Living with Autism Spectrum Disorder: An auto-ethnographic study on educational support

by

Emile Gouws

Submitted in partial fulfilment in accordance with the requirements for the degree of

Magister Educationis

At the

University of Pretoria

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November 2018

DECLARATION

I, Emile Gouws, student number 12106543, hereby declare that this dissertation, "*Living with Autism Spectrum Disorder: An auto-ethnographic study on educational support,*" is submitted in accordance with the requirements for the Magister Educationis degree at University of Pretoria, is my own original work and has not previously been submitted to any other institution of higher learning. All sources cited or quoted in this research paper are indicated and acknowledged with a comprehensive list of references.

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Emile Gouws

November 2018

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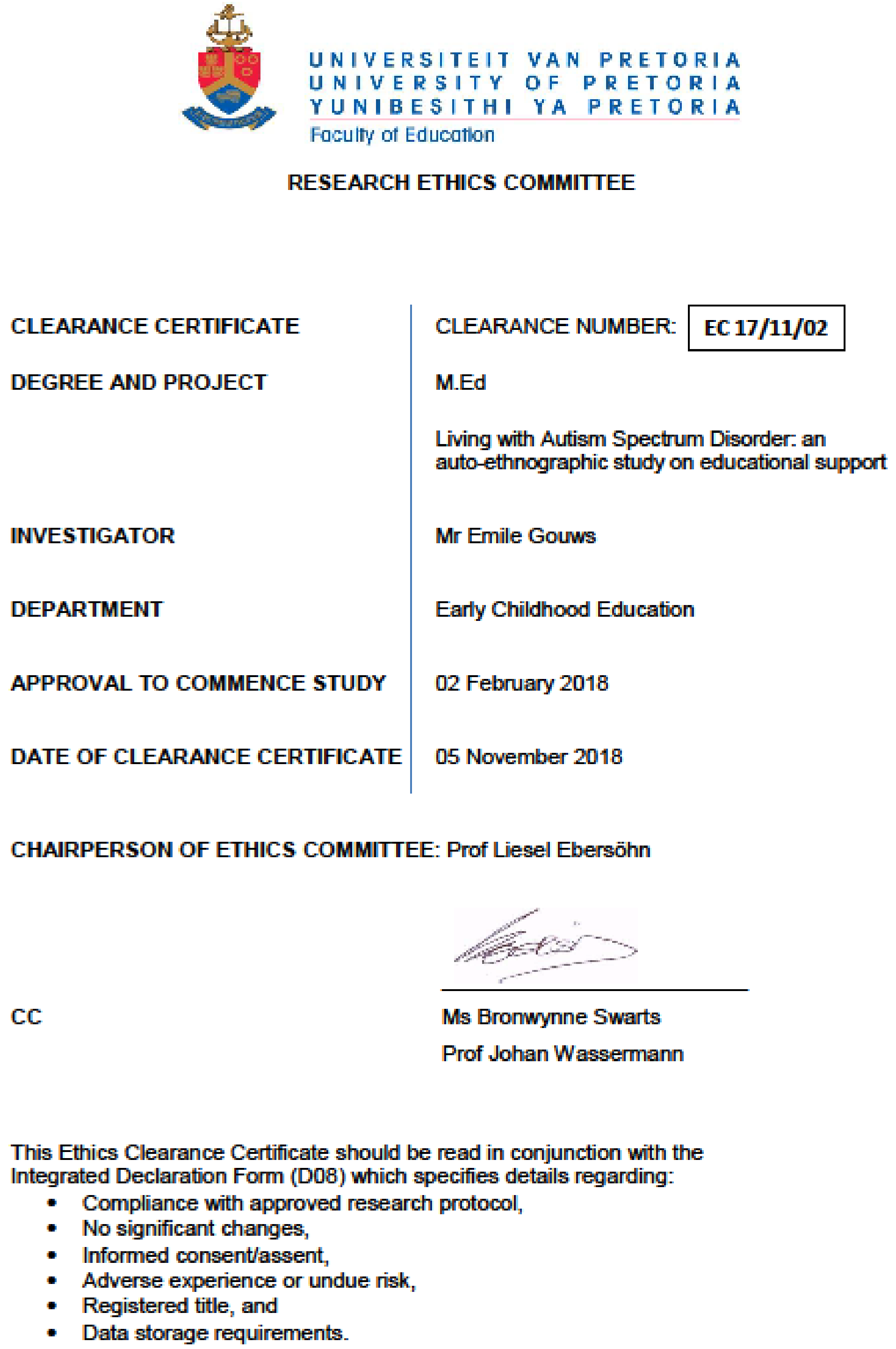

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CLEARANCE CERTIFICATE	CLEARANCE NUMBER: EC 17/11/02
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ABSTRACT

I was diagnosed with autism spectrum disorder (ASD) at the age of four and a half years with a prognosis of not being able to attend a mainstream school or function optimally in society. The purpose of this study was to illustrate the importance of educational support for development in the cognitive, social, emotional and physical domains to enable me to complete my school career with university exemption. Although numerous studies on ASD and the child's functioning in society have been conducted, no study could be identified where the journey with ASD is described from the perspective of a person with this disorder.

The theoretical framework which guided my study was Vygotsky's First Generation Theory (FGT), which views the support process as consisting of three elements, namely subject, object and tools, all standing in a reciprocal relationship with one another, thus implying mutual interaction.

