthened their marital relationship. Thabo said that 'it [marital relationship] has really improved; we are in a good space. We don't let autism get between us because we know how to handle autism; it is not even affecting our relationship'.

**Couple B**

In the first interview, Joshua acknowledged that autism put a lot of pressure on their marital relationship, 'like big luggage you have to carry around.' Mary added that it gave her hope knowing they are together in this.

In the second interview, the couple agreed that autism has strengthened their relationship. Joshua explained that 'it brings us together. We are like a team now fighting'. Mary summarised her experience of autism's relationship with their marital relationship as follows:

> It [autism] does not have as much power as it had before on our marriage. Before we could not spend time to go out as we were thinking more about what we could do because of the autism

> that Dumi has. Now we have more solutions to reduce the power of autism so it is not as much as before, not as strong as it was before.

In the third interview, the couple were in agreement that their marital relationship was improving. Mary said that 'I am happy to see we are pulling in the same direction; there is a lot of hope, I see a difference'. Joshua agreed: 'It [our relationship] is getting better than before because there is hope and a little light. We are spending less time on autism than before.'

In the fourth interview, Mary stated that they now had a 'normal' martial relationship, 'not affected by autism.' Their focus in life had changed: Joshua added that 'autism is something that we can live with. We have more time now on our hands and we can focus on some other things and not really on autism'.

In the final interview four years later, their marital relationship was in a positive space. The couple said that they were now able to exercise together and in the past year went on an overseas trip. Joshua explained that 'it all helps us to understand each other and our challenges'. Mary described how their view of autism had changed:

> We are getting used to it [autism] now. It is not the same as before. We are no longer fighting it away; we are giving it its own space. Fighting it is a losing battle; it is not helping us. To accept that we live with autism, it is better that way. Whatever we do, we know autism is there.

**Couple C**

In the first interview, the couple explained how they supported each other in their marital relationship amidst autism. Rick remembered their journey with autism:

> It was heart-breaking for us and we had a horrible roller-coaster the last five months because we fought a lot, but at the end of the day we worked through it. It made us stronger [Dit was vir ons hartseer en ons het n vreeslike 'roaller coaster' gehad in die laaste vyf maande, want ek en sy baklei, maar aan die einde van die dag werk ons dit uit. Dit maak ons sterker].

In the second interview Rick spoke about the journey of their marital relationship:

> It has improved since the first diagnosis. The relationship was not so strong. Now we are drawing closer to each other every day [Dit is baie beter vandat hulle hom die eerste keer gediagnoseer het. Die verhouding was nie so sterk nie. Ons trek elke dag nou bietjie nader aan mekaar].

Rick referred to the effect that autism initially had on their marriage: ‘We blamed each other but then one realises that it’s a thing that happened and we had to accept it and work on it’ [‘Ons het mekaar geblameer maar dan besef mens dit is ‘n ding wat gebeur het en ons moet dit aanvaar en ons werk daaraan’]. Erica concluded by saying what her husband meant to her: ‘He is the strong one and he keeps us together. I can always rely on him’ [‘Hy is die sterk een en hou ons bymekaar. Ek kan enige tyd op hom staatmaak’].

The third interview addressed the roller-coaster in the marital relationship. Rick spoke about the ups and downs in their marital relationship:

> Very stressful some days, because when Cobus was at his best she was a little moody and then you have to approach her obliquely. But on other days it goes well again. You get your up days and your down days. [Baie stresvol party dae, want toe Cobus op sy beste was, was sy maar bietjie ‘moody’ en dan moet mens haar maar so om ‘n hoekie eers benader. Maar ander dae gaan dit weer goed. Jy kry jou ‘aan’ dae en jou ‘af’ dae.]

He added that there had been improvement in their relationship:

> Since the beginning she told me that it came from my side of the family, with me being slow, but she hasn’t mentioned it for a long time. [Van die begin af het sy vir my gesê dit kom van my kant van die familie af met my stadigheid, maar sy het dit lanklaas genoem.]

Erica spoke about how they made time for each other: ‘Eight o’clock is bedtime and then it gives us time to just relax together.’ [‘Agtuur is dit bedtyd dan gee dit ons tyd om bietjie net saam te ‘relax’’].

In the fourth interview, Rick explained that they also entered another phase in their marital relationship: ‘The denial stage is now fortunately past. We accepted it and are busy moving forward. It’s actually much better’ [‘Die ontkenning stadium is nou gelukkig verby. Ons het dit aanvaar en ons is besig om aan te beweeg. Dit is eintlik baie beter’]. Rick also commented that as a couple they were emotionally in a better space: ‘There is less fighting and heartache. When I get home I help her and she helps me. At least we have a kind of routine’ [‘Daar is minder bakleiery en hartseer. Wanneer ek by die huis aankom help ek haar en sy help my. Ten minste het ons so half ‘n roetine’].

In the final interview four years later, the couple spoke about their marital relationship in a positive manner. Both agreed when Erica said: ‘We could always look forward. We don't stay in one place; we can move forward’ [‘Ons kon altyd vorentoe kyk. Ons sit nie op een plek nie; ons kan aanbeweeg’].

### The Marital Relationship: What does the literature say?

Existing research demonstrates diverse findings regarding autism and parents’ relationships. On the one hand, having a child with autism can add additional stress and pressure to the participants’ relationships (Hock et al., 2012; Reddy et al., 2019; Woodgate et al., 2008), lead to a higher rate of divorce (Hartley et al., 2010), result in lower marital satisfaction (Lee, 2009; Shtayermman, 2013), lower levels of marital intimacy (Fisman et al., 1989; Hirsch & Paquin, 2019), lead to an escalation in conflict (Hirsch & Paquin, 2019; Papadopoulos, 2021), result in emotional distance within the marital relationship (Papadopoulos, 2021) and lower levels of marital happiness (Higgins et al., 2005).

On the other hand, having a child with autism can also enrich or strengthen a relationship (Blair et al., 1996; Myers et al., 2009). Hock et al. (2012) maintain that as parents adapt, deeper intimacy and commitment can be forged. In this study, findings from the narratives of all three couples over the period of five years, concluded that autism strengthened their marital relationship. With couple A, descriptions like ‘autism bought us closer … we need each other … we are supporting each other’ sketched a picture of a stronger bond between them. With couple B, words like 'we are together in this … we are like a team now fighting … we are pulling in the same direction, there is hope … we accept that we live with autism' were descriptive of their marital bond. With couple C, phrases like 'we fought a lot but at the end we got through it … autism made us stronger … my husband keeps us together and I can depend on him … we accepted autism and are moving forward … there are less fighting and sadness' also speak of a growing marital relationship.

### *Theme 5: The Mother's Relationship with Autism*

#### Couple A

In the first interview the mother's relationship with autism received attention when Jane stated how she initially felt that autism was 'keeping me prisoner' but that this changed when she took control and turned her focus to raising Taki 'like any other child' while treating autism. Whereas Jane had previously described her relationship with autism as 'difficult and frustrating', in the second interview she said that 'I moved on with my life. I am living with my son like any other child'. Jane used to ask questions like, 'why me at such a young age do I have to go through this?' but realised that autism was beyond her control: 'it [autism] is something you could not have prevented and there is other people going through the same thing.' She was now more at peace: 'I don't have all those question like before. All I know is that I have a son and I love him.' She uttered these profound words: 'It [autism] has taught me to love deeply and it has taken me to another level that I have ever known in my life.' Thabo spoke highly of how his wife dealt with their situation: 'She helps everyone us to understand it [autism]. I am proud of her. I think I am what I am today in terms of autism because of her.'

In the third interview, while talking about the mother's relationship with autism, Jane expressed feeling more in control as she 'developed coping mechanisms' and 'I know it [autism] better now'. She did express concern should they fall pregnant with a second child but acknowledged that 'there is nothing I can do at this stage and I will just have to accept it and prepare myself for whatever is coming our way'.

In the fourth interview, Jane stated that their relationship kept changing. She said that 'I would not want to have Taki any other way. I do not think I would have loved the way I do if my son was not autistic. It helped me realise I can be a greater person'.

In the final interview four years later, while looking at the mother's relationship with autism, Jane highlighted the importance of being in control: 'Right now I am ahead of it [autism]. I would say it [autism] does not have power over us anymore. I am always conscious, and I do not give up. I have also stopped to say it is good or bad. It is what it is. This is my life; this is how it is.'

**Couple B**

In the first interview, Mary explained the hard reality of autism when she said:

> It is not easy, it is hard. It is holding my life back. I am learning about it and sometimes I don't believe it is something that is in our life. But I see now it is real and there is nothing you can do to make it go away.

However, she realised that their relationship did not stop there and she tried to make sense of it when she said: 'I am trying to accept it and to learn about it; I need to always be there for him.'

Joshua agreed that autism frustrated her in that 'it has actually broken that warmth that you will find in a mother-son relationship' but said that Mary was trying to find a way to manage autism.

In the second interview Mary noted that initially, she blamed herself for autism as she thought, 'maybe it was something that I did not do when I was pregnant and maybe there was something that I did not do that I was supposed to do to protect the child. I thought it was my fault.' However, she realised that it was not because of her: 'Now I know that it is nothing that I did before. I cannot blame myself because nobody knows actually what the cause of autism is.' She also acknowledged that autism was 'difficult and draining' but that autism now had 'less power, there is much more time to spend on myself'.

In the third interview, there had been an improvement in the mother's experience of her relationship with autism. Mary explained that she was feeling better about autism and living a more balanced life:

> It is better than before: I am no longer afraid of autism. I can now concentrate on the other child and our marriage also. I was no longer socialising and used to keep everything to myself. Now it is a relief, the load is lesser.

Her view of Dumi also changed:

> I have hope now. I know that autism cannot be cured but I now know that Dumi has more options in life with autism. Even if it [autism] is still there, I can reach to the child and it is a relief.

She concluded with a sense of peace as she said: 'It is a relief not to question yourself all the time, now I know that any child can have autism and it is not because of what I did as a parent.'

In the fourth interview, Mary explained how she used to worry in the past but now she was 'taking control'. Joshua added that as his wife started to understand autism better she was 'relaxed now and starting to enjoy life'.

In the interview four years later, Mary explained her perspective of 'fighting autism' in the beginning versus 'accommodating' it now and concluded that it was more important to accommodate autism in the family: 'Fighting autism is draining and it makes us not have time for the kids and even for us. Accommodating it gives you more time with the kids.' She added that 'it is better now to know that you can live with it'.

**Couple C**

In the first interview, Erica explained her experience of autism: 'Autism is like a heavy thing for a mother to undergo' ['Outisme is soos 'n swaar ding vir 'n moeder om deur te gaan']. However, she gave her perspective: ‘I see him as a normal boy. I cannot love him less’ [‘Ek sien hom soos ‘n normale seuntjie. Ek kan hom nie minder liefhê nie’]. Rick added: ‘I realise that she goes out of her way with Cobus’ [‘Ek besef sy gaan uit haar pad met Cobus’].

In the second interview, Erica recalled how before, she felt negative. Since then, she has experienced changes within herself:

> I think I look ahead more now, see more light than I saw before. I didn’t want to know anything; it was all negativity. It feels good being a mommy of such a special boy. [Ek dink ek kyk nou meer vorentoe, sien meer lig as wat ek laas keer gesien het. Ek wou niks weet nie, dit was net negatiwiteit. Dit voel vir my lekker om ‘n mamma van so spesiale seuntjie te wees].

Rick confirmed this:

> I think she feels better. There is no longer that uncertainty, depression and difficulty. At least she can talk about it. She’s found the balance to do her things and to spend time with the children. [Ek dink sy voel beter. Daar is nie meer daai onsekerheid, depressie en moeilikheid nie. Sy kan darem daaroor praat. Sy het die balans gevind om haar goedjies te doen en om tyd met die kinders te spandeer].

In the third interview, Erica admitted that it could be difficult, as autism tended to pull in the opposite direction:

> At the moment things are tough. He is too lively for me. He tries to show us that he won’t do the things you say he cannot do. [Op die oomblik gaan dit rof. Hy is te lewendig vir my. Hy probeer ons bewys dat hy nie sal doen wat julle sê hy nie kan doen nie].

However, she learned more about her own capabilities:

> At first I first thought Cobus wouldn’t come right. When we got to the school they showed me the words he can say and the little things he can do. My heart nearly burst with happiness. [Ek het

> eers gedink Cobus gaan nie regkom nie. Toe ons by die skool kom toe wys hulle my die woorde wat hy sê en die dingetjies wat hy kan doen. My hart het amper uit my bors geklop van blydskap].

Rick supported his wife and spoke highly of her: ‘She manages it very well. She often sits with the children; I have quite a lot of respect for her’ [‘Sy hanteer dit baie goed. Sy sit baie saam met die kinders; ek het nogal baie respek vir haar’].

In the fourth interview, Erica reflected on her own emotional journey: ‘There are actually small things that ‘trigger’ me and then I get angry, but otherwise I no longer feel much rage. I have it under control’ [‘Daar is wel klein dingetjies wat my ‘trigger’ en kwaad maak, maar andersins voel ek nie meer so baie woede nie. Ek hou dit onder beheer’]. She added that she adored Cobus and wouldn’t want to change anything about him.

In the final interview four years later, Erica spoke about her perspective on the new diagnosis: ‘The diagnosis can be a bit frustrating. I think I coped better with it than with autism’ [‘Die diagnose kan bietjie frustrerend wees. Ek dink ek het dit beter hanteer as outisme’]. She added:

> You can’t blame yourself because it could be many things. But still in the back of your mind you’ll walk and think about what happened, so you won’t forget it. [Jy kan nie jouself blameer nie, want dit kan baie dinge wees. Maar steeds in die agterkant van jou kop loop en dink jy aan dit wat gebeur het, so jy sal dit nie vergeet nie].

Rick agreed: ‘I must say she's no longer so emotional. She's no longer so insecure’ [‘Ek moet sê sy is nie meer so emosioneel nie. Sy is nie meer so onseker nie’].

### The Mother’s Relationship with Autism: What does the literature say?

Mothers living with a child with autism seem to share many experiences. Studies by Papadopoulos (2021) and Manono and Clasquin-Johnson (2023) reported mothers’ experiences of stigmatisation, which increasingly isolated them from social relationships. Papadopoulos (2021) also reported problems with spouses and siblings, and financial strain with regard to treatment cost. Navot et al. (2017) were a voice for mothers raising girls with autism as they confirmed the need for information on girls with autism. They also touched on the social demands for their daughters and challenges associated with puberty. These mothers had to adjust to different expectations regarding their relationship with their children – some very painful and others positive. Both these studies also reported the mothers' concerns regarding their children's future. Mothers in a study by Reddy et al. (2019) expressed feeling guilty about spending less time with their other child. Manono and Clasquin-Johnson (2023) stated that they conducted in-depth interviews during 2021 and expressed how the mothers initially encountered a lack of comprehension from their immediate families and religious communities but as the process unfolded, close friends and family gradually became a source of increased support. Mothers in a study by Hirsch and Paquin (2019) blamed themselves for their child's symptoms and experienced emotions of guilt and depression.

These study findings align with the experiences of the mothers in this study. Over a period of five years, Jane's relationship with her child with autism grew from being very difficult and frustrating, and filled with questions at first, into a relationship of accepting and being in control. Mary's relationship with her child also started off as strained and she blamed herself for autism. However, their relationship improved as she was able to find a balance in life and a way to accommodate autism in it. Living life in this manner was a relief for her and gave her hope again. Erica spoke about a heaviness in the beginning of their relationship and that life with autism was challenging. However, coping mechanisms taught her to be more in control, and made her realise the strength in her love for her child.