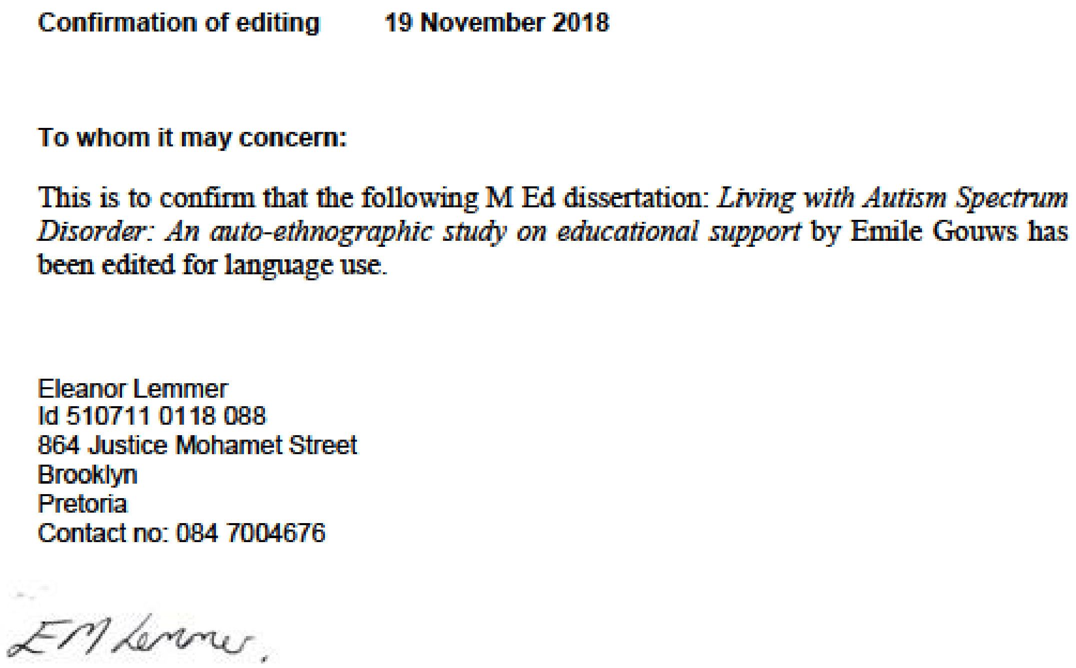
This study was situated within the interpretive paradigm, following a qualitative approach by making use of an auto-ethnographic design which allowed me to share my experiences as an individual with ASD. Participants included members from both my internal (family members) and external support systems (therapists and school psychologist). Data were gathered through semi-structured interviews and documents, such as my mother's book, my school performance cards and psychological and therapist reports.

Support emerged as main theme with sub-categories: dedication, structure, finances, loss and decisions, which are all indispensable in the educational support process. The overall significance of the research study is the importance of educational support in establishing the child with ASD so that he/she can complete a school career with university exemption.

Key Words:

Educational support, autism spectrum disorder, First Generation Theory.

LANGUAGE EDITOR



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To whom it may concern:

This is to confirm that the following M Ed dissertation: *Living with Autism Spectrum Disorder: An auto-ethnographic study on educational support* by Emile Gouws has been edited for language use.

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DEDICATION

This study is dedicated to my mother, Marié Gouws – the personification of support.

Mom, you put your dreams and your life on hold to support me throughout my school career. You sacrificed your job, your time and your relationships to ensure that I have your full-time attention and support. This auto-ethnography would not be possible without your dedication, commitment and unconditional love that I have experienced since my diagnosis. Throughout the years you never doubted my abilities and always motivated me to become the best that I can be. Through the good and bad times you stood by me and taught me the value of perseverance - never to give up no matter the challenges that I am confronted with. You looked beyond the boy with the downward gaze, the emotionless expression, the flapping hands, the asocial behaviour and you saw a child who could finish his school career, gain university entrance and lead a productive and esteemed life in society.

For this I want to salute you – my mother, my rock, my supporter. With this dissertation we refute critics and by the grace of God, we can show today that anything is possible if there is support.

WE MADE IT!!!!!

The sky is the limit…

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- To my family (internal support system) who were also my participants: my parents, Marie and Ettienne, thank you for your love and support throughout my life so far. To my brother, Ruan, whom I love dearly, in spite of my inability to meet your brotherly needs. Thank you, Ouma, for taking care of me;

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- To my Technical Editor, Lizelle Swart – thank you for your kindness and professionalism in making sure that all the figures and photographs were placed correctly. I do appreciate your help with my bibliography and with the meticulous care you undertook in ensuring that I could submit a dissertation that reflects my hard work!

LIST OF ABBREVIATIONS

ABA - American Behaviour Analysis

ADD - Attention Deficit Disorder

ADHD - Attention deficit hyperactive disorder

APA - American Psychiatric Association

ASD - Autism Spectrum Disorder

CAST - Children’s Apperception Storytelling Test

CDC - Centre of Disease Control

DA - Draw-a-person test

DIR - Developmental individual-difference relationship-based model

Dr. - Doctor

ECG - Electrocardiogram

FGT - First Generation Theory

HFA - High Functioning Autism

I.T.P.A - Illinois test of Psycholinguistic abilities

IQ - Intelligence Quotient

JSAIS - Junior South African Individual Scales

KFD - Kinetic Family drawing

KG - Kilograms

LFA - Low Functioning Autism

MBS - For ethical reasons, the High school (remedial) name was changed

Mr - Mister

Miss - Miss

RAU - Randse Afrikaanse Universiteit

TV - Television

ZPD - Zone of Proximal Development

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ORIENTATION TO THE STUDY

“If we have been researched to death... maybe it’s time we started researching ourselves back to life’(Castellano, 2016:45)

1.1 INTRODUCTION

At the age of four and a half years, I was diagnosed with autism spectrum disorder (ASD). Ghaziuddin and Mountain-Kimchi (2004:47) define ASD as “a pervasive developmental disorder characterised by autistic social dysfunction and isolated idiosyncratic interests, in the presence of normal intelligence.” In other words, albeit a normal intelligence quotient (IQ), diagnosis with this disorder presupposes abnormal functioning in society. The American Psychiatric Association (APA, 2013:51) concurs when mentioning that this abnormal behaviour entails failure to make eye contact, an inability to show emotion, lack of facial expression and an inability to speak fluently. Bornman and Rose (2013:197) add that individuals on the spectrum struggle to communicate, socialise and to display socially appropriate behaviour.

Davis and Carter (2008) add that individuals who are diagnosed with ASD experience physical, emotional and neurological symptoms. These authors postulate that distinguishing physical characteristics entail movement rituals when a person is confronted with emotional, social or psychological challenging situations. Bornman and Rose (2013:197) mention that these behaviour patterns can be classified as abnormal; therefore, the possibility of stereotyping is very likely. The physical rituals involve movements, such as hand flapping and rocking body movements, which are aggravated by over-stimulation and anxiety (Rinehart, Bradshaw, Brereton & Tonge, 2016:764). Furthermore, the underdevelopment of the emotional and social skills of the individual influences expressive and receptive language skills which results in the individual’s incapability to pronounce words and form sentences. It is a chain effect that can influence academic capabilities such as the reading and writing (Bornman & Rose, 2013:200).

The latest DSM-diagnostic manual (DSM-V, 2013:52, 53) describes autism as a childhood disorder, which can be diagnosed from the age of three years, which affects the individual’s ability to function normally in society. Bornman and Rose (2013:197) hold that the diagnosis of ASD presents in different forms and can vary from general to severe. In this regard, Rinehart *et al.* (2016:764) refer to research based on 23 surveys on ASD; the findings indicate that only seven out of 10 000 children are diagnosed with high functioning autism. This percentage does not entail the success ratio and functioning levels in the school environment.

When confronted with such a ‘sentence’, parents usually go to great lengths in trying to make their children more acceptable to society (Du Plessis, 2016), which was also the case with my parents. I was taken to numerous therapists and had sessions with an occupational and a speech therapist to help me to acquire socially acceptable skills. In her quest to turn around the prognoses of this disorder, my mother decided to take this diagnosis as a challenge and spent her days stimulating me cognitively, socially, physically and emotionally in order to equip me in functioning in and coping with the mainstream school environment.

Taking my life story into consideration, it is evident that ASD is not a death sentence as I am living proof that these individuals can function normally in society through unwavering support, dedication, hard work and constant stimulation. In this study I made use of auto-ethnography as research method, by reflecting on my journey with ASD, through the lens of a literature review on the topic as well as an empirical investigation into the support that I received from my parents and therapists. Lemmer (2012:79) encapsulates my aim with this study when referring to Ellis and Bochner (2000:6) when she states: “Auto-ethnography explores how the self has been influenced and moulded by the surrounding context and how the self has responded and reacted to, or conflicted with, contextual influences”. With this study, I reflected on how I was influenced by ASD, and what the impact of the systemic support environment was on my voyage to become ‘acceptable’ in society.

In this study, I made use of reflexive evocative ethnography in order to verify the accuracy of the existing research, as well as validating the advice that parents get from experts in the field of ASD once their child has been diagnosed. According to Ellis (2004:84), “reflection is seen as a pedagogical strength of auto-ethnography”. She furthermore asserts that using auto-ethnography as research method is an evocative calling that allows individuals to think freely about personal experiences and to share their views about a certain phenomenon. Ellis (2004:140) also states that “evocative writings encourage the writer to share personal feelings, experiences and conflicts.”

1.2 RATIONALE

Du Plessis (2017) asserts that one of the biggest fears that parents of young children have is hearing that their child has been diagnosed with a disability as it implies that, among others, their child will not be able to function normally in a mainstream school environment. Nel, Nel and Hugo (2013:19-20) as well as Manjiviona and Prior (1999:328) concur that experts, such as psychologists, speech- and physical therapists, believe that children diagnosed with ASD have a lower chance of functioning normally in their early school careers. Young and inexperienced parents are ignorant and often overwhelmed by the diagnosis, and tend to follow experts’ verdicts and advice, which may have far-reaching effects on the child’s academic future (Manjiviona & Prior, 1999:328).