### *Theme 6: The Father's Relationship with Autism*

#### Couple A

In the first interview, the father's relationship with autism was addressed when Thabo stated that he was in the process of accepting it [autism] but he admitted it was very hard; he even 'hate(d) the disease'.

In the second interview, the father's relationship with autism reflected acceptance. Thabo said he was 'no longer fighting it. Because I accepted that my son is autistic, I can feel like any other parent where previously I used to say maybe I am not a parent enough'. Jane mentioned how her husband 'developed a coping mechanism around autism which he did not have before'. Both parents also commented on how Thabo understood autism better and the positive emotional effect this had: 'Frustration is now less than before because now I know how to handle Taki.'

In the third interview, the father's relationship with autism also seemed better as Thabo said that 'I think I am dealing with it much better as compared to its initial stages. I think it came with accepting the condition that my son is like that and I must just love him for who he is'. He added that he put himself in his son's shoes and felt 'hurt when Taki wanted to do something but couldn't because of autism'. Jane highlighted that her husband improved a lot and 'he became a better person because it, it made him much more caring and gentler'.

In the fourth interview, the father's relationship with autism had also 'improved and keeps improving'. Thabo shared that 'seeing my son doing something [communicate] we never thought he would, give me joy'.

In the final interview four years later, Thabo supported his wife in saying 'she is a superstar. Her understanding definitely cascades to us'. In the father's relationship with autism, Thabo realised that he had to let go. He said 'the first thing I had to do was to release … I was in denial at first. As time went by, I started to accept'. He added that he now felt in control of autism: 'I can handle him and understand him now better than I did before.' Jane also highlighted that her husband was in a better position: 'He has improved a lot. I also think he has now totally accepted it [autism]. He is much more comfortable. In the beginning he was blaming himself for it, but I think he is over that now.'

#### Couple B

In the first interview, Joshua experienced autism as an obstruction between him and his child: 'It is like seeing your child inside the walls; like they have put him in a prison and I can only talk over a wall with some big glass that you cannot even hear the voice". However, Joshua desperately wanted to reach out to Dumi: 'There is hope and that strengthens my relationship with Dumi.' Mary added how patient her husband was with Dumi amidst the struggling.

In the second interview, Joshua said: 'Now I have accepted it [autism]. I am not as strongly feeling like it is defeating me than before. I don't feel like a failure any more. It [autism] is manageable.' Mary agreed that her husband was 'more relaxed now that he knows what to do so there is less stress'.

In the third interview, acceptance entered the father's relationship with autism. Joshua acknowledged that 'you cannot take autism away, but it is more like something we can work around it now'. He added that they had changed their focus more towards Dumi:

> There are things we can do now to reach Dumi. If I can say we are trying to learn a new language that will work as some sort of like communication medium to the child. It gives me hope, it motivates you to keep trying.

In the fourth interview, Joshua pointed out that the relationship had become much more manageable. He described autism and said that 'autism is no longer something I really hate, it is more something that is much more acceptable'. Mary commented on the growth in her husband when she said, 'He is less stressed now and have even improved the communication at home with the rest of the family.'

In the final interview four years later, the father's relationship with autism moved away from autism and more towards Dumi. Joshua explained that 'we don't have that much of an issue with autism. It is not something we keep on thinking about anymore. We are now trying to find a way that our son will be a better person in life'. Mary also commented on their relationship: 'Before knowing about autism he was a bit stressed, but now it helps to talk about autism and getting help from other people.'

### Couple C

There was reference to Rick's relationship with autism in the first interview when he admitted that initially, he was in 'total denial' but explained how his stance changed:

> One must just sit for a day and cry your eyes out and get your emotions under control; then you realise, okay, your child is a bit behind; he just needs more help. ['n Mens moet net 'n dag gaan sit en jou oë uithuil en jou emosies agtermekaar kry; dan besef jy dat, okay, jou kind is bietjie agter, hy het net meer hulp nodig].

Erica said that her husband had a lot of patience and spoke about the effect it had on her:

> He also gives me courage; it's because of what he does that I'm still able to stand up straight and do the same for my child' [Hy gee my ook moed, want dit is wat hy doen dat ek nog kan regop staan en dieselfde doen vir my kind].

In the second interview, Rick related to his earlier experience of autism:

> Four months ago I was so dejected and so negative about what had been going on. I had a 'no-care' attitude [Vier maande terug was ek so platgeslaan en was ek so negatief oor wat aangegaan het. Ek het 'n 'no-care' houding gehad].

He described the turning point for him: 'The acceptance of autism made life so much easier. If one moves forward and works at it, then it gets better.' ['Aanvaarding van outisme maak die lewe net soveel makliker. As mens vorentoe beweeg en daaraan werk, dan word dit beter.'] Erica praised her husband: ‘He’s handling it well. He keeps everything together and makes progress with everything.’ [‘Hy hanteer dit goed. Hy hou alles bymekaar en vorder met alles.’]

In the third interview, the father described his feelings:

> For me it's still hard that he cannot speak. It's still a bitter pill that saddens me a bit. You just have to realise that you need to be more patient with him. You know he is special and just be more patient [Vir my is dit steeds hard dat hy nog nie kan praat nie. Dit is steeds vir my ‘n bitter pil wat my bietjie hartseer maak. Jy moet maar steeds besef jy moet meer geduld met hom hê. Jy weet hy is spesiaal en net meer geduldig wees].

Erica commented how good it was for her to experience her husband’s acceptance of Cobus:

> It is great to see Rick cares – that he doesn’t push Cobus away because he can do a little less than a normal child can do [Dit is lekker om te sien Rick gee om – dat hy Cobus nie wegstoot omdat hy net ‘n bietjie minder kan doen as wat die normale kind kan doen nie].

In the fourth interview, Rick also referred to his own emotional journey:

> In the beginning I was unsure and as you move forward … if you get past the uncertainty and denial, you then reach acceptance and then you start to see progress. I have basically forgotten about it [autism] [Aan die begin was ek onseker en soos ‘n mens aanstap … As jy kom by die onsekerheid, dan ‘denial’, dan kom jy by aanvaarding en dan kom jy by aanbeweeg en dan is daar darem vordering. Ek het nou eintik basies daarvan [outisme] vergeet].

In the final interview four years later, Rick spoke about the certainty that it provided:

> I was never really happy that Cobus had autism until the diagnosis changed. I now had peace for my soul. There is no longer that uncertainty. We can now plan our future [Ek het nooit werklik vrede gehad dat Cobus outisme het nie tot en met die diagnose verander het. Ek het vrede vir my siel gekry. Dit is nie meer daai onsekerheid nie. Ons kan nou ons toekoms beplan].

Erica confirmed this: ‘I think he coped much better with it.’ [‘Ek dink hy [Pa] het dit [die nuwe diagnose] baie beter hanteer.’]

### The Father’s Relationship with Autism: What does the literature say?

Studies exploring the fathers’ perspective are scarce. A father in a study by Mount and Dillon (2014) explained that as a result of his own anxious personality, living with a child with autism affected him more than it affected his wife. A father in a study by Reddy et al. (2019) expressed his anger at the professionals as their child’s diagnosis took three years, which was much longer than in the private sector. Both studies by Mount and Dillon (2014) and Reddy et al. (2019) interviewed participants once-off. In the study conducted by De Aguiar and Pondé (2020), most fathers described the diagnosis as challenging, saddening, and shocking. The fathers in the study by Burrell et al. (2017) realised that something was wrong prior to the diagnosis of autism. The fathers experienced frustration, guilt and embarrassment but eventually felt a sense of acceptance. The diagnosis provided an understanding, although it was difficult to process. Information on autism allowed the fathers a sense of control over their circumstances. The fathers acknowledged the significance of fostering independence in their children with autism, particularly concerning employment opportunities. However, they were acutely aware of the delicate balance required in managing both their own aspirations and the expectations placed upon their children. Moreover, participants openly acknowledged their reliance on support mechanisms, be it through an informal social support network or support from their spouses.

The fact that the father’s relationships with autism in this study was constructed over a period of five years, assisted me as the researcher to document the progress in their relationship over time. Joshua’s relationship with autism started off filled with frustration and ‘hate (for) the disease’. Acceptance then played a big role as it made him feel like ‘any other parent’ who ‘love him (his son) for who he is’. He eventually felt that he understood his son better and that their relationship improved. For Joshua, autism was like an obstruction between him and his child: ‘It is like seeing your child inside the walls.' As acceptance found its place in their relationship, he became more focused on his child with autism. This assisted him to not 'feel like a failure any more'. Joshua became more comfortable in their relationship and started to think about assisting others in the same position. Autism initially made Rick feel negative and in denial of the diagnosis. Acceptance played a big role in Rick's life as it allowed him to 'accept and move forward'. Much of Rick's uncertainty disappeared as the new diagnosis allowed him peace.

### *Theme 7: The Child with Autism*

#### Couple A

In the first interview, Jane explained that autism controlled Taki to either do things out of character like 'scream when we go to the mall' or limited him by keeping him indoors instead of enjoying the outdoors with the family. Both Jane and Thabo sensed that autism frustrated Taki in that 'there is a willingness to play with other kids and to talk to them but here is autism preventing him from doing that'. Thabo stated that 'he wants to play with other kids and in the end he just claps them because he wants to play with them but cannot talk to them'. One area where Jane felt that autism could not take control of their son was when there was routine. When we have routine 'there won't be any screams or freaking out, he would just be like any other child'.

In the second interview, both Jane and Thabo experienced a change in the relationship between autism and Taki. Thabo mentioned improvement in his speech and understanding. Taki would say 'good boy' when he obeyed them and they forgot to praise him. Jane and Thabo experienced how Taki was also fighting autism. Jane explained that 'you would find that he wants to play with other kids and autism is pulling him back. He will now go and rub the other kid or hugs the other kid or do something. Before he just pretended the other kids does not exist. For me that is fighting'.

In the third interview, the couple picked up on frustration and anxiety in Taki as a result of his relationship with autism. However, both Jane and Thabo agreed that there had been improvement as there were more moments where ‘you can see Taki much more in control than autism controlling him’.

In the fourth interview, the couple were in agreement that Taki was getting stronger in his fight against autism. Jane said that ‘he would not let it [autism] control him’. Thabo mentioned that ‘he can speak when he needs something where previously he would just scream and cry every day. He also socialises much better with other children’. Jane also mentioned that they were 24 weeks pregnant with their second born and expressed her excitement at being able to see how the children would interact.

In the final interview four years later, the couple identified a lot of improvements in Taki. Thabo spoke about ‘milestones’ as he mentioned that Taki was more ‘independent and do things for himself’. Jane added that ‘you can go shopping with him and he adjusts and there is no screaming’. Jane explained that ‘most of the time he is trying to fight it [autism]’.

### Couple B

In the first interview, the couple were in agreement that Dumi experienced frustration as a result of autism. Joshua said that ‘autism is holding him back or closing his mouth’. Jane added that autism confused Dumi: ‘I see it in his eyes; he does not understand and because of that he cannot socialise.’

In the second interview, Mary shared how their focus had shifted away from autism itself towards Dumi. She expressed how it ‘gives me hope that I can deal with everything’.

In the third interview, Joshua acknowledged that Dumi still experienced frustration as a result of his communication difficulties, but he also recognised great improvements in his functioning. He understood and executed certain tasks much better.

In the fourth interview, the couple experienced improvements in Dumi’s relationship with autism. Mary pointed out that ‘he used to be confused before, when he was trying to talk to us, but now when he talks to us there is no longer that much of confusion'. There had also been improvement in social relationships as 'before, he used to just run around trying to be alone, but now he sort of socialises directly'. Joshua also identified improvement in his concentration when he spoke. There had even been improvement in his behaviour in the shops as Joshua concluded that 'it shows that he can be more independent now. It shows that if you give him a task he will do it'.

In the final interview four years later, the couple affirmed that Dumi was not negatively affected by his relationship with autism. Mary said that he 'does not feel inferior' and Joshua added that Dumi might not realise what was going on, when he said:

> I don't know if he really understands what autism is, for now. I don't think it actually came into his mind yet because that is why he keeps on trying to do things that other children does. So that shows me that he hasn't yet recognised that.

**Couple C**

In the first interview, Erica said of Cobus: 'He is a little fighter; he is very strong.' ['Hy is 'n klein vegtertjie; hy is baie sterk.' She added:

> It's because he can't communicate that he gets frustrated. I don't think he realises what is going on with him. He is still small [Dis omdat hy nie kan kommunikeer nie dat hy frustreerd raak. Ek dink nie hy besef nog werklik wat met hom aan die gang is nie. Hy is nog klein].

In the second interview, Rick focused on Cobus's frustration:

> Cobus gets extremely frustrated some days that he does not know how to express himself and other days it goes better. You don't see it in him, except for the speech [Cobus het party dae wat hy vreeslik frustreerd raak dat hy nie weet hoe om homself uit te druk nie en ander dae gaan dit beter. Jy sien dit nie in hom nie. Hy gee nie so toe nie, behalwe die spraak gedeelte].

In the third interview, Erica was more positive:

> At first, the speech therapist was worried but after six weeks she said Cobus was busy picking up

> speed. He also has difficulty in planning [Die spraakterapeut het eers ge'worry' en toe na ses weke sê sy Cobus is besig om spoed op te tel. Hy het ook 'n beplanningsprobleem].

Rick continued:

> Ag, there is still a long road ahead with Cobus, but it makes me very happy to see there is progress [Ag, ons het nog 'n baie baie lang pad met Cobus, maar dit maak my baie bly om te sien daar is vordering].

In the fourth interview, the couple were still ambivalent:

> We can see that it is frustrating for him because he wants to communicate. There has also already been a vast improvement [Ons kan sien dit is frustrerend vir hom want hy wil kommunikeer. Daar is ook al baie verbetering].

Erica added:

> Cobus pours his own little cooldrinks and spreads his own sandwiches. That tells me he's growing; he's going to get there [Cobus gooi sy eie koeldrankies in en smeer sy eie broodjies. Dit sê vir my hy groei; hy gaan daar kom].

In the final interview four years later, Erica reported that Cobus had been diagnosed with cerebral palsy and apraxia:

> The new diagnosis frustrates him. I don't think he's very bothered by it, except when he struggles to do something and he can't tell me about it. That's the only time it really bothers him [Die nuwe diagnose maak hom frustreerd. Ek dink nie dit pla hom so baie nie, tensy hy nou sukkel om iets gedoen te kry en hy kan dit nie vir my sê nie. Dit is al wanneer dit hom werklik pla].

Apart from the communication difficulty, she spoke about his achievements:

> It's actually only communication that's difficult for him. He already does little things himself. He makes friends quickly. He gets emotional quickly, but he is an extremely strong child. You won't believe it – he does athletics; he's a pro. He believes he wins and that's it. And he runs without

getting tired. [Net eintlik kommunikasie wat vir hom moeilik is. Hy doen al dingetjies self. Hy maak so vinnig maatjies. Hy kan gou emosioneel raak, maar hy is 'n vreeslike sterk kind. Jy sal nie glo nie, hy doen atletiek, hy is 'n pro. Hy glo dat hy wen en 'that's it. En hy hardloop sonder om moeg te word].

**The Child's Relationship with Autism: What does the literature say?**

There seem to be very little literature on children diagnosed with autism's experience of living with autism. Wijnhoven et al. (2019) found that children with autism experience increased anxiety and depression. In this study, the parents of the children with autism also spoke about their child's experience of autism. The fact that the children's experiences were noted in this study gives them a voice in current research. Couple A mentioned that there were times when autism took control of their child and other times when their child was more in control of autism. They recognised autism's control when their child acted outside of his character, such as screaming in a mall or when autism prevented him from talking and playing in an acceptable manner with other children. They could see the anxiety and frustration in their child. Their son was more in control of autism when he was in a good routine, and as his speech and understanding improved. Joshua explained that their child with autism would now 'hug the other kid. Before he just pretended the other kid does not exist'. As time went by, couple A experienced their child becoming even stronger and fighting autism as he became more 'independent and do things for himself'. Couple B sensed their child's frustration as a result of autism. Jane also recognised that autism confused her son, as she said, 'I see it in his eyes he does not understand and because of that he cannot socialise.' As time went by Mary pointed out that 'he used to be confused before, when he was trying to talk to us, but now when he talks to us there is no longer that much of confusion'. They also picked up improvements in his social relationships, concentration and behaviour in general. Mary concluded that her son 'does not feel inferior' in relation to autism anymore. Couple C experienced frustration in their child as Erica pointed out that 'communication difficulties frustrate him'.

They also portrayed their son as a strong individual with the characteristics of a fighter. They saw great improvement in terms of his communication and independence. However, even when his diagnosis was changed to cerebral palsy and apraxia he would still be frustrated as he struggled to communicate his needs.

### *Theme 8: The Sibling's Relationship with Autism*

#### Couple A

In the final interview, the couple agreed that having a sibling positively affected Taki. Jane explained that 'Taki can express himself better and being more sympathetic to other people'. Thabo also said that he thought autism 'brought them closer because Taki started to share'.

#### Couple B

In the first interview, the parents experienced the sibling relationship as solid. Mary explained that 'he just sees his brother and there is nothing wrong with him'. Joshua expressed his joy in how they cared for each other: 'It gives me pleasure to see his older brother protecting Dumi.'

In the second interview, in commenting on the sibling relationship, Joshua explained that:

> Autism is not a good thing because we now spend much more time trying to deal with autism. Every chance we get we try and show love so that his older brother does not feel neglected. Autism is time consuming.

Mary expressed her concern about the future of the sibling relationship. However, she was content at the time to explain to the sibling that 'You and your brother might not think the same way'.

In the fourth interview, the couple agreed that autism did not have an impact on the sibling relationship. Mary said that 'the young child does not really see what is happening with Dumi because they enjoy their company because they have become like naughty boys'.

In the final interview four years later, the couple were in agreement that autism did not have an impact on the sibling relationship. Mary said that 'Dumi doesn't see any difference with his brother, he treats him normal' and Joshua said in support that 'they are friends, they play together, they have their difficulties and fighting and stuff like that, but they are friends'.

### Couple C

In the first interview, the couple described a normal sibling relationship: 'They sometimes clash like a typical brother and sister. When she gets hurt he helps her' ['Soms 'clash' hulle soos tipiese boetie en sussie. Wanneer sy seerkry dan help hy haar'].

In the third interview, Erica was even more positive: 'I'm just glad they click like brother and sister' ['Ek is net bly dat hulle kliek soos boetie en sussie'].

In the fourth interview, Rick confirmed this: 'These two accept each other' ['Hierdie twee aanvaar mekaar']. Erica also mentioned moments of conflict between them.

In the interview four years later, Erica said of the siblings: 'They are also very close. They'll stand by each other. His sister accepts him as he is' ['Hulle is baie 'close' ook. Hulle sal bymekaar staan. Sy [jonger sussie] aanvaar hom soos hy is']. Rick agreed: 'You still get your sibling rivalry but they're also inseparable' [Jy kry maar steeds jou 'sibling rivalry' maar hulle is ook onskeidbaar'].

### The Sibling's Relationship with Autism: What does the literature say?

Research on siblings when their brother or sister has autism is inconsistent. The relationship can be characterised by feelings of warmth, affection, compassion, gratitude, empathy and comprehension (Connell et al., 2014; Guidotti et al., 2021; Iannuzzi et al., 2022; Watson et al., 2021). Watson et al. (2021) added that the presence of a sibling diagnosed with ASD influenced the typically developing sibling to develop coping skills. Van der Merwe et al. (2017) concluded that the siblings' relationship becomes more positive as they grow older.

Negative sibling relationships are also prevalent and can be characterised by anxiety, conflict, anger, social isolation and avoidant behaviour (Connell et al., 2014; Guidotti et al., 2021; Iannuzzi et al., 2022; Watson et al., 2021). Longobardi et al. (2019) found that behavioural difficulties in the child with autism are associated with negative sibling relationships. Watson et al. (2021) reported that siblings have assumed responsibilities that surpass the expectations for their developmental age and phase. For some, their sibling with autism affected their social life as they were subject to disapproving comments from others. Papadopoulos (2021) indicated that having a child with autism influenced the mothers' relationship with their other children as the child with autism demanded more time from the parents. There were, therefore, less time available to spend with their typically developing children.

This findings of this study align with those in the literature as it found elements of both the positive and the negative in the sibling relationship. Couple A concluded that having a sibling positively affected their child with autism. Joshua said that he thought autism 'brought them closer because [child with autism] started to share'. Couple B's experience of the sibling relationship started off by describing the sibling relationship as not being influenced by autism. Mary explained that 'he just sees his brother and there is nothing wrong with him'.

After some time, the participants' understanding of the sibling relationship changed as their concern grew because of autism's time-consuming nature. Joshua explained that 'autism is not a good thing because we now spend much more time trying to deal with autism. Every chance we get we try and show love so that he (their other child) does not feel neglected'. However, towards the end of our journey, the participants concluded that autism did not have an impact on the sibling relationship, as Mary stated, 'they enjoy their company because they have become like naughty boys'. Couple C were consistent in their experience of a good sibling relationship characterised by acceptance.

### *Theme 9: The Community and Extended Family*

#### Couple A

In the first interview, when discussing their extended family, Jane mentioned that they (extended family) did not recognise autism: 'They do not know autism. They only know that Taki has speech problems and see the child as being spoilt.' Jane was of the opinion that they did not want to know about autism. Thabo explained that they had not told the extended family about autism as they believed in bewitchment and ‘they (extended family) would suggest that we take our child to the sangoma’. In the same interview Jane pointed out that most people in the Black communities would only be familiar with autism if they had such a child themselves. She said that ‘most, if not all, Black families don’t know about autism. They would think it is some sort of witchcraft or something’.

In the second interview, the focus shifted. Both Jane and Thabo were in agreement that the extended family did not understand autism: Jane reiterated that the extended family still saw only that Taki had a speech problem; they still thought he was ‘spoilt’. Thabo stated that there were different sides to the extended family knowing about autism: ‘I know it will be difficult for them and you have to explain it to them because most of them are illiterate. They will think he is bewitched and we don’t want to go that route. But if we tell them they can relate with it and deal with it.’ Also in the second meeting, Jane pointed out that the Black community ‘cannot relate’ and ‘do not know what you talk about’ when you mention autism. Thabo said that they will say ‘your child is bewitched’. Thabo added that ‘most of the guys like the African know nothing about this thing. The little bit that I share with them can change their mind’.

By the third interview the couple had told their extended family about autism. Jane’s parents ‘will take a long time to understand it [autism] because they have never heard of it before’, whereas her brother understood autism as he ‘had a neighbour with a child with similar characteristics so he could relate to it’. Jane pointed out that ‘society does not focus on autism the same as it focuses on something like HIV or cancer awareness’.

In the fourth interview, the couple again expressed their frustration as they felt most of the extended family did not understand autism. Jane said that they ‘see him with an inability to speak and, now that that has improved, they think he is fine and has outgrown it [autism]’. Thabo said that his brother-in-law was educated and understood autism. The couple were in agreement that there was a ‘slight improvement’ in the understanding of such disorders in society but Thabo added that awareness in specifically Black communities could still improve.

In the final interview four years later, the couple had experienced some form of understanding from the extended family: Jane stated that because ‘they (extended family) understand that their child is different, it helped them to accept him’. Thabo added that they, however, ‘don’t understand autism.’ The couple were in agreement that there was now a better awareness of autism in communities. Thabo concluded by saying that ‘we need more awareness and a support structure’.

### Couple B

Although, in the first interview, Mary experienced some members in the extended family as very supportive, for Joshua, the opinions of others hit home as he said, ‘To me they are just views, they don’t know what they are actually talking about.’ Joshua stressed that he first wanted to understand autism before dealing with the extended family’s opinions. As he explained: ‘I just told them that “my child is not talking”, to stop the comments.’ Joshua added that the community needed to be more aware of autism.

In the second interview, Mary explained that in their extended family her mother did not accept autism; she believed that Dumi was bewitched. She said that her mother did not want her help in understanding autism better. Within the bigger community, Mary said confidently: ‘I can now teach my child how to stand up for himself, not having to hide him from society.’

In the third interview, Mary explained that her mother perceived them as being bewitched:

> After the marriage my mom thought that because we stayed five years in the marriage without having a child – and in our culture that is a bit too long – so my mom thought that I was bewitched. Now, because the child has autism, this sort of confirms what my mom said that Dumi is bewitched and has now got autism.

She added that her anger stemmed from the fact that ‘my mom does not want to accept or listen that some of the things in life you cannot control’. Joshua added that they could give her more information but he was unsure whether it would assist.

In the final interview four years later, turning to the extended family, Joshua said that his mother understood autism whereas Mary said that her mother still thought their son was bewitched. Mary explained the effect on her when she said, ‘I don’t feel comfortable if my mom spends more time and become attached to him. We don’t know what maybe she will try to help as she might do something wrong that counteracts what we think.’ They also experienced opinions from the wider community where Mary said that they think ‘a person who has autism is crazy’, and Joshua said that ‘some people think we were over-reacting and fussed over nothing because we kept on telling them he is autistic. Others thought we are just running from the fact that he needs to be taught how to behave’.

**Couple C**

Looking at the extended family in the first interview, Erica welcomed the family’s acceptance of Cobus: ‘The family treats Cobus like a normal boy and that’s how I want it’ [‘Die familie hanteer Cobus soos ‘n normale seuntjie en dit is hoe ek dit wil hê’]. Rick added: ‘The parents on my side know he has a handicap. At least they give a bit more attention now’ [‘My kant se ouers weet hy het nou bietjie van ‘n agterstand. Hulle gee hom darem nou bietjie meer aandag’].

In the second interview, Rick spoke about improvement: ‘You can see that Erika’s parents are also no longer so negative. It is better’ [‘Jy kan sien Erika se ouers is ook nie meer vol van daai kwaadgeid nie; dit is beter’]. He added: ‘It is to get those people to realise that it isn’t an illness; it is just a small thing’ [‘Dit is om daai mense op ‘n verstaanpunt te bring dat dit nie ‘n siekte is nie, dit is net ‘n klein dingetjie’].

In the third interview, the couple spoke about a difficult relationship with the one side of the extended family. There had been conflict with Rick’s parents about arrangements regarding Cobus:

> It doesn't feel as if my parents really care. I am not going to try to keep the peace anymore; it just causes trouble. It is emotionally draining to keep the peace between everyone' ['Dit voel nie of my ouers werklik omgee nie. Ek gaan nie meer probeer om die vrede te hou nie; dit bring net moeilikheid. Dit is emosioneel dreinerend om die vrede tussen almal te bewaar'].

In the fourth interview, the couple spoke about difficulties in their relationship with the extended family, as Erica explained:

> They blame me for everything. I'm not going to worry about what they think or say. The in-laws are completely out of the picture; it's better that way. There's no longer that incessant fighting. [Hulle blameer my vir alles. Ek gaan nie meer 'worry' oor wat hulle dink of sê nie. Die skoonfamilie is helemal uit die prentjie, alles is beter so. Dit is nie meer daardie aanhoudende bakleiery nie].

Rick liked the fact that Erica's brother treated Cobus as a normal child:

> Her bother and those people carry on as if he's a normal child. It's also nice when people treat him as if her were normal because it gives us as a chance to relax a bit. [Haar broer en daai mense, hulle gaan aan asof hy 'n normale kind is. Dit is ook lekker as mense hom hanteer asof hy normal is, want dit gee ons kans om bietjie te 'relax'].

In the final interview four years later, Erica noted developments in the relationship between Cobus and her parents now that he had been diagnosed with cerebral palsy and apraxia:

> They have been with us to Nuwe Hoop School many times. Then you see the different disabilities and it affects a person. I don't think my parents think there's anything wrong with Cobus. They believe that when the time is right he'll be fine. [Hulle was al baie keer saam met die kinders by Nuwe Hoop. Dan sien jy die verskillende 'disabilities' en dit raak 'n mens. Ek dink nie my ouers dink daar is fout met Cobus nie. Hulle glo vas wanneer die tyd reg is sal hy reg wees].

### The Community and the Extended Family's Relationship with Autism: What does the literature say?

Literature relating to the extended family speaks of different perspectives. Hutton and Caron (2005) reported that most of the grandparents in their study were accepting of their grandchild's diagnosis, although some were seen as not accepting. Most of the parents' siblings were accepting and supportive, while only some were not actively involved with the child with autism. Anyanwu et al. (2019) added that extended family members sometimes assisted with childcare or financial assistance. A study by Prendeville and Kinsella (2019) indicated that the role of the grandfathers was overwhelmingly positive and that the grandparents played a strengthening role in the family systems. Hillman et al. (2017) indicated that the absence of verbal communication and inappropriate autism behaviour presented difficulties for grandparents to connect with their grandchild. The grandparents also experienced emotions of concern, despair, and extreme highs and lows.

In this study, couple A agreed that the extended family did not understand autism. This caused frustration as they 'do not know autism, they only know that (child with autism) has speech problems and they see Taki as being spoilt'. Joshua stated that his brother-in-law is educated and understood autism. The fact that education plays a big role in the awareness of autism was very prominent. Couple B experienced support from some of the extended family members and Joshua's mother had a good understanding of autism. However, couple B was also exposed to a lot of unwanted opinions from the extended family. According to Mary, her mother did not want assistance to understand autism better. For this reason, she was uncomfortable for Dumi spending time with her mother as she feared that she could negatively influence him. Couple C welcomed the fact that part of the family treated Cobus like 'a normal boy'. However, they also experienced difficulties in the relationship with the extended family. Erica said that her in-laws 'blamed her for everything, but it was better as they were not in the picture anymore’. She was also aware of her parents’ belief that Cobus, later diagnosed with cerebral palsy and apraxia, would completely recover.

Religious views in communities also seemed to play an integral role. A study by Cloete and Obaigwa (2019) addressed the community’s views of the causes of autism. They identified three traits as contributing factors to autism: the woman (as the main cause), marrying into the wrong tribe, and supernatural causes. Kamau (2017) corroborated this and also found that after diagnosis, parents would take their child with autism to a religious leader or traditional healer before seeking other interventions. Responses in a study by Reddy et al. (2019) confirmed these religious practices.

In this study, both couples A and B agreed with these authors as they referred to their extended family’s view of bewitchment as a cause of autism. Joshua stated that ‘they (extended family) would suggest that we take our child to the sangoma’ and ‘they will think he is bewitched’. Mary mentioned that ‘my mother did not accept autism, she believed that Dumi was bewitched’. She added that the community reasoned that ‘a person who has autism is crazy’.

### *Theme 10: The Future*

#### Couple A

Talking about the child’s future in the first interview, Jane had a lot of questions like, ‘will he grow into a normal young man, is he going to be interested in girls, what is going to happen?’ However, she concluded that those questions would remain unanswered for the time being.