When I was diagnosed with ASD, my parents were faced by the option of either enrolling me in a special school for autistic learners or using all the resources at their disposal to provide me with a chance to function normally in a mainstream school environment with additional assistance. Experts specifically discouraged my mother from stimulating me physically, emotionally, socially and cognitively as it was believed that I only had a three percent chance of ever functioning in an acceptable way in society. Although there are numerous studies on ASD and the child’s functioning in society (Huws & Jones, 2015:85; Scahill, Aman, Lecavalier, Halladay, Somer, Bishop, Bodfish, Grondhuis, Jones, Horrigan, Cook, Handen, King, Pearson, McCracken, Sullivan & Dawson, 2015:39), as well as articles where recommendations are directed towards parents, no study could be found where ASD is described from the perspective of a person with this disorder. Various researchers also focus on the support of family members that is critical for the child’s well-being (Herlihy, Knoch, Vibert & Fein, 2015:22; Haglund & Kallen, 2011; Rinehart *et al*. 2002; Ozonhoff, South & Miller, 2000:30; Manjiviona, 1999), but I noted a scarcity in research on the functioning levels of a child diagnosed with ASD in the school environment.

By making use of auto-ethnography as research method, I challenged certain statements in the literature, as I believe some of these findings do not consider the love of a mother, the child's support structure, as well as the internal locus of control and resilience of the person with ASD – in this case – me.

I hope that my account of the educational support I received detailed in this auto-ethnographic report will be a beacon of hope and will inspire young parents who are confused and do not have the necessary knowledge and foresight to assist their child educationally and to believe in their child's abilities irrespective of the diagnosis or prognosis.

1.3 FOCUS OF STUDY

Being told that a child has a disability can be as traumatising as hearing of a family member's sudden passing (Fiedler, Simpson & Clark, 2007). Due to the emotional impact of such news, and the lack of experience with regard to the diagnosis, parents tend to follow the advice of experts, without taking their child's capabilities and potential into account. Bornman and Rose (2013:197) mention that fear and anxiety contribute to the parents' decision to isolate their child in a protective environment and not to stimulate their child on cognitive, emotional and social levels. Zhang, Yan, Barribal, While and Liu (2015:31) claim that experts base their diagnoses and subsequent recommendations to parents on the social competency of the child and the verbal and non-verbal cues the child displays, without taking the child's context into account.

My study is based on the premise that children on the spectrum can function normally in a school environment and society with necessary educational support as suggested by the empirical data.

The following research questions guided this study:

1.3.1 Primary research question

How was I educationally supported in dealing with autism during my school years?

1.3.2 Secondary research questions

- What were the experiences of my educational support system?
- What are the key elements of an educational support structure for a child with ASD?

1.4 CONCEPT CLARIFICATION

For the purpose of this study, the following concepts were clarified, namely auto-ethnography studies, autism spectrum disorder (ASD), educational support and neuro-typical children.

1.4.1 Auto-ethnography

Auto-ethnography is seen as a personal process where the writer reflects and shares his/her personal experience about the cultural expectancy of a certain phenomenon, and therefore refers to personal experiences in a cultural context (Ellis, 2013:37). Auto-ethnographic studies serve as a wider lens to understand the world and thereby guide the researcher to gain self-understanding (Le Roux, 2017:196). Sanduliak (2016:196) believe that three values come to mind in auto-ethnographic studies: self-exploration, introspection and interpretation. Therefore, the researcher must create self-understanding of his/her own knowledge in relation to the cultural world and this is why Lemmer (2012:95) maintains that auto-ethnography is evocative as it evokes emotion in the reader. For the purpose of my study, auto-ethnographic research was used to give an account of my story and to share my personal perspectives regarding ASD during my school years.

1.4.2 Autism spectrum disorder (ASD)

ASD can be classified as a childhood disorder which affects the normal functioning of an individual from a very young age towards adulthood (Haglund & Kallen, 2011:164). Khouzam, El-Gabalawi, Prawn and Priest (2004) define ASD as a developmental disorder that is characterised by a restriction in social communication, repetitive behaviours and restricted interests. The diagnosis of ASD is based on the coping capabilities of these children as well as their functioning on cognitive, emotional and social domains (APA, 2013:53). Although the physical domain is not mentioned in literature on ASD, I included it in my study, as many of my challenges also manifested in a physical way. Children on the ASD spectrum often have low muscle tone which hampers their physical abilities, specifically when having to participate in sports. Depending on the severity of the diagnosis and the individual's idiosyncratic interests, Ghaziuddin and Mountain-Kimchi (2004) emphasise that the intelligence levels of a person with ASD are above normal and this often raises the expectation for these children to perform in a mainstream school.

1.4.3 Educational support

Mantsha (2016:1) defines educational support as the various methods which are employed to help the learner in overcoming barriers associated with holistic development. This definition corresponds with one of the main principles of the White Paper 6 (Department of Education, 2001:6) which holds that educational support involves “education structures, systems and learning methodologies to meet the needs of all learners”.

Capriotti and Pfiffner (2017:10) note that additional assistance in the form of parental support and that of specialised services are part of educational support to enable the child to reach developmental outcomes.

Educational support for the child with ASD will therefore imply that skills related to the educational progress of the child need to be developed by continuous support in all domains, namely the cognitive, emotional, social and physical, in order to reach his/her full potential and enable to child to function independently in society.