In the fourth interview, Jane experienced mixed emotions as she thought about Taki’s future. They were expecting another baby boy and ‘the fear of having another autistic child resurfaced’. However, she was also hopeful because ‘I can see he does not allow autism to punch him around and control him’ and hoped that he ‘will be able to develop ways to deal with it (autism) and live a normal life’.

In the final interview four years later the couple spoke with hope about the future. Jane said ‘now there is a space of triumph to say we have soldiered on, we have pushed and we are still soldiering on and also for me it is to give hope and not to let your life revolve around it [autism]’. Thabo also envisioned ‘positive things’ and ‘a lot of improvement’.

**Couple B**

In the first interview, the couple had future dreams for Dumi. Joshua said, ‘I would like to see him have a relationship’ and Mary hoped that Dumi ‘one day can ask me questions like that boy (in the park)’.

In the second interview, there was a focus shift as Joshua explained that their future plans were to start a part-time farming business. He reasoned that the income would support them with Dumi (‘The finances will give us more to fight against autism with things like nutrition and a place where he can join for swimming’) and ‘Anxiety will be low and maybe we might have more time which will help with the bonding’.

In the third interview, talks about the future focused less on autism per se and more on what support Dumi would need. Joshua spoke about the importance of the family business: ‘If he does not get a job we will have something that if we die we will give him something to sustain himself with.’ Mary said that although she wanted him to have a significant career, ‘now I know that Dumi can grow up to be something else that is not as high profile and that also makes me happy.’

In the fourth interview, the couple seemed less worried about Dumi’s future or the fact that their child had autism. Joshua said that they started their business and were selling chickens. He hoped that his son with autism would be able to learn a trade.

In the final interview four years later, the couple concluded that they ‘would like to see Dumi sustain himself.’ Their business had not succeeded. It was therefore important that Dumi would be able to stand on his own feet in the future.

**Couple C**

In the first interview, talks about the future for Erica was focused on the fact that they had to get Cobus into a special needs school: ‘So, that’s the way forward for us: to get Cobus to a better place’ [‘So, dit is die pad vorentoe vir ons: om vir Cobus op ‘n beter plek te kry’].

In the second interview, the couple seemed optimistic:

> Cobus was diagnosed five months ago. It is unbelievable what we’ve already done in the past months. There is a light that shines and already somewhat fewer uncertainties. In a year we’ll be able to make other people more positive with their circumstances. [Cobus is vyf maande gelede gediagnoseer. Dit is ongelooflik wat ons al gedoen het die laaste maande. Daar is ‘n lig wat skyn en al bietjie minder onduidelikhede. Oor ‘n jaar begin ons weer vir ander mense positief kry met wat hulle omstandighede is].

In the third interview, Rick compared the doctor’s initial diagnosis with the opinions of specialists later on:

> When the doctor said on the first day that he would never speak or function on his own and that sort of stuff, my whole world collapsed. And now at New Hope he’s seen all the specialists—he’s going to be a normal boy. [Toe dokter daai eerste dag gesê het dat hy nooit sal kan praat of self funksioneer en daai tipe goeters nie, toe het my hele wêreld in mekaar gestort. En nou by Nuwe Hoop het hy al die spesialiste gesien – hy gaan ‘n normale seuntjie wees].

Erica spoke about her dream for Cobus: ‘We want him to achieve what any other child achieves’ [‘Ons wil hê hy moet bereik wat enige ander kind bereik’].

In the final interview four years later, Erica admitted that Cobus’s future was uncertain:

> He has already made so much progress, but now I wonder how much more progress before he’s finally independent [Hy het nou al so ver gevorder, maar nou dink ek aan hoe ver gaan hy nog vorder voor hy uiteindelik op sy eie moet wees].

Rick ended on a philosophical note: ‘Erica has already planned the whole thing so I can take it day by day’ [‘Erica het al die hele plan voorberei, so ek vat dit dag vir dag’].

### A Future with Autism: What does the literature say?

Conversations about the future also surfaced in literature. Participants in a study by Papadopoulos (2021) experienced frustration and worry about the child’s future. Navot et al. (2017) specified that these worries were about the future functioning of a child with autism: would they be able to hold a job, maintain a relationship and care for a family of their own? The experience was consistent as a study by Manono and Clasquin-Johnson (2023) expressed mothers’ concerns and uncertainty about their child's future, education, and ability to transition to adulthood.

These conversations also surfaced in this study. In couple A, Jane had future-related questions: ‘Will he grow into a normal young man; is he going to be interested in girls; what is going to happen?’ But she realised that such questions would remain unanswered. As time went by they expected another baby boy and feared that there might be a chance that their second son would also have autism. Couple B spoke about their dreams for their child. Joshua ‘would like to see him have a relationship’ and Mary hoped that her son ‘one day can ask me questions like that boy (in the park)’. They also tried to invest in a future by starting a part-time farming business to assist with an added income to support their child with autism’s extra needs, but the business did not succeed. As time went by the couple seemed less worried about the future of their child with autism and concluded that they ‘would like to see him (child with autism) sustain himself’. Couple C spoke about short- and long-term thoughts about the future. Erica was firstly focused on the fact that they had to get him into a school catering for special needs. She then spoke about her dream for Cobus: ‘We want him to achieve what any other child achieves.’ Erica admitted her fear: ‘He has made so much progress, but think how much further he must progress before he can eventually be on his own.’

## Findings related to Objective 2: Development of the Narratives

The previous section discussed the themes derived from the interviews. The themes were also linked to relevant literature. The themes highlight the common threads in the stories of the three couples. This section will focus on the construction of each couple's narrative consisting of four interviews over a period of a year and then one interview four years later. This will be done with the focus on narrative inquiry and the narrative practices discussed in chapter three. This section is not written as a transcript of interviews but merely as a story of statements in order to herald identity statements. The researcher deemed it important to honour the storying process of each participants' narrative and to capture the construction of their identities throughout the meaning-making process. White and Epston (1990), cited in Freedman and Combs (1996, p. 10) speak of the essence of a narrative:

> In striving to make sense of life, persons face the task of arranging their experiences of events in sequences across time in such a way as to arrive to a coherent account of themselves and the world around them… This account can be referred to as a story or a self-narrative. The success of this storying of experience provides persons with a sense of continuity and meaning in their lives, and this is relied upon for the ordering of daily lives and for the interpretation of further experiences.

De Shazer (1991), cited in Freedman and Combs (1996, p. 92) maintains that, 'Like any story, each case…has a beginning, a middle and an ending. Like any story, the conversation is held together by the patterns involved, by the plot'. For the purpose for this study I discuss each narrative as having a beginning, a middle (the plot) and an ending.

### *Couple A: Thabo, Jane and Taki's Narrative*

#### Coming to Terms

Thabo and Jane are a Venda-speaking couple living in Pretoria. I met them shortly after the diagnosis that Taki, their then three-year-old son, had autism. This news shattered Thabo, who battled to reconcile himself with the diagnosis and stressed how he hated autism. Taki did not speak and Thabo was deeply hurt and concerned by the lack of communication between father and son. Jane also found the diagnosis heart-breaking. She felt alone and afraid and she was bombarded by unanswered questions about her little boy and his prospects. Yet, ironically the diagnosis was also 'liberating': her son's condition now had a name. She empowered herself by doing her own research on autism and the knowledge she uncovered was enlightening. This had a powerful positive effect on her relationship with her husband. Thabo confided that 'it bought us closer … because she was also supporting me with information'. Although a barrage of questions assailed them about the kind of future that faced their son, information about autism illuminated the darkness. The couple began to understand autism and their growing insights helped them cope. Taki experienced intense frustration as a result of autism and the limitations it imposed on him; however, the one thing that autism could not control was the sound daily routine his parents provided for him.

A pressing decision that confronted Thabo and Jane after the diagnosis was whether to disclose Taki's autism to their parents. They decided to keep the diagnosis to themselves at that stage as they felt that the cultural discourse of bewitchment prevalent among traditional African families might cloud their parents' response to Taki's condition. They were apprehensive that their parents would resort to traditional folk wisdom and would advise Thabo and Jane to consult a sangoma (a traditional healer). According to Jane, Black communities were largely uninformed about autism. Jane explained that 'they would think it is some sort of witchcraft'. In many cases only African families with some experience of a child with autism were familiar with its symptoms and medical causes.

### Acceptance and Improvement

Over time, Taki's symptoms of autism improved, while others, like his speech difficulty and outbursts of screaming, persisted. Thabo and Jane's own grasp of the diagnosis clarified, and learning more about autism added positively to their identities as parents of a child with autism. Jane aptly summed it up when she said that knowledge 'makes you realise that you are stronger than you think you are'.

As individuals, Thabo and Jane were gradually transformed: Jane assessed her own personal growth and recognised that she had become too independent and had to learn to accommodate Thabo again, whereas Thabo discovered an inner peace about autism that allowed him to focus more on Jane and their relationship. They experienced a strength between them that was not present before.

Taki also started to fight autism as he was visibly proud of himself when he succeeded in communicating or understanding instructions. Unfortunately, autism never entirely disappears, and this would frustrate him, especially when he could not speak. Thabo and Jane stuck to their decision not to tell their parents about autism. However, as the Black community in general were uninformed about autism, Thabo felt he had a role in changing social perspectives by sharing what he knew with his friends in the community.

### Becoming Stronger

Taki's symptoms of autism continued to abate, and expanding knowledge about autism made an important contribution to Thabo and Jane's wellbeing. Thabo's strength became more visible and was evident when he talked about his relationship with his wife. He said that 'autism brought us together ... in the beginning she was strong and I was not at that level ... now we are almost at the same level'. Jane recognised the change in her husband, who had become 'caring and gentle'.

As Jane spoke, I sensed her love for Taki. His good days gave her joy and when he was in a difficult space, she was prepared to do anything to relieve him. In general, coping with autism became much easier for her. When we had our third interview, Jane was pregnant with their second child. She admitted that in the beginning she had been overcome with the concern that she may bear another child with autism, but as the pregnancy progressed she accepted whatever would come her way and was generally happier. The bond between Thabo and Jane grew even stronger as they described the mutual support and appreciation they felt for each other. Thabo and Jane recognised Taki's frustration and anxiety in certain situations but also identified moments when he was more in control than autism and showed sympathy towards other children.

Thabo and Jane also took another major step in their encounter with autism: they shared their son's diagnosis with their parents. Although they realised that their parents needed time to comprehend it fully, they realised that this might be the first breakthrough in their journey to understanding autism. Jane expressed her desire that society would highlight autism awareness in the same way that it focuses on HIV and cancer awareness.

### Taking Back Control

Thabo and Jane's experience demonstrated how their approach to autism was changing. Although it was still present, it no longer controlled their little family. This change in perception allowed them to get to know Taki better and to enjoy his unique personality. Jane was adamant that she 'would not want to have him any other way'. She reflected on her own relationship with Taki and admitted that having him as her son had stretched her to become more than she ever thought she could be. Thabo also spoke warmly about his relationship with Taki. He was delighted as he observed Taki accomplish things that before, would have been unthinkable.

Both Thabo and Jane agreed that autism had not damaged their marital relationship. In Jane's apt words: 'I told myself that we got married way before autism and it was not even there when we got married. It cannot come now and dictate as to how we live our lives.' Thabo and Jane also witnessed Taki's brave fight against autism. Although autism was still evident at times, Taki could now communicate his needs and consequently his outbursts decreased. Taki interacted better with friends and was happier and stronger. This made his parents hopeful for his future. Meanwhile, Jane and Thabo received the news that they were expecting another baby boy and fears of having a second child with autism resurfaced. Foremost in Jane's mind was the statistic that autism affects more males than females. Her fear and distress returned and she was plagued by doubts. But regardless of the uncertainties, she also shared her excitement about how the two brothers would interact with each other.

Within the extended family, autism remained a sensitive topic, and Thabo and Jane shared their frustration about their families's lack of understanding. Jane was concerned that the family might think that the improvement in Taki's speech meant that he would outgrow his difficulties. Where most of the family were apathetic towards autism, Thabo was enthusiastic about his brother-in-law who understood what autism was about. He attributed his brother-in-law's perspective to his education and Thabo appreciated his relative's unconditional love for and acceptance of Taki just as he was. Again, Thabo and Jane regretted the very limited awareness about autism, especially in Black communities.

### Co-existing

When we met four years later, autism still occasionally challenged Thabo and Jane. Nevertheless, they were grateful for Taki's improved speech and comprehension and they were constantly alert to how essential it was to prepare him for any change in his routine. Knowledge about autism was a beacon of hope for Thabo and Jane, especially positive stories of other families in the same situation. Jane's motto was to be in control of autism at all times. She was determined not to give up and always sought better coping strategies. Her inner peace was tangible and she voiced her acceptance when she said, 'I have stopped to say it [autism] is good or bad, it is what it is. This is my life, this is how it is.'

I also observed a major change in Thabo's identity: he could now talk openly about autism and was at peace with it. He reflected on his own development, saying, 'The first thing I had to do was to release. I was in denial at first. As time went by, I started to accept autism. I can handle him [Taki] and understand him [Taki] now better than I did before.' Jane attributed this transformation to the fact that Thabo had stopped blaming himself for autism; he recognised Taki's progress and now understood and accepted autism. As a couple, Thabo and Jane supported each other and took turns during rough periods to manage the effects of autism. They spoke about their closeness and were determined that they would not let autism drive a wedge between them.

Thabo and Jane spoke about Taki with pride, especially mentioning his independence which he showed by making himself snacks and showering without help. Taki also revealed striking self-awareness. He once remarked to his mother, 'Mommy, I am different.' Moreover, he now consciously fought autism. As Jane explained, '[Taki] will have a meltdown or say something that he sees is not appropriate then immediately say, 'Guys, I am sorry.' Thabo and Jane also gave a glowing description of how protective Taki was of his little brother; having a sibling stimulated his attempts to express himself and show empathy towards others. As Jane explained, 'I think seeing his little brother fragile [vulnerable] and crying helped him to evoke and think about other people as well.'

The perspective of Thabo and Jane's parents also gradually changed as they came to accept that Taki was different. They still did not understand autism but they respected Thabo and Jane's refusal to consult a sangoma or a priest. Jane remarked, 'I think they have come to realise that by denying and not accepting [Taki], they are also denying themselves of the relationship with him.' Thabo and Jane noticed their greater awareness of autism and stressed the importance of education and good support structures. Thabo closed off our discussion by envisioning a future for Taki. Jane said, 'From a space of triumph we have soldiered on; we have pushed and we are still soldiering on and for me, it is to give hope and not to let life revolve around autism.' Thus, my journey with Thabo and Jane ended on a powerful and triumphant note as they shared their joint decision to co-exist at peace with autism.

### A collection of narrative practices from Thabo, Jane and Taki's journey

***Thin description***. Thabo and Jane's journey with autism began where they told their story as a thin description of how autism impacted them. Thabo developed a relationship with hatred because of autism and for Jane autism was accompanied by worry and isolation.

***Unique outcome***. Jane learned that information about autism could become a guiding light during these challenging times. This newfound knowledge not only empowered her but also shaped her identity, fostering a sense of independence that had not been there before. A unique outcome was her realisation that this transformation was not confined to personal growth but it also had intense implications for their marital dynamics. Recognising the importance of inclusivity in their relationship, Jane started to involve Thabo more actively in decision-making processes, moving away from coping in isolation. This shift not only strengthened their marriage but also allowed Jane to construct a new meaning in her relationship with autism. Letting go of autism's control made way for acceptance as she realised that, 'I have stopped to say it [autism] is good or bad, it is what it is. This is my life, this is how it is.'

***Problem-saturated story***. The problem-saturated story of autism resurfaced when Jane was pregnant with their second son. It created uncertainty as Jane referred to statistics suggesting a higher likelihood for boys having autism. Although my journey with the couple came to an end at that point in time, Jane's inner strength remained undiminished, bolstered by her acceptance of autism and the potential friendship between her sons.

***Identity formation.*** Identity formation was significant for Thabo as his relationship with autism changed. Hatred made way for an inner peace about autism which strengthened their marital relationship. A unique outcome connected to this was when Jane observed that Thabo became more

’caring and gentle’. This statement positively impacted Thabo’s self-perception and their marital relationship as he discovered how the acceptance of autism set him free.

***Externalising autism.*** Externalising autism allowed Thabo and Jane to construct autism in Taki’s life in such a way that would minimise the dominant story of autism as a burden, and instead highlight and focus on the alternative moments where Taki’s unique personality and achievements (Taki demonstrating affection) were celebrated. This approach allowed Thabo and Jane to recognise their son’s strength and their growing love for him as an alternative story with possibilities. Taki’s stronger identity was also evident towards the end of our journey as his parents reflected on his growing independence and emotional awareness.

***Alternative narrative****.* An alternative narrative emerged through the support and insights of Thabo's brother-in-law, who had previous experience with autism. This provided Thabo and Jane with additional perspectives and strategies, enriching their understanding and management of their situation. The name of the couple’s final interview gained significant meaning as being able to co-exist with autism empowered them to find a balance within their family system. Jane and Thabo reflected on Taki’s grandparents’ story as one that held little knowledge about autism. As a result of a lack of information, they initially avoided Taki. As time went by, they could construct a new relationship with their grandson. They were able to put their lack of knowledge about autism and the African influences aside (their problem-saturated story) as they focused on building a relationship with Taki. This was a wonderful unique outcome as it has the possibility to create new relational experiences within the family system and construct new meanings. This narrative highlights not only the challenges posed by autism but also the profound growth, acceptance, and resilience that can emerge from navigating such a life-altering experience.

### *Couple B: Joshua, Mary and Dumi's Narrative*

#### Devastation

Joshua and Mary are a Zulu-speaking couple living in Pretoria. I met them soon after the diagnosis of Dumi, their then five-year-old son. Dumi's brother is almost four years older than him. Joshua was devastated by the diagnosis: the news was unexpected and the doctor's blunt verdict 'There is nothing we can do', left Joshua in complete despair. All his dreams for Dumi suddenly disintegrated. Joshua said that autism was 'killing me inside'. He was desperate to get closer to Dumi. He found autism was 'something that is taking my child away from me'.

Mary found the diagnosis confusing, and it was very hard for her to process the news. She soon realised that autism was incurable and that there was nothing they could do to eliminate it. They had no choice but to live with it. Mary experienced intense frustration as autism deprived her of the warm mother-son relationship she yearned for. It was evident that autism also exasperated Dumi as it prevented him from doing what he wanted to do. Joshua said that autism 'have [sic] put him [Dumi] in a prison'. Dumi also seemed confused as he struggled to socialise and communicate like those around him.

Joshua and Mary's quest for information about autism began in earnest: Mary wanted to understand how she could better support her loved ones, whereas Joshua hoped to 'find some sort of normality on dealing with things'. Their solace and hope were that that they were together in this situation, but for Joshua the intense weight and pressure of autism on their marital relationship was worrying.

Amidst everything, Joshua and Mary spoke confidently about the relationship between Dumi and his brother, as the siblings enjoyed each other's company. Although Joshua's parents supported them, Joshua admitted that, because of the difficult space he found himself in personally, he could not also manage the extended family's views regarding Dumi. To avoid difficult conversations he decided to tell the family that Dumi could not talk and did not expand further. Joshua emphasised the importance of awareness of autism in society.

### The Power Struggle

A few months after the previous conversation, Joshua and Mary still suffered under the burden of autism. Mary explained that they had to 'fight to get through to their child'. For Joshua the fight was never-ending. He had to reconcile himself with Dumi's emotional distance, which angered and grieved him.

As they continued fighting autism, their view began to change. Joshua spoke about the value of equipping himself with knowledge about autism. Acquiring information reduced his stress, gave him hope and strengthened his relationship with his son. Learning about autism assisted Joshua to understand, for example, a sensory meltdown, which relieved the pressure Dumi felt in the presence of onlookers in social situations.

Initially Mary felt guilty that she had done something wrong during her pregnancy and, in the process, had not protected Dumi. Slowly she realised that that autism was not her fault as its exact cause remains unclear. As her views changed, she found that autism lost some of its power and she could focus more on Dumi and less on autism. She could now encourage Dumi to grow stronger within himself as she did not feel the pressure from society to hide him anymore. Joshua also discovered an inner strength which he expressed by saying, 'I do not as strongly feel like it [autism] is defeating me like before.' This lightened his burden and he found autism more manageable.

Joshua and Mary agreed that autism had brought them closer and this new intimacy diminished autism's power to affect their marriage. Mary re-imagined their experience as fighting 'a big battle now' and was reassured that they had 'more solutions to reduce the power of autism'. Joshua looked ahead as he told me about their business plan to start farming. The success of this business venture would assist with the extra expenses caused by autism and would in turn lessen his anxiety. Joshua remained vigilant of their need to balance the time spent between their sons as they wished both to experience their love equally. They also acknowledged that Dumi and his brother might pick up on differences between them and that they might have to explain to Dumi’s brother in future why they saw and did things differently. Mary’s burden was exacerbated by the cultural discourse of bewitchment which shaped how her own mother perceived Dumi. She tried to help her mother to understand autism, but it remained challenging.

### Acceptance and Improvement

After some time, Joshua and Mary received test results indicating that Dumi had an iron deficiency. This new information and a change in medication gave Joshua hope that practical steps could be taken to improve Dumi’s prospects. It dawned on Joshua that autism could not rob them of Dumi and that they were competent to manage autism. Slowly Joshua’s pain over his son lessened as he accepted the nature of autism and started to focus on building a sound relationship with his son. This realisation helped the couple to live with autism and to act proactively instead of allowing uncertainties to consume them like they had in the beginning. Fresh hope spurred them to move forward. Mary was encouraged and her fear of autism receded. Her increasing interest in and concern for Dumi, their other son and their marriage replaced her obsession with autism. Mary found it liberating to be able to talk openly and honestly about Dumi’s autism and abandon attempts to conceal it. As a result of her changed perspective, parenting became easier because she now understood Dumi’s behaviour. Contentment grew as she remarked, ‘It is a relief not to question yourself all the time, now I know that any child can have autism and it is not because of what I did as a parent.’

Joshua and Mary were further heartened as they discovered new strength in their marital relationship. Spending less time on autism allowed them more time to discuss other matters. Every now and then Joshua could still sense a frustration within Dumi, but he also noticed progress as Dumi’s overall grasp of instructions improved. Joshua and Mary’s perspective on the future changed as conversations shifted from autism towards constructive planning for their children's future. Mary initially cherished big career dreams for Dumi, but as reality set in, her only dream was for her son's happiness. Joshua realised that the onus would be on him to equip his mother-in-law with information about autism. However, Mary's uncertainty remained, as she explained:

> After the marriage, my mom thought that because we stayed four years in the marriage without having a child – and in our culture that is a bit too long – my mom thought that I was bewitched, and now because the child has autism this sort of confirms what my mom said that the child is bewitched and has now got autism.

This angered Mary as she felt that her mother did not want to listen to them or accept what one cannot control in life.

### Normality

As acceptance grew, Joshua, Mary and their sons started to experience what they called 'normal'. Mary felt more in control and less anxious. She even voiced how 'it [autism] is something that I can live with'. Joshua saw a lighter side to his wife again. His experience of autism changed: 'Autism is no longer something I really hate, it is more something that is much more acceptable.' Mary noticed how Joshua started to communicate better with his family at home. She felt they now had a 'normal relationship' whereas previously their relationship was dominated by autism and the effort to better life for Dumi. Dumi's communication and problem solving skills improved and his concentration sharpened. He acted more independently and with less confusion. Their approach to searching for information regarding autism also became more balanced. Mary explained:

> We are now more focused on [Dumi] and not really researching autism. We are no longer searching. We were fighting fires. We were hungry for survival but now we see the results. We would now rather concentrate on trying to make him develop speech and develop the survival skill of life.

Both Joshua and Mary were at peace as they observed their sons enjoying each other's company and acting 'like naughty boys'. I sensed Joshua and Mary's excitement about their up-and-running business. As I listened I also noticed that Joshua had rekindled his dream for Dumi as he realised that he would be able to teach him a trade despite his speech difficulty.

### Finding Freedom

Over the past four years Mary's perspective about autism had been transformed. The trauma of the initial diagnosis had been matched by her relief at being able to name and identify autism. Her situation centred more about 'accommodating autism in the family and not to fight it'. She described the changes as follows: 'Fighting autism is draining and it makes us not have time for the kids and even for us. Accommodating it gives you more time with the kids. It gives hope.' She found herself living a more balanced life with autism occupying only a minor part. Similarly, Joshua focused less on autism and more on developing Dumi's social skills and building his relationship with his son. He also became more hopeful and less stressed. The couple began to spend more time together: they enjoyed exercising and travelling together. Mutual understanding grew and they recognised the other's hardships and assisted where possible.

It was difficult for Joshua and Mary to pinpoint to what extent Dumi was aware of autism. On the one hand, Dumi would asked Joshua, 'Daddy, are you proud of me? Am I making you happy?' which made Joshua think that he might feel he was different from other children. On the other hand, both Joshua and Mary recognised how Dumi tried to do what other children were doing, and that made them think that he might not see himself as different from others.

However, they were always grateful for all the improvements Dumi had shown. Dumi and his brother were firm friends and did not appear to experience any difference between them. They responded to each as normal siblings.

Joshua and Mary also valued new research on the topic of autism as it provided advanced insights about its treatment. However, Joshua maintained a balanced approach to the amount of time and effort to be spent on this kind of research as he recognised that it was time-consuming and detracted from available time to be spent with their son and the nurturing of their father-son relationship.

Joshua and Mary's parents remained largely in the dark about autism. Joshua's mother made an effort to show kindness and empathy for Dumi whereas Mary's mother held to her view that he was bewitched. Mary was careful to restrict the time Dumi spent with her mother as she did not want to see his progress being undone. Joshua was always aware of social perceptions regarding autism: as parents they were either judged for spoiling Dumi or accused of poor discipline. As Dumi developed personal preferences and could thus make decisions more easily, Joshua and Mary's aspirations grew that he would be able to sustain himself in future. To share in Joshua and Mary's journey towards freedom while living with autism was indeed a learning experience and a privilege which I greatly appreciated.

### A collection of narrative practices from Joshua, Mary and Dumi's journey

***Thin description.*** In the narrative of Joshua and Mary, the emergence of autism was sudden and unexpected. Initially, autism was constructed as an overwhelming burden that dominated their lives. Joshua developed a relationship with despair and felt as though hope had abandoned him, while Mary was left with overwhelming sadness and accepted that autism would be a permanent part of their family dynamics. This thin description of autism was further highlighted as the couple reflected on how autism created a distance between them and their son, Dumi.

***Unique outcome.*** Mary was particularly weighed down by a narrative that suggested her inability to protect Dumi during pregnancy and might have contributed to autism. This story allowed a relationship with guilt to enter her life. However, a unique outcome occurred when Mary recognised that this narrative was unfounded. This realisation was transformative, enabling her to support Dumi in the development of his own identity.

***Alternative story.*** The construction of knowledge about autism emerged as a powerful alternative story for the family, empowering both Joshua and Mary as they realised that they were on this journey together. Both Joshua and Mary were confronted with the impact of their extended family's taken-for-granted ideas of autism as their beliefs and cultural discourse of bewitchment was visible. While Mary's mother persisted with this narrative until the end of our contact in the research study, Joshua's mother offered kindness and empathy towards Dumi providing a significant alternative story. Joshua held onto the power of knowledge to educate his in-laws, challenging the prevailing perceptions within the family. Although the couple remained aware that autism's problem-saturated story of being a burden could surface in Dumi and his brother's relationship in the future (which has not happened during the time of our research journey), the fact that the siblings enjoyed each other's company was of particular significance for their parents.

***Identity information.*** An alternative story emerged as Joshua and Mary's relationship with autism started to change. Defeat made way for an inner strength as Joshua experienced the burden of autism becoming lighter. Mary discovered strategies to reduce autism's control as empowerment in her story grew. Mary's own identity formation was significant as she started to talk openly about autism instead of hiding it. This unique outcome had an empowering effect on her as she described that 'it is a relief not to question yourself all the time'. Mary constructed an identity of 'we can now life with it [autism]' as acceptance settled in.

***Externalising autism.*** By externalising autism, Joshua and Mary constructed a narrative that freed them from its control. As anxiety lessened for Mary towards the end of our research journey, new possibilities emerged in constructing a story of living a more balanced life with autism. Mary reflected that as Joshua communicated with more ease, their marital bond was enhanced. As a result of this changing dominant story, the couple's focus shifted from autism to Dumi himself, improving the relationship between him and Mary. Autism's burden was also lifted for Dumi as improvement in his skills and independence was noted. This made way for constructive conversations about the family's future possibilities and more quality time as a family. Another unique outcome was when new information led to a change in Dumi's medication, reinforcing hope for a stronger bond with their son. Hope grew and uncertainty diminished as they turned their focus to their relationship with Dumi, their other son and their marriage (compared to a thin story that only focused on autism).

As the couple's story with autism progressed, their relationship with information took a back seat and their sense of self did not depend on knowledge anymore. Mary pointed out 'we are no longer searching' and Joshua expressed that they developed a balanced relationship between gathering information and spending time with the family. This narrative construction marked a profound shift from a life dominated by autism to one enriched by acceptance and mutual support.

### *Couple C: Rick, Eria and Cobus' Narrative*

#### The Power Struggle

Rick and Erica are an Afrikaans-speaking couple residing in Pretoria. As with the other two families, I met them for the first time soon after the diagnosis of Cobus, their then three-year-old son. The diagnosis deeply shocked Erica and she struggled to come to terms with autism. In her experience, Cobus was a loving little boy, capable of eye contact, but with a speech difficulty; he was capable of far more than what might be expected of a child with autism. Although Rick and Erica had intuitively felt that something was amiss with their child, the diagnosis set them on a roller-coaster of emotions. For Rick, the diagnosis made autism an inescapable part of their future. As Erica looked ahead she realised that they would have to enrol Cobus in a school that provided necessary support from speech- and occupational therapists. The burden of autism weighed heavily on Erica. But it did nothing to alter her unconditional love for her son and did not affect their mutual understanding. She also walked the extra mile to enhance Cobus' developmental progress. Rick struggled to make sense of autism and he even denied it at some point. Nevertheless, he understood the importance of allowing and processing his own emotions for the sake of his child. Sadness gave way to understanding, which enabled him to make the necessary adaptations to the family routine to give Cobus the attention he needed.

Although the events since the diagnosis initially increased conflict between Rick and Erica, they managed to work through their challenges together. Facing autism strengthened their relationship and their understanding of each other. Erica spoke about Rick with appreciation, mentioning that 'If it was not for him, we would not have been here [at the consultation] as I do not like to talk about stuff. I rather keep it to myself, but it really feels good to talk'.

Erica and Rick described Cobus as a fighter who did not allow autism to take control of his life. They attributed Cobus' frustration to his speech difficulty. He and his sister had a loving and spontaneous brother-sister relationship where they would comfort and tease each other without being negatively affected by autism. Erica and Rick's parents also loved and supported Cobus by giving him the necessary extra attention.