1.4.4 Neuro-typical children

This concept appears frequently in this dissertation and should also be clarified. The term ‘neuro-typical' has become increasingly popular during autism awareness campaigns as the behaviour and emotional state of the child with ASD is compared with other children (neuro-typical) in numerous social environments (Bagatell, 2010:40). Jordan and Caldwell-Harris (2012:392) explain that the term neuro-typical refers to children who are not diagnosed with any form of intellectual or developmental disorder (e.g., autism).Sedgewick, Hill and Pellicano (2018:1) postulate that society has its own standards for acceptable social and emotional behaviour and therefore neuro-typicals fit cultural and social standards.

1.5 PRELIMINARY LITERATURE REVIEW

In order to contextualise my study and understand the significance of ASD, the reader needs to be familiar with the characteristics of this disorder and the effect on the cognitive, social, emotional and physical development of the individual on the spectrum.

1.5.1 Characteristics of Autism Spectrum Disorder (ASD)

ASD is a developmental disorder which could hamper the individual's capabilities to function normally in society (Gaspar de Alba &Bodfish, 2011; Ludlow *et al*. 2012; Pottie& Ingram in Zang, wayans, Bariball, While & Liu, 2005:30). The social, emotional and cognitive abilities of the individual are affected from early childhood towards adulthood (APA, 2013:55). Drawing on both versions of the criteria identified by DSM-V-R (APA, 1987; 2013), the behaviour traits of individuals with ASD manifest before the age of five years (Robinson, 2016:552). The diagnosis of ASD entails the development of different disorders such as communication disorders, intellectual disorders, stereotypical disorders, intellectual disorders, movement disorders, attention deficit hyperactivity disorder and schizophrenia (APA, 2013:52; Robinson, 2016:3).

Based on the latest version of the DSM-V-R manual, about 70% of children with ASD may have only one combined mental disorder, while 30% of these individuals have two or more combined mental disorders (APA, 2013:54). The behaviour traits of the individual on the spectrum's behaviour patterns are visible in sleeping and eating patterns, which may cause anxiety and depression and research reports that ASD manifests in all developmental levels.

1.5.1.1 Cognitive manifestation

Neurologically the development of the hippocampus is larger and more sensitive in children with ASD than any other human being (Nel, Nel & Hugo, 2013:19-20). These authors furthermore explain that the hippocampus is responsible for the visual and auditive memory and intellectual development. The neurological development of the child with ASD has a major effect on the cognitive capabilities of the individual. Bornman and Rose (2013:197) argue that these individuals' auditive memory is above average which is beneficial for academic success as their sensitivity towards visual and auditive stimulation results in the retention of large chunks of information which eases the processing of information. In this regard Davis and Carter (2008) warn that although these children's capabilities may be extraordinary, they need assistance with basic academic skills such as planning, organisation, study methods and general academic and psychological support.

These children can also easily be over-stimulated with the result that they may tend to pay attention to detail and therefore find it difficult to focus on other important aspects, which explain their need for special education to ensure that they achieve their academic goals (WHO, 1999). It is therefore evident that these learners have numerous challenges with basic academic skills such as problem solving, concept identification and in-depth reading. Nel *et al*. (2013:19-20) mention that they tend to struggle in subjects such as mathematics and languages whereas they tend to cope better with subjects such as social and physical sciences, which require the learner to remember facts and to make use of their automatic long-term memory.

The development of an individual's perceptual skills is seen as the fundamental aspect required for developing basic reading and writing skills (Rinehart *et al*. 2002:276). The underdevelopment of these individuals' perceptual skills and motor development is the corresponding factor that effects the participation in academic and basic physical activities. The above-mentioned perceptual skills entail balance, motor movement, hand and eye coordination and finer motor skills.

1.5.1.2 Emotional manifestation

Individuals with ASD tend to struggle with their emotions in challenging situations. Weiten (2013:95) asserts that emotional behaviour and social control is influenced by the development of the thalamus, which is responsible for social stimulation. As the brains of individuals with ASD are neurologically different, their social and emotional abilities are usually affected.

Due to the sensitivity towards emotionally demanding situations, the individual often reacts socially and resort to a fight- or flight response. Weiten (2013:95) explains that the individual has a choice to confront or to avoid certain challenges or situations, which are referred to as the "fight or flight response", which involves a physiological reaction to threat in which the autonomic nervous system mobilizes the organism for attacking (fight) or fleeing (flight) an enemy (Weiten, 2013:95). This author further explains that this reaction is a natural response when a person feels threatened or confronted with uncomfortable situations. In order to avoid these stressful or emotionally demanding situations, the individual tends to resort to a flight rather than a fight response. Nel *et al*. (2013:19-20) furthermore report that individuals with ASD resort to certain rituals in order to deal with stressful situations, which can vary from symbolic and imaginative play.

1.5.1.3 Social manifestation

Individuals with ASD require additional assistance during social situations. These individuals may also struggle to create and form relationships with other human beings, due to the underdevelopment of expressive language, as the ability to follow conversations is compromised (Nel, *et al*., 2013:19-20).

The typical emotional behaviour corresponds with the social behaviour of an individual and the fight or flight action also plays a role in the social domain. In this regard Davis and Carter (2008:123) explain a fight response as the willingness to form relationships and participate in social activities, which demands participation in social communication events. The flight response entails the avoidance of social interaction and emotional challenging situations. Behaviour traits such as anxiety with regard to social situations are visible in the behaviour of children with ASD. Obsessive thoughts of possible prejudice and discrimination may control the individual’s thoughts during social situations (Davis & Carter, 2008:124). Although individuals with ASD usually avoid social interaction, some can form relationships with other human beings, but a relationship of trust must first be established in order for the individual/child to feel emotionally safe (WHO, 1999:329).