### Accepting and Improving

The diagnosis of autism came as a huge disappointment for Erica and Rick, and at first the future seemed bleak. As time went on, Cobus began to show more and more improvements and started to say short sentences like 'I love you'. This heralded light at the end of the tunnel. Rick saw that the problem was not his son himself, and they could focus on improving the 'symptoms' (e.g., speech difficulty). Rick and Erica felt immensely relieved. Increased knowledge about autism lessened Rick's feeling of intense sadness which the diagnosis had caused; his acceptance of autism facilitated moving forward. The uncertainty and despair that had overwhelmed Erica after the diagnosis dissipated and she could direct her energy into the joy of motherhood and spending more time with her children. She was now able to talk about autism and envisage a future.

However, it was not all plain sailing for Rick and Erica. Rick recalled how the diagnosis of autism had marred their marital relationship. They blamed and avoided each other. However, in time, they realised the importance of accepting autism, which had a positive influence on their relationship. They were together on this journey as Erica depended on Rick and trusted that he would never leave them. She could only see the speech difficulty in Cobus and described autism as being ‘camouflaged’. His frustration was still present but he made progress on many other levels. With growing excitement and joy, Rick and Erica observed their son play rugby and do pottery. Rick watched how his in-laws’ internal anger and resentment towards autism diminished. Erica looked back to the time when she initially thought Cobus would have to be placed in a home-care facility if they should pass away. As Cobus made steady progress, she realised their biggest fear was no longer a problem. Rick even looked ahead to supporting and educating others about autism.

### Being Hopeful

Rick reflected on how his world fell apart at the initial news that Cobus would never be able to speak and function independently. Progress in Cobus’s speech became more noticeable and although Cobus would require speech therapy and assistance with planning for the foreseeable future, hope emerged. Rick found managing autism easier and it no longer consumed his entire life. Similarly, although autism was still there, Erica became less aware of it. She lost her fear of autism and enjoyed Cobus like any normal boy. Hope burgeoned in a situation where autism no longer threatened as it had before. Erica hoped that Cobus would function even more independently in future, with a family of his own and an occupation. She was proud of his progress and of Rick for his care and acceptance. Rick still found it disappointing that Cobus would never speak normally and he acknowledged that he needed more patience. He and Erica stopped blaming each other for autism and spent more time together again. Cobus and his sister sustained a good relationship, unaffected by autism. However, the promised support from Rick’s mother was not forthcoming. She did not consistently take Cobus to school as was arranged, which led to him missing therapy sessions. This led to conflict in the family.

### More Progress

As time went on, Rick and Erica found that they hardly spoke about autism as the theme of their conversations centred on Cobus’ progress and the way forward. Although autism still left Rick emotional when he saw his son with his peers, uncertainty and denial made way for acceptance and progress. Erica also proudly recognised how much more effectively she coped with her anger than in the past. Her unconditional love for Cobus was not shaken. The couple also experienced fewer arguments and less grief. They stood together as a team: they both assisted with the children’s routines and allowed each other space to recharge after long tough days. Although Cobus still experienced some frustration, his ability to communicate improved as did his independence. Erica could leave Cobus to carry out tasks such as pouring juice for himself and making his own sandwiches. Cobus and his sister accepted each other and experienced the normal ups and downs in a sibling relationship, unaffected by autism. Erica was relieved when her in-laws reduced their involvement as it eased a lot of conflict. She also stopped worrying about what they thought or said. Rick saw that Erica’s family treated Cobus as a normal child which he felt gave them more time to relax.

### Moving Forward Together

Four years after our last conversation, Rick and Erica consulted a new doctor, who changed Cobus’ diagnosis to cerebral palsy and apraxia. This doctor also addressed the emotional turbulence within Rick and Erica by assuring them that mutual blame was destructive; instead she encouraged them to ‘accept it, deal with it and move forward’. The couple were reassured by the new diagnosis and realised it as a better fit. For Erica, Cobus’ apraxia meant that he knew what he wanted to do but it was difficult for him to tell them. They noticed an improvement in his behaviour and they started to understand him better. For Rick, the fact that Cobus could walk and ride a bicycle was grace from above.

He and Erica read a lot about cerebral palsy as both they and the specialists recognised that it was a miracle that Cobus could walk. Rick thought back to the day autism was (mis)diagnosed and how he had pulled the car off the highway and sat in stunned disbelief. The message that the first doctor had given the shocked parents was that ‘Cobus will never be able to talk, walk or function socially’. Rick recalled how they had decided that they would prove the doctor wrong – and Cobus had done just that.

Erica explained that Cobus had suffered brain damage at birth. During premature labour, Cobus’s lungs collapsed and deprived him of oxygen for a prolonged period. Erica’s pregnancy was complicated as a scan had initially showed triplets and she had bled badly in the early stage of the pregnancy. Her pregnancy with Cobus had also been preceded by a miscarriage five months earlier.

Although cerebral palsy and apraxia also gave them frustrating moments, Erica’s daily contact with the children meant she learned to understand intuitively what Cobus wanted or she could devise a way for him to show her his needs. She received the new diagnosis positively and gratefully as she realised it could have been worse. Rick also perceived his wife as less emotional and more stable.

The new diagnosis also removed Rick’s uncertainty, enabled him to plan the future and gave rise to a new peace, something he never experienced with the autism diagnosis. Rick and Erica’s marital relationship improved as Erica noticed ‘a light in the tunnel’ that enabled them to look forward. They found themselves engaging in more activities together as a family. Rick acknowledged that they had put blame behind them and they strove to heed the doctor’s advice to ‘manage it, make plans and move forward’.

Communication remained challenging for Cobus, especially when his family could not understand what he tried to say. Although Erica realised that they would have to rely on sign language, Cobus was a very strong child with a powerful will and he excelled in athletics. Rick observed a new balance in their relationship as parents “challenging Cobus and him challenging them”. Cobus and his sister maintained their close supportive relationship. They accepted and understood each other in their own language.

As Erica looked ahead, she “wished that I (she) could see ahead in order to prepare a path for him”. She earnestly hoped that this path would emerge before Cobus would have to fend for himself. Rick’s parents were still very upset by Cobus’ disability and struggled to accept it. Conversely, Erica’s parents did not see anything wrong with Cobus and believed that he would recover fully. Erica realised this was unrealistic and hoped they would eventually come to terms with the concrete situation.

As my journey with Rick and Erica came to an end, their challenges were still present. However, my reward lay in the courageous way they saw themselves moving forward together with their son. What a pleasure to know that, through thick and thin, they do not travel alone.

### A collection of narrative practices from Rick, Erica and Cobus’ journey

***Problem-saturated story.*** The diagnosis of autism shocked Erica and imposed a heavy burden on her. Rick developed a relationship with sadness as he grappled with the reality of the diagnosis. He even denied autism in the beginning. The early narrative of autism significantly strained Rick and Erica’s marital relationship, leading to blame, avoidance and escalated conflicts.

***Alternative narrative.*** However, over time, an alternative narrative developed when the couple began to spend more time together and successfully navigated their challenges. A unique outcome was when the acceptance of autism not only strengthened their marital relationship but also a deeper understanding between them. Erica realised her reliance on Rick as she voiced ‘I depend on Rick and trust that he would never leave her’. She also expressed her pride in Rick’s caring and accepting nature.

As time progressed, Rick and Erica constructed a new meaning in their marital relationship as they united as a solid team. They developed a balanced relationship in managing the children’s routines and allowing each other space to unwind. Their conversations increasingly focused on Cobus’ progress rather than autism itself. The accumulation of knowledge about autism enabled them to plan for Cobus' future needs, as he would need assistance with a speech difficulty and planning-skills.

***Identity formation.*** As Rick's relationship with understanding and acceptance grew, sadness took a back seat. This change allowed Rick to make the necessary adjustments in family routines and focused attention on Cobus. Rick's identity formation was significant as he discovered his own strength as autism became more manageable and less all-consuming. Denial and uncertainty that initially clouded their lives made way for acceptance and noticeable progress. Erica observed improvement in Cobus' speech and independence, which brought her great relief. A unique outcome for Erica was when she realised that her biggest fear concerning Cobus' future would not actualise. In the thin narrative of the beginning she expressed concern of who would care for Cobus should she and Rick pass away, but Erica found peace with Cobus' improved progress.

Although Erica's unconditional love for Cobus was constant, her identity formation as a mother was reinforced as she found joy in spending more time with her children. An alternative story was introduced as she recognised her ability to communicate more openly about autism. Erica admitted that it was very difficult for her to open up in the beginning of their research journey. Contrary to the story of keeping to herself she admitted that 'it really feels good to talk'.

***Problem-saturated story.*** The narrative concerning Cobus' relationship with his sister remained positive, unaffected by the problem-saturated story of autism. However, the narrative of Cobus' grandparents did not go untouched by autism. The fact that Erica's family did not focus on autism allowed Cobus to be a calm and peaceful child in their presence. The couple faced challenges with inconsistent support form Rick's mother, leading to familial conflicts. A shift occurred when their involvement with Rick's parents was minimised, reducing conflicts significantly.

***Unique outcome.*** Four years later, a pivotal change in the narrative emerged when a different doctor suggested that Cobus' diagnosis was not autism but rather cerebral palsy and apraxia. Rick and

Erica described this diagnosis as a unique outcome seeing it as a more accurate understanding, providing them a renewed perspective. For the first time on our journey, Erica disclosed the context of her complicated pregnancy (continuing with her alternative story of communicating with more ease). She explained that Cobus suffered brain damage due to premature labour, which underscored the understanding of the new diagnosis.

Knowledge about cerebral palsy and apraxia was yet again significant in the family's narrative as it assisted Rick and Erica to understand Cobus better. Rick referred to the problem-saturated story of autism as the message portrayed by the initial doctor was that Cobus would never be able to talk, walk or function independently. For them the new diagnosis and improvement in Cobus' behaviour became an alternative story signalling that Cobus 'proved them wrong'. The new diagnosis was significant in Rick and Erica's identity formation. Rick experienced Erica as more stable and less emotional while peace settled within Rick. He expressed a newfound certainty – a stark contrast to the ambiguity associated with the initial diagnosis of autism.

***Thin description.*** Cobus and his sister maintained a strong bond throughout our research journey, despite their grandparents still holding onto a thin description of Cobus. Rick's parents struggled with acceptance while Erica's parents remained oblivious to the diagnosis.

***Alternative narrative.*** As our journey continued, Rick and Erica's marital relationship improved and they were able to move past blame. Although they would have to rely on sign language to manage Cobus' communication challenge, his family now looked forward to constructing a fuller story of him, also appreciating his strong nature, powerful will and love for life.

### Findings related to Objective 3: Narratives as Framework for Healthcare Professionals

The third objective of this study is to utilise the narratives as a framework (alternative lens) for healthcare professionals while in consultation with these families. This study provided a thorough understanding of parents' experiences of raising a child with autism and how these families make sense of their experience from the moment of the diagnosis of autism and the years to follow. The manner in which this study was conducted, poses to be a guiding framework for healthcare professionals assisting families with a child with autism. This study proved the efficacy of working with the entire family and identified that the diagnosis of autism does not only affect the individual with autism, but the whole family. Rich data obtained in this study indicated the effect of autism on various members in a family e.g. the mother, the father, the sibling, the child with autism and the grandparents. It is therefore advised that professionals on this team (eg a paediatrician, occupational therapist, speech therapist, psychologist) (see chapter 2) journeys with as much family members as possible. This study also proved narrative inquiry as a constructive sense-making tool for these families within a difficult adjustment period after the autism diagnosis. The fact that this study was conducted over a period of five years, afforded me with an ongoing process of connection with the participants. My hope is that healthcare professionals journeying with these families will provide them with support over a period of time, applying the principles of narrative inquiry allowing a trusting, safe space for individuals to construct an alternative meaning at a very vulnerable time in their lives.

## Conclusion

In the initial section of this chapter, ten themes were identified and explored from the conversations with each couple. These themes included the characteristics of autism, diagnosis, knowledge acquisition, dynamics within the marital relationship, and the individual experiences of the mother, father, and siblings with autism. Additionally, the impact on the community, extended family, and considerations for the future were discussed. These themes were not only elaborated upon but also integrated with both historical and contemporary research findings, establishing connections with recent scholarly literature.

The second section of the chapter delved into the narrative construction of each couple's experience, linking these narratives with the methodologies of narrative inquiry and narrative practices.

These methods constitute the conceptual framework of this study, providing a structured approach to understanding the narratives. The stories of the three couples, despite their unique details, shared a common trajectory - from initial shock and distress through a journey towards acceptance and eventual peace. These narratives offer valuable insights into the lived experiences of parents dealing with autism, particularly how it affects their intimate relationships and family dynamics.

Chapter six, the concluding chapter of this thesis, will offer my reflections on the study. It will detail the contributions and limitations of the research and provide recommendations for future studies. This final chapter encapsulates the significant findings and the broader implications of the study, contributing to a deeper understanding of the narratives of parents navigating life with autism.

# CHAPTER VI. Conclusion

This final chapter concludes by reflecting on my personal and research journey. It also identifies the contributions of the study, its strengths and limitations, implications for the field and recommendations for future research.

## A Reflexive Process on the Research Journey

In reflexive thematic analysis, both the researcher and the participants play an equally important role in the research process to arrive at a comprehensive, reflexive understanding of the research findings. In this section, I reflect on what the research journey meant for me as a professional psychologist, from both a personal and a research point of view.

### *Personal Reflections*

As a researcher, I believe it is important to be reflexive about my story, to make explicit my own position and experience in undertaking this PhD on autism in families. This is in line with qualitative research methods and specifically, narrative inquiry (Dubnewick et al., 2018).

While discussing my research ideas during the early stages of the journey, my colleague posed me a question that I will never forget: ‘Carin, where don’t you have a voice?’ I knew he referred to a speech deficit as a criterion of autism. However, I was baffled as I, up until then, only thought about autism in the context of the diagnosis. However, the question never left me …

For me, this project became a long, extended journey... During this process our little family grew and my husband and I became parents of two lovely boys. Life got busier and the juggle of parenting became a reality. As a new mother, I quickly learned my first lesson as my *alternative story* of asking for assistance emerged. I had to learn to ask for help as asking for help did not come naturally for me. To enable me to work, take a shower, a nap or go for a much needed run, I had to learn to welcome the support from loved ones to assist in taking care of the children when the need arose. It became easier as time went on. I realised that by remaining silent, I would isolate myself which would weigh me down. I learned to welcome the figurative village in raising children and doing life together with those who care.

When the mother of my son's friend was diagnosed with cancer, taking meals and checking in with a message or phone call came easy for me. However, after her year-long cancer journey she was in remission and I had to learn how to be in a more natural relationship with her. As my best friend immigrated around the same time, I knew I could do with a new friendship. I learned to be more open and transparent and to also ask questions and advice from her. Soon, the relationship felt more 'equal' and today we support and understand each other well.

In the last few months before submitting my PhD, my computer broke down. It literally refused to start one morning! The walls came crumbling down that day! The feeling of powerlessness was not only about the computer, but also about the long research days that took its toll. From out of nowhere, my plans were being changed for me. I phoned a close family member who assisted me on a practical level and assured me that I was not alone. I felt better as we had a plan.