1.5.1.4 Physical manifestation

According to Tekindal and Cilga (2017:181), the physical domain consists of the ability to participate in any physical activity. Hauck (2018:1) report that gross and fine motor skills of children on the spectrum are underdeveloped and this is visible from a very young age. The delay in gross motor and fine motor skills affects the child’s abilities to portray general academic skills such as writing, to colour and to cut out pictures. Intervention from a young age is very important and the assistance from an occupational therapist is vital for future academic success (Schoen & Miller, Brett-Green and Nielsen, 2009:1).

1.6 THEORETICAL AND CONCEPTUAL FRAMEWORK

My study made use of a theoretical as well as a conceptual framework.

1.6.1 Theoretical framework

Joubert, Hartell and Lombard (2016:281) define the role of a theory as providing a framework that serves as a lens for the researcher to conduct a particular study. Le Roux (2017:203) further explains that it is the responsibility of the researcher to link the research problem to a specific theory in order to understand the phenomenon studied. In my study the lens through which I conducted my literature review and which served as the basis for my data interpretation, is the so-called first-generation triangle which emerged from Vygotsky's theory of cultural mediation (Vygotsky, 1978). This is depicted as follows:

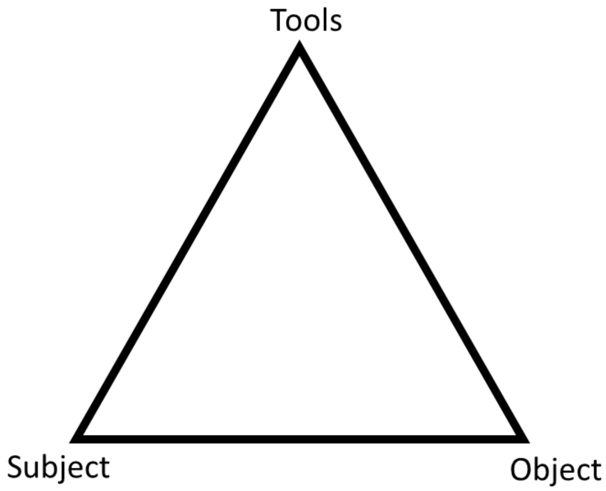


Figure 1.1: First generation triangle (FGT) (Vygotsky, 1978)

Engelstrőm (2001:134) explains that the first generation of the activity theory focuses on individual development and how stimulus and response influence each other. This triangle features three elements, namely subject, object and tools, all standing in a reciprocal relationship with one another, thus implying mutual interaction. Vygotsky (1978) explains that there is a synergy between the subject, usually a human being, and an object, which refers to some or other outcome. This relationship is never direct and always involves social and cultural actions (Vygotsky, 1978). To put it differently, in order for the subject (person) to reach an outcome (specific goal), certain interventions (by people, cultural artifacts and so on) must be used.

For the purpose of this study, the subject represents me, a person with ASD who is the main participant in the study. The "tools" are represented by participants, such as my mother, father, brother, grandmother and therapists, and the various resources they used to support me to reach the third point of the triangle, namely the object or outcome. The outcome was that I should finish my school career. These three points stress the importance of the stimulation the child receives from the cultural and social environment (Nielson & Wrein, 2012:186).Yamagata-Lynch (2010:15) emphasises the importance of support to reach a specific goal. Without the support from both my internal and external support systems, it would have been impossible for me to achieve my personal goals throughout my school career.

As my study focused on my journey through my school years and specifically on the support I received to enable me to finish my school career, this framework was appropriate as it addressed all the elements that played a role in opening the doors to tertiary education.

1.6.2 Conceptual framework

Adom, Hussein and Agyem (2018:438) define a conceptual framework as a structure that the researcher employs to make the research more accessible. Grant and Osanloo (2014) explain that a conceptual framework is based on how the researcher uses certain concepts in relation to each other. For the purpose of my study, four concepts, namely the cognitive, emotional, social and physical domain, constituted my conceptual framework and acted as lens for my literature review, data analysis and data interpretation.

1.7 RESEARCH METHODOLOGY

McMillan and Schumacher (2010) describe a research methodology as a systematic and purposeful plan in order to answer the questions from an identified research problem. For the purpose of this study, this consisted of the research design and research methods. I have outlined these aspects here to give an overview of the methodology that was followed; however, they will be discussed in detail in Chapter 3.

1.7.1 Research design

The research design can be explained as a self-evaluation process where the researcher identifies the critical values of what is needed to conduct research (Joubert *et al*, 2016:282). This consists of the research paradigm in which my study was situated as well as the approach that I followed.

As the aim of this study was to share my personal account of my journey with ASD and the support I received throughout my school years, the study was situated within the interpretive paradigm, which allowed me to share my own meaning about reality (Nieuwenhuis, 2007:48). Goldkuhl (2012:2) furthermore suggests that a researcher who functions from an interpretivist philosophy believes that knowledge and information gained is socially constructed. In other words, data are gathered from people in the researcher's social environment. For the purpose of this study, I gathered information from my participants' subjective experiences while they were supporting me. Levers (2013:3) explains an interpretivist paradigm as a description of subjective experiences, where the truth is not necessarily discovered. As this is an auto-ethnographic study, my own perception of my journey with autism, as well as my mother's experiences as she was my main supporter were described. Insights from various specialists such as the occupational therapist, speech therapist and school psychologist who assisted me were also sought.

Okeke and Van Wyk (2015) maintain that interpretivism is usually used in qualitative research as the depth of a phenomenon is being investigated. I therefore followed a qualitative approach, which Gill, Stewart, Treasure and Chadwick (2008:2) postulate implements humanistic values due to the fact that the participants' personal points of view, opinions and experiences are taken into consideration.

1.7.2 Research methods

Le Roux (2017:196) explains that research methods refer to the overall process of the research procedure and serve as a guideline for a researcher to follow to ensure that the research process is conducted in an ethical manner.

As this study involved a personal account of my journey throughout my school career with ASD, as well as the documentation of the experiences of my support network, an auto-ethnographic methodology was followed.

1.7.2.1 Auto-ethnography

Ellis, Adams and Bochner (2011:3) succinctly summarise an auto-ethnographic study as “a unique and information rich process that takes the researcher, the participants and the readers on a journey of self-exploration and discovery”. They further suggest that this type of research method involves the emotions and past personal experiences of the researcher. Joubert *et al.* (2016:20) add that auto–ethnography sets a platform where the researcher and participants share subjective experiences. In the case of this study, as researcher, I shared my story as a learner with ASD throughout my school career, and my participants, who are the people who supported me on this journey, also shared their experiences. Lemmer (2013:12) refers to Adams, Holman Jones, and Ellis (2015:79) when explaining that auto-ethnography is a combination of “ethnography (looking outward at the world beyond one’s own) and autobiography (gazing inward of a story of one’s self)”.

In the words of Ellis *et al*. (2011:3): “Auto- ethnography is an approach to research and writing that seeks to describe and systematically analyze personal experiences in order to understand cultural experiences”. In other words, I’m writing about ASD in general, how society responds to this syndrome (looking outward), but also about my personal and subjective experiences as I had to navigate through school as a learner with ASD (gazing inward).

Le Roux (2017) furthermore explains that auto-ethnographic studies are based on honesty and ethics. My study was based on my own experiences as well as the experiences of other people within my support network. I gave an honest account of my experiences and used my participants’ experiences as validation. This was conducted in line with the interpretivist paradigm to give deeper meaning and understanding of my experiences. Mendez (2013:280) postulates that the main aim of auto-ethnography is to indicate and recognise the gap in the specific research field and to identify the major contribution the researcher can make towards the research process. I believe that my contribution will be to raise awareness about the potential that may be unleashed in someone with ASD, providing that a strong support network is in place. In so doing, I am following the standards to meet the requirement as set by Le Roux (2017:199) that research outcomes should add value to the broader community and that common values must occur in order to teach the unteachable, to inform and to inspire. It therefore is clear that auto-ethnography is a unique way of conducting research. Lemmer (2012:3) specifically refers to the role of the researcher in this regard and postulates that this type of methodology leads the researcher into a whole new dimension of research investigation and data gathering.

1.7.2.2 Role of the researcher

The most important aspect of the research methodology is for the writer to acknowledge him/herself as a researcher and to respect and appreciate the role that he/she is playing during the data collection process (Maree, 2012:70). Le Roux (2017:196) explains this role as part of a unique research process that involves the researcher as an active participant in a cultural and social experience, which allows him/her an opportunity to fulfil the role of observer and participant in his/her own study. I was the researcher as well as the main participant in this study, which comprised my personal story as a person on the autism spectrum. I was also an observer, in the sense that I distanced myself from the research in order to gain the perceptions and insights from other participants, from both my internal support system (mother, father, brother and grandmother) as well as my external support system (therapists).

1.7.2.3 Participants

My study focused on the support I have received during my early school years. Therefore, apart from myself, my participants included members from both my internal and external support systems. My internal support structure included my mother, father, brother and grandmother whereas my external support structure included the occupational, speech therapist and the school psychologist. Therapy started when I was four years and two months and ended when I was nine years old. The speech therapist provided therapy for eight months. The occupational therapist provided therapy for two and a half years and the school psychologist provided assistance for five years.

As I can be regarded as the main participant in this study, I share my own account of the challenges with which I was confronted during my school years and the educational support I received to achieve my goals.

1.7.2.4 The self as participant

Reflection is a qualitative research method that is used as a tool to remember important moments and experiences that had a significant influence on the life of the participant (Allet, Keightley & Pickering, 2011:1). This research method entails that I, as the researcher, recalled memories and experiences of how the support given by both my internal and external support system helped me to achieve personal goals throughout my school career (Allet *et al*. 2011:2). Photographs and personal historical documents can be helpful tools to recall and remember important information and memories (Allet *et al*. 2011:2).

1.8 DATA COLLECTION METHODS

Creswell (2012:118) defines data collection methods as a process to achieve a common research goal, the latter which guides the researcher in gathering information to answer the research questions. As I gathered personal, subjective data, the data collection methods I used consisted of different qualitative methods such as a narrative, interviews, document analysis, and personal historic artifacts and photographs.