Suddenly, my colleague's question started to make sense. I realised how my identity was formed while in the process of discovering my own voice. I had to learn to open up and to be more transparent to build friendships. Like the participants in this study, being in uncomfortable spaces allowed me to grow. I came to realise the impact of my own process on my family system: being more transparent now allowed my children to see that it is okay to not be okay. They now witnessed moments when bumping my toe hurts or when slipping causes a freshly baked milk tart to land on the floor, right in the middle of the shopping mall. My openness to new friendships meant more friends for my children and adult conversations for my husband and I. I can now look back knowing that I did regain my voice: the voice within myself and in relationships.

This study provided me with a voice to follow my own new path in relation to my family. It was just as liberating for me as for the participants in the last interviews. Couple A could co-exist in peace with autism; couple B found freedom with autism in their lives, and couple C could move forward together. This dissertation also allowed me to develop my personal and professional identity. As a professional, being so deeply involved in the narrative underpinnings of the study allowed me to understand more deeply and to apply these skills in my practice. I will forever be grateful for the meaning the participants added to my life.

In this research, I have adopted a reflexive stance, acknowledging how my voice, decisions, and interactions with the data have influenced both the research process and the findings. While I initially reflected on how my research process paralleled the unfolding of the study, I now extend this reflection to consider how my presence and choices as the researcher actively shaped the construction and interpretation of the data.

As a social constructionist, I recognise that my role is not neutral; my interpretations and engagement with the participants, the narratives, and the data were influenced by my own background, assumptions, and evolving understanding throughout the research. For example, the questions I selected, the themes I highlighted, and the way I interpreted participant responses were all shaped by my own experiences and theoretical lens. This inevitably influenced the formation of the findings, as my role went beyond mere observation.

This study also allowed my voice as researcher to influence the unfolding research process and findings. The analysis of the interviews was at first (and for a very long time) the most difficult part of the study. As a result, I questioned my ability and purpose with the project. This discomfort allowed me to spend more time with the transcriptions and my research notes in a manner that allowed me a construction of the participants’ voices that was not possible in the earlier stages of the project. In retrospect, the analysis of the themes, the narrative process and linking it with literature would not have been possible without the sense-making process this research study provided me.

### *Research Reflections*

My journey with each couple was that of a collaborative relationship, where both parties were active participants in the research process (Terre Blanche et al., 2006). This relationship acknowledges both the participants and I as co-journeyers and thus as experts in our life and the stories we tell (Swart, 2013).

As I explained the terminology of the externalisation to the participants in one of the earlier interviews, I observed how they grappled to come to terms with this 'different' way of talking about autism. However, as they came to understand the implication thereof, I witnessed how constructing autism in a different way allowed them to make sense of autism and its relationship in their families, in an alternative and empowering way. Looking back on my journey with the participants, this was a unique outcome for them to let go of the problematic meaning autism had for them.

In my relationship with the participants, their willingness to participate in this study is a deed that I will forever be grateful for. They demonstrated transparency regarding their families at a very vulnerable time in their lives. Looking back on our journey, I am witness to how the process of making sense of the participants' stories assisted in the construction of their identity formation.

## Contributions of the Study

The study contributes to the discipline at both a practical and an academic level.

### *Relevance*

At a practical level, the study provides much needed empirical evidence on the effectiveness of using a narrative approach to help families raising a child with autism, make sense of their experiences. In this regard, it responds to calls made by Romney and Jones (2020), Goepfert et al. (2015), Neely et al. (2012) and Helps (2016). Their reviews found that although narrative inquiry was found to be an effective tool for these families, more empirical evidence was needed. The empirical findings of this study add value to the discipline in a number of ways. Firstly. The study findings are evidence that raising a child with autism is not the death sentence it is made out to be upon receiving the diagnosis. This study demonstrates how a narrative approach facilitates a collaborative environment and puts the family in charge of authoring their story, rather than having a problem-saturated narrative being authored by the effects of ASD. Secondly. The study elaborates on the findings used by similar studies such as Olinger (2010), Ramisch (2012) and Monteiro (2021), and confirms that it is through narrative that we can bring a sense of order to the seeming disorder in our world (Murray, 2003). Thirdly. Although this study focuses on families raising a child with autism, narrative inquiry as a sense-making tool does not only apply to these families. Narrative inquiry will also benefit families having to make sense of other adjustment challenges and diagnoses (see for example, Cashin, 2008; Erbes et al., 2014; Johnson et al., 2019; Vromans & Schweitzer, 2011; Weber et al., 2006). Each narrative is characterised by the emergence of wisdom, thereby empowering the author and reader of the narrative (Doan, 1997; Kearney, 2002). As a therapist, it is empowering to know that there is a structure in assisting those in need. Finally. The study also elaborates on the methodologies used by similar studies, especially those that used a cross-sectional approach. This study's time frame over a period of five years proved to be of therapeutic value in allowing for the construction of stories over a period of time. Allowing time between conversations provided the opportunity for narratives to be constructed in a meaningful way (Kearney, 2002).

### ***Significance***

Cridland et al. (2013) identified the lack of a common theoretical framework in the literature on autism and the family to better understand the impact of the disorder and to inform clinical support services to these families. At an academic level, this study joins the discourse that argues for a family-focused therapy approach situated in FST which presents the family as an organised whole with the individuals (the parts) all being viewed in relationship (interconnected) with each other (for example, Karpa, 2021). This viewpoint believes that problems cannot be seen in isolation or be investigated from the viewpoint of only one family member. At an academic level, the study therefore contributes to the discipline by adding a new perspective, one recognising the family as a system. In that regard the study adds useful insights to studies that only consider the voice of one family member (see for example, Burrell et al., 2017; Gao et al., 2023; Hartley et al., 2010; Hillman et al., 2017; Hock et al., 2012; Lee, 2009; Manono & Clasquin-Johnson, 2023; Papadopoulos, 2021; Rodrigue et al., 1990; Shtayermman, 2013; Woodgate et al., 2008). As proposed by FST, the diagnosis of a child with autism affects not only the child with autism, but the family in its entirety. This study hightlights how families of children with autism faces various adjustment priods over time to maintain its autonomy. These families can therefore be best understood and supported within a family-focused, collaborative environment, and not only on the individual with autism self.

## Implications of the Study

The study holds the following implications for the practice of support services focused on autism. While some individuals with autism can lead independent lives, others face severe disabilities and rely on ongoing care and support. This implies that therapeutic interventions for autism should extend beyond the individual with autism to include the family members. Though various types of family therapy exist, this study adds to the body of findings confirming the effectiveness of narrative therapy. Also, the findings reiterate the need for an integrated treatment plan for autism. This requires collaboration between the health sector and other sectors, particularly education, employment and social care.

The study holds the following implications for research in the field of support services focused on autism. Firstly, family systems theory is a suitable theoretical framework for studying autism and families, and the findings of this study adds to that of others which also used FST as theoretical framework (Cashin et al., 2013; Laghi et al., 2018; Prendeville & Kinsella, 2019; Romney & Jones, 2020) Autism introduces additional stress and pressure into the relationships of participants, which can be explained by FST (how individual family members interconnect with one another). But also, the principle of homeostasis explains why family members can, despite the additional stress and pressure, grow closer to each other to restore the equilibrium within the family system. Secondly, this study is evidence of the effectiveness of using a narrative inquiry to study the experiences of families affected by autism and to help these families make sense of their experiences. Finally, the use of a longitudinal approach in this type of research helps to shape the narrative of these families.

## Strengths

The study showed several strengths with regard to its choice of data collection method, research design and selection of time frame. For example, the data collection of this study was based on 15 interviews (5 interviews with each couple), each being three hours in duration. The intensity of this process ensured that rich descriptions of data was obtained. Secondly, using narratives as data allowed for an opportunity to make sense of and create meaning within a difficult adjustment period for the participants. The narrative research design contributed to an empowering process for both the participants and me. Thirdly, this study was longitudinal in nature and thus allowed for the narratives of parents raising a child with autism to unfold over a period of time. This time frame contributed to an unique understanding of the experiences of these families. Longitudinal narrative research builds on the notion that stories are told to organise experiences in a meaningful way, knowing that stories are not stable because meaning making is not static (McKibben & Breheny, 2023).

## Limitations

The study had the following limitations. Firstly, although all three children in the study were formally diagnosed with autism at the time when participant selection took place, the one child’s diagnosis changed later in the study. As the study was conducted over a period of five years, the change in diagnosis can be attributed to the initial criteria being visible to the paediatrician at the time of consultation compared to a doctor’s visit at a later stage. I decided to keep this family in the study as the diagnosis correlated with the selection criteria in the beginning of the study and the aims and objectives of the study was still maintained. Although this was my decision as the researcher, it can be viewed as a limitation as this couple's selection criteria was not met at the end of the study. The study's selected sampling method and size are not viewed as limitations since it is not the purpose of a narrative inquiry to arrive at insights that can be generalised to a larger audience, but instead to obtain an in-depth understanding of participants' experiences. Secondly, although relying on mothers' and father's perspectives in this study added to previous research where individuals' experiences were used, reporting on more family members' perspectives like that of siblings or grandparents could contribute to a broader understanding of the relationship between these family members and autism.

## Recommendations

The study recommends the inclusion of family therapy as part of an integrated approach to treating autism. This integrated approach requires collaboration between the health sector and other sectors, particularly education, employment and social care.

The study further recommends the use of family systems therapy as a common theoretical framework to study autism and families.

Also, support for families with a child with autism should be an ongoing process as this longitudinal study confirmed the sense-making process with these families over a period of time.

Finally, the study is one of few studying autism and families in a developing country, and specifically South African context (Manono & Clasquin-Johnson, 2023). There is a need for further research in creating awareness of autism in a developing context like South Africa to ensure an early diagnosis and refute stigmas around the disorder.

This study adds to the body of literature conducted on autism and families undertaken in a South African context. From a FST perspective, this study adds to the study by Prendeville and Kinsella (2019) who conducted research from a FST focusing on the grandparents of a child with autism and a study by Laghi et al. (2018) who focused on the experiences of typically developing siblings of an individual with autism from a family systems approach. From a narrative inquiry perspective, this study adds to the findings of Romney and Jones (2020) and Cashin et al. (2013) who investigated narrative inquiry as a modality for assisting families with a child with autism.

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## Appendices

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## Appendix A:Glossary of terms

Key terms that are used within each of the following chapters are outlined below:

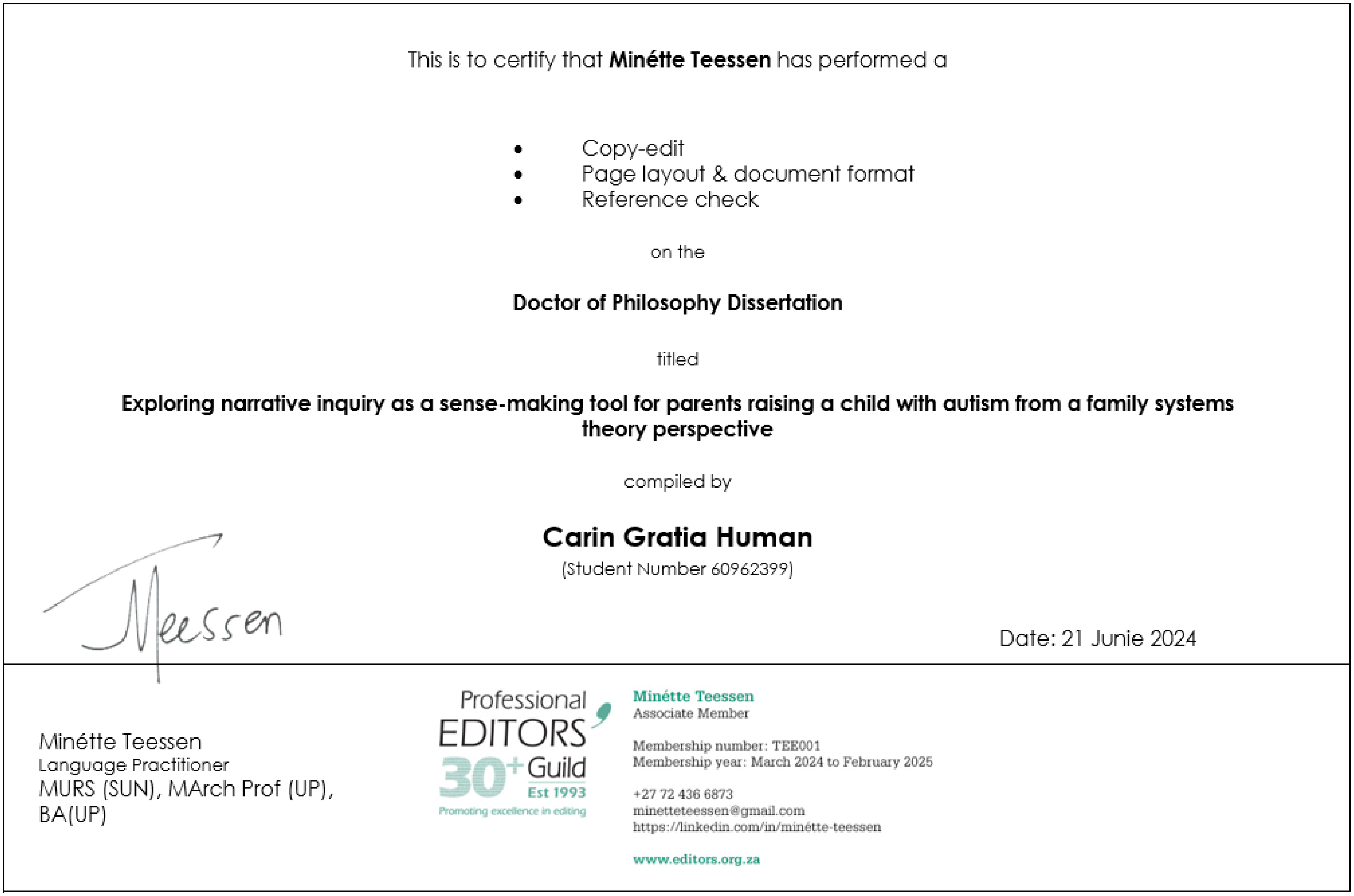
**Autism**: Also called autism spectrum disorder (ASD) is a neurodevelopmental disorder characterised by social communication impairments, difficulties in social interaction and restricted repetitive patterns of behaviour (APA, 2013).

**Family System**: A special set of people with relationships between them. These relationships are established, maintained and evidenced by the members in the community. Patterns are formed over time in family relationships. This patterning over time is the essence of a family system (Bavelas & Segal, 1982; Cridland et al., 2013).

**Subsystem**: Semi-independent systems operating within a family system. Examples of subsystems include ‘maternal’ (mother and child), ‘paternal’ (father and child), ‘parental’ (both parents with child), ‘marital’ (husband and wife) and ‘sibling’ (child and child) (Cridland et al., 2013).

**Social Constructionism**: The view that knowledge is socially constructed and that narratives allow people to communicate knowledge that has been socially and culturally created (Freedman & Combs, 1996).

## Appendix B: Certificate Language Editor



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**Exploring narrative inquiry as a sense-making tool for parents raising a child with autism from a family systems theory perspective**

compiled by

**Carin Gratia Human**
(Student Number 60962399)

Teessen

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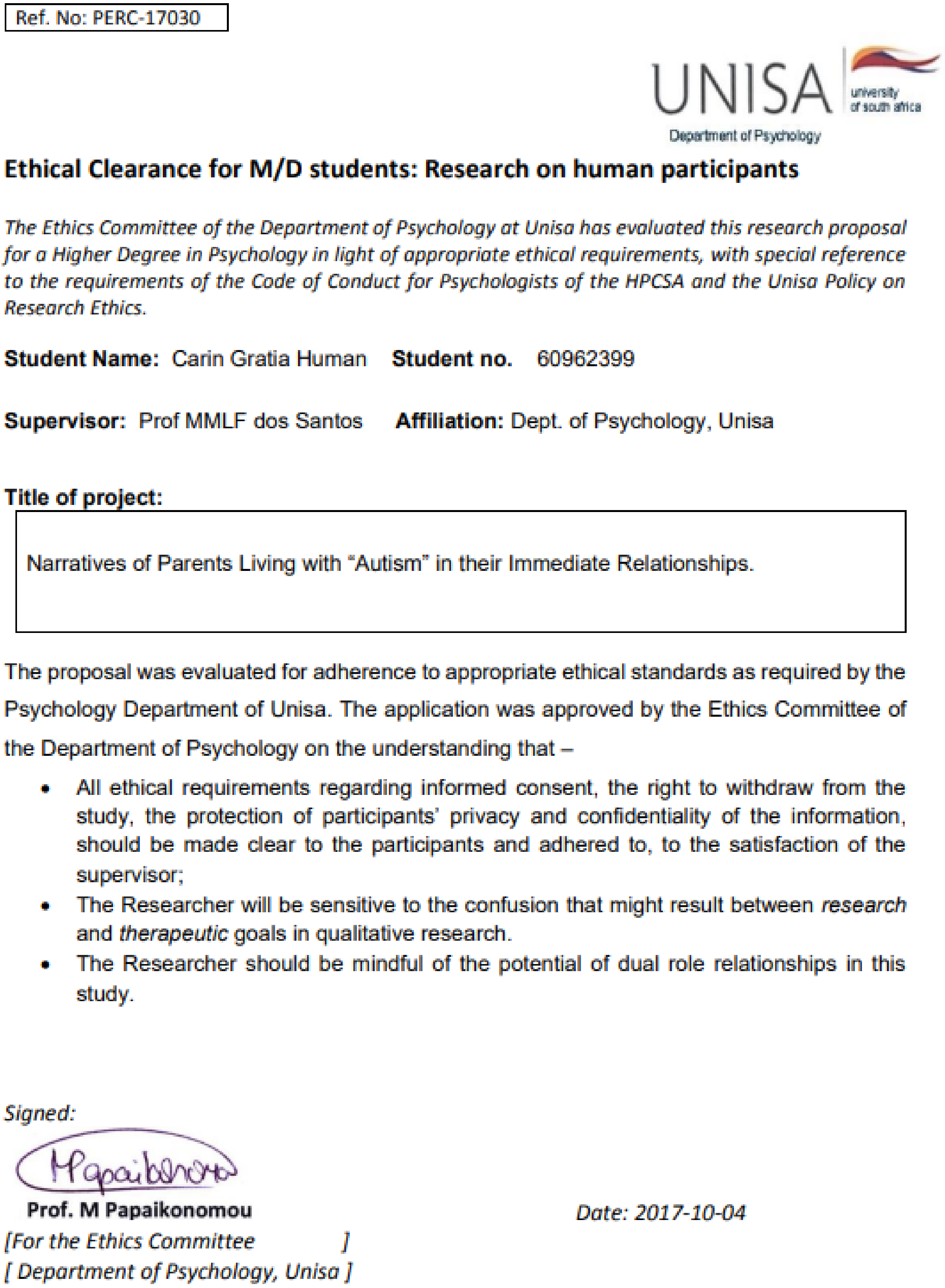
## Appendix C: Ethical Approval Form



Ref. No: PERC-17030

UNISA university of south africa
Department of Psychology

### Ethical Clearance for M/D students: Research on human participants

*The Ethics Committee of the Department of Psychology at Unisa has evaluated this research proposal for a Higher Degree in Psychology in light of appropriate ethical requirements, with special reference to the requirements of the Code of Conduct for Psychologists of the HPCSA and the Unisa Policy on Research Ethics.*

**Student Name:** Carin Gratia Human **Student no.** 60962399

**Supervisor:** Prof MMLF dos Santos **Affiliation:** Dept. of Psychology, Unisa

**Title of project:**

Narratives of Parents Living with "Autism" in their Immediate Relationships.

The proposal was evaluated for adherence to appropriate ethical standards as required by the Psychology Department of Unisa. The application was approved by the Ethics Committee of the Department of Psychology on the understanding that –

- All ethical requirements regarding informed consent, the right to withdraw from the study, the protection of participants' privacy and confidentiality of the information, should be made clear to the participants and adhered to, to the satisfaction of the supervisor;
- The Researcher will be sensitive to the confusion that might result between *research* and *therapeutic* goals in qualitative research.
- The Researcher should be mindful of the potential of dual role relationships in this study.

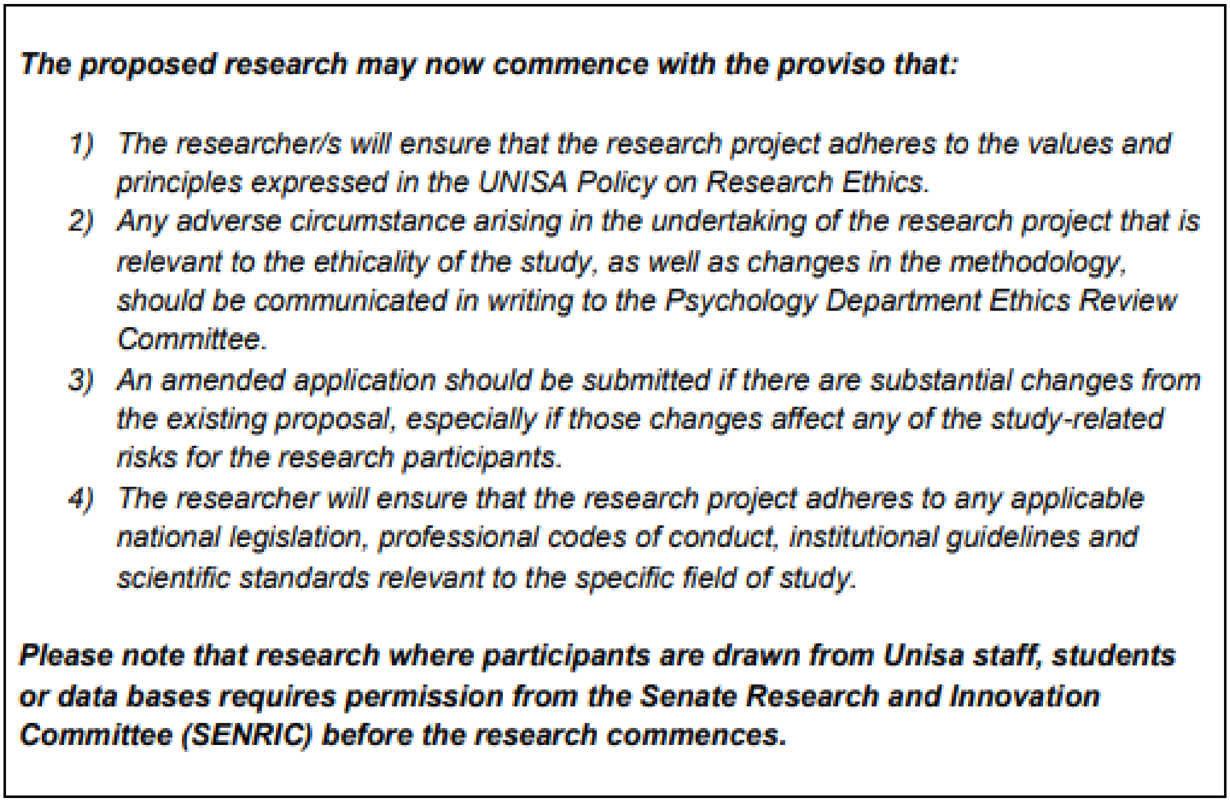
*Signed:*

MPapaikonomou

**Prof. M Papaikonomou**

*[For the Ethics Committee ]*
*[ Department of Psychology, Unisa ]*

*Date: 2017-10-04*



***The proposed research may now commence with the proviso that:***

1) *The researcher/s will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.*
2) *Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study, as well as changes in the methodology, should be communicated in writing to the Psychology Department Ethics Review Committee.*
3) *An amended application should be submitted if there are substantial changes from the existing proposal, especially if those changes affect any of the study-related risks for the research participants.*
4) *The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study.*

***Please note that research where participants are drawn from Unisa staff, students or data bases requires permission from the Senate Research and Innovation Committee (SENRIC) before the research commences.***

## Appendix D: Research Invitation and Research Contract

### SECTION A

### RESEARCH INVITATION

Dear Parent,

I am a counselling psychologist registered at the Health Professions Council of South Africa and am currently enrolled for my PhD Psychology degree at Unisa.

My research intent is to explore how parents of children with autism make sense of the relationship between their family and autism as well as the relationship between their relationship and autism. The reason for my choice is the lack of research on autism and couples' relationships. Literature on research conducted in South Africa is also very limited. Available research indicates that autism does not limit itself to the child's life, but can also become part of the parent's relationship, the lives of siblings and that of the extended family.

Literature tells a certain story of autism in the child's life, being part of the parents' relationship, the lives of siblings and that of the extended family. However, literature is only one body of knowledge. I am interested in what living with autism is like for you. As parents living with autism, I believe that your wisdom can construct a different narrative that can even be more important than the narrative of the literature. I would feel honoured to be part of such a journey…

Although the limited research is a justification for the intended study, your participation will also provide Dr Johan Erasmus with the opportunity to use the process and findings of the research to enhance the scope of the multi-disciplinary team in his paediatric practice. Besides having research and practice justifications, this research also has a professional justification. As a young counselling psychologist I would like to improve my research and practice abilities through this PhD project. This research project forms part of my continuous professional development (CPD) as a researcher and a practising counselling psychologist.

Of equal importance in the possible personal benefit you could gain by sharing your experience. Your story may also benefit other couples in your position as well as assist professionals in understanding the experiences of people living with autism in their relationships.

To achieve the biggest possible benefit for all I would like to spend time with the parents of children with autism to better understand their experiences of living with autism in their relationship. I would like to provide parents with the opportunity to make sense of living with autism in their relationship through talking about their experiences.

I would like to invite you to consider taking part in my research project.

Should you be interested in detailed information regarding this study, please complete Section B of this document in order to grant me permission to contact you.

Kind regards,
Carin Human

## SECTION B

## RESEARCH CONTRACT

We, ...................................................... (Full name and surname of father) and ................................................................ (Full name and surname of mother) hereby provide Carin Davel permission to contact us regarding the research project titled "Narratives of parents living with 'autism' in their relationship".

Name of Father: ....................................................
Signature: ....................................................
Date: ....................................................
Landline no.: ....................................................
Cell no.: ....................................................
E-mail: ....................................................

Name of Mother: ....................................................
Signature: ....................................................
Date: ....................................................
Landline no.: ....................................................
Cell no.: ....................................................
E-mail: ....................................................

## Appendix E: Research Information and Informed Consent

Dear Parent,

The following information is important regarding my research project.

**Information:** I, Carin Human, am a registered counselling psychologist at the Health Professions Council of South Africa (HPCSA), and currently enrolled for my PhD Psychology degree at the University of South Africa (Unisa). Prof. Monika dos Santos from the Department of Psychology at Unisa is my research supervisor, who can be contacted at dsantmml@unisa.ac.za if you have any concernts or queries about the study. I am interested in how you experience living with autism in your immediate relationships.

**Title:** The title of the study is: ‘Narratives of parents living with ‘autism’ in their immediate relationships’.

**Aim:** The aim of the research is to allow parents to make sense of living with autism in their relationships through narrating their experiences.

**Procedures:** You will be required to play the role of a storyteller about your experience of living with autism in your marriage. The study is qualitative in nature and entails four interviews of approximately three hours long over a period of a year. Walking this journey with the families, another interview will take place within five years after the previous conversations. I will interview the father and mother concurrently in each other’s presence. You and I will collaboratively be involved in the reflection of your stories as it will be verified with you at various stages throughout the process.

The interview process will be audio taped in order to transcribe it accurately for the purpose of the analysis. After each interview, I will transcribe and analyse your stories. You will have time to read through the analysed material of the previous interview before each interview. Each interview will then commence with a reflection on our previous conversation. The audio recording will be destroyed after three years upon completion of the study.

**Risks:** There are no perceived physical risks for you while participating in the research. However, should you feel overwhelmed by sharing your experience, the researcher will arrange for therapeutic debriefings.

**Benefits:** There are no financial gains for participating in the research. You may benefit personally by sharing your experience. Your story may also benefit other couples in your position as well as assist professionals in understanding people's experiences of living with autism in their relationships.

**Rights:** Participation is completely voluntary. You may withdraw from participating at any point in time and without any negative consequences in doing so.

**Confidentiality:** All information will be treated as confidential. You are not compelled to share everything about your experience and can decide what to share and what to withhold. Anonymity will be assured and the material will be destroyed should you wish to withdraw from participating.

**Material:** After completion of the research, the research narratives as well as audiotaped interviews will be stored in a secure cabinet of the researcher for a 3-year period upon completion of the study thesis, after which all material will be destroyed.

**Researcher:** If any clarity or more detailed information is needed, please do not hesitate to contact me. My contact details are as follows:

Name: Carin Human

Cell no.: 076 222 7241

E-mail: caringratia@mweb.co.za

We, ...................................................... (Full name and surname of father) and ................................................................. (Full name and surname of mother) hereby acknowledge that we have read and understand the above-mentioned research information. We hereby agree to participate in this research project. We accept and agree with the conditions as stated above.

Please indicate whether you would like to participate in this study by making the appropriate statement:

| | |
|---|---|
| I agree to participate | |
| I decline to participate | |

Father: ------------------------------------------------

Date: ------------------------------------------------

Mother: ------------------------------------------------

Date: ------------------------------------------------

Researcher: ------------------------------------------------

Date: ------------------------------------------------

Witness: ------------------------------------------------

Date: ------------------------------------------------

Witness: ------------------------------------------------

Date: ------------------------------------------------

## Appendix F: Transcriber Confidentiality Statement

**TO WHOM IT MAY CONCERN**

I, .........................................., am willing and able to transcribe Carin Human's research interviews for her dissertation. I undertake to keep confidential all information contained in the work. I shall not disclose any of the said confidential information to any third party and will under no circumstances divulge the identities of the participants or any information relating to the study to anyone. I shall also hand over all audio tapes to Carin Human after the transcriptions have been done and will not keep any transcriptions in my possession.

Transcriber (): ................................

Date: ................................

Researcher (Carin Human) .................................

Date: .................................

## Appendix G: Counselling Services

**TO WHOM IT MAY CONCERN**

I, Estie Janse van Rensburg, am a registered counselling psychologist with the Health Professions Council of South Africa (HPCSA). I am willing to assist those participating in Carin Human's research with counselling free of charge should they wish to be assisted.

Kind regards,

Dr E. Janse van Rensburg

## Appendix H: Interview Guide

The interviews were structured along the following guidelines:

- Introduction (30 min)

  Each interview consist of the following three questions: (i) Describe how you experienced the diagnosis of autism, (ii) Describe how you experience the interplay between autism and your family, and (iii) Describe how you experience the interplay between autism and your relationship with each other.

- Interview Parent 1 (45 min)

  Reflect with Parent 2 on Interview with Parent 1 (15 min).

- Interview Parent 2 (45 min)

  Reflect with Parent 1 on Interview with Parent 2 (15 min).

- Conclusion (30 min)

A period of four month lapsed between each interview. All interviews were structured in a similar manner. After the first interview, each interview commenced with a reflection in the previous interview (30 min) and was then followed by the process as explained above. Five years passed before the last interview.