1.8.1 Semi-structured interviews

Interviews entail the gathering of data from different participants through direct contact (Okeke & Van Wyk, 2015:211). The goal is to gather the participants' opinions, perceptions and definitions about certain situations and how they perceive reality (Okeke & van Wyk, 2015:211). Hayes (2011:36) explains that interviews with the participants give the researcher an opportunity to gain insight into people's behaviour and experiences. The interview can be open-ended or semi-structured (Okeke & Van Wyk, 2015:115). For the purpose of my study, I made use of semi-structured focus group Interviews conducted with my internal support structure, namely my mother, father, brother and grandmother as well as my external support structure who consisted of the school psychologist, occupational and speech therapist. Maree (2016:75) explains that semi-structured Interviews entail the setting of open questions where themes are pre-selected. It is a qualitative method that encourages the participant to give answers to pre-selected questions without limitations. The questions were carefully examined and developed in order to get a required response (Maree, 2016:75). Each interview was unique and different questions were developed as each participant was present in a different timeframe in my development. The pre-selected questions were developed according to a general structure as it ranged from personal experiences with me towards their general observations.

1.8.2 Document analysis

Hayes (2011:36) suggests that document analysis is a way of conducting psychological research which involves gathering of data from written records or other documents. In my research I made use of different documents such as my mother's book, my school performance cards and psychological and therapist reports. The latter served as written evidence of the account of my physical, emotional and communication development.

1.8.2.1 My mother's book (Unpublished manuscript)

Personal biographies are examples of personal versions of individual stories (Rydne, 2012:1). These stories are the richest published research because personal first-hand experience and feelings are portrayed (Joubert *et al*. 2016:233). My mother documented in a book all her experiences as well as the milestones I reached and every setback I experienced throughout my school career. The information contained in this book gave me insight into her experiences in raising and supporting a child with ASD.

1.8.2.2 School performance cards

The school performance cards serve as evidence of the hard work and long road I took in order to achieve academic success.

1.8.2.3 Psychological and therapist reports

Psychological and therapist reports serve as written evidence of my progress and physical challenges that I encountered throughout my school years.

1.9 DATA ANALYSIS

For the analysis of my data, I made use of both deductive and inductive approaches. Creswell (2013:93) defines the deductive method as the researcher's opportunity to test an existing theory through a self-developing hypothesis. Certain questions and themes are derived from the research findings and must therefore be verified. On the other hand the inductive research method refers to the ability of the researcher to collect data from personal perspectives and interviews. General themes are selected though the continuous interaction between literature and analysis (Creswell, 2013:32). Translated to my study, I used my conceptual framework, namely the four developmental domains as categories to write my novella (deductive method), and sub-categories emerged from the data which acted as the basis for the interpretation (inductive method).

1.9.1 Narrative (novella)

The way in which I reported on my experiences was through a novella, which Hayes (2011:32) explains as a short well-structured narrative with a common social theme or context. The author furthermore explains it as a significant process which is longer than a short story but shorter than a novel. Okeke and Van Wyk (2015:115) suggest that the word "narrative" entails interpretive research where the researcher describes or retells his/her personal story, experiences and feelings which give the reader a direct front seat experience. The personal experiences are retold and gathered through active participation (Okeke & Van Wyk, 2015:115).

Hayes (2011:32) further explains that all narratives must contain three elements, namely personal and social dimensions, which include the social interaction with the selected participants as well as the description of the different situations and the timing of events that took place. To illustrate and supplement my novella, I included photographs, which Burke (2011:165) explains as audio-visual material where the researcher can display his/her personal feelings and experience.

1.10 OVERVIEW OF THE STUDY

This study focused on the support that I, as an individual diagnosed with autism, received on different levels during my pre-primary, primary and high school years. Chapter 1 therefore presented a bird's eye view of my study, explaining the context and rationale of my study, as well as the theoretical and conceptual framework that informed this study. The research methodology that was followed throughout this dissertation was also explained.

In Chapter 2 an overview is presented of the literature that was consulted. The chapter commences with an explanation of my theoretical framework that underlies this study, and which contains the three elements of a support system according to Vygotsky (1978). Literature was also reviewed to explain what autism involves, as well as how this syndrome manifests in the four developmental domains, namely cognitive, social, emotional and physical.

Chapter 3 explains the research design that was followed as well as the research methods that guided my study. Auto-ethnography as methodology was discussed in detail and my participants were introduced. Trustworthiness was also justified as well as the ethical principles that guided the empirical study.

In Chapter 4 my novella is presented by using the four domains as points of reference. The voices of my participants and my own experiences come to the fore, and the reader gets a glimpse on the challenges that are experienced by a child with autism and the support that is needed to overcome these challenges.

Chapter 5 presents the interpretation of my data. All the facts which informed my study are assembled to make meaning of my data. By means of the four categories and sub-categories which emerged from the analysis, the literature, theoretical framework, research questions as well as the contributions of my participants were combined to make sense of my data.

Chapter 6 is the final chapter of this study and commenced with the key findings of the literature and empirical studies. This was followed by the answering of my research questions as well as what I consider to be the contribution of my study. The chapter was concluded by the presentation of various recommendations for role-players in the education of a child with autism.

1.11 CONCLUSION

This chapter served to provide a general overview of the study by introducing the various concepts that guided this study as well as explaining the methods that were followed to collect theoretical and empirical evidence.

Chapter 2 will present the theoretical framework that acted as lens for the investigation into various research studies on the topic of autism. The chapter will report on relevant literature sources which undergirded the academic insights on autism and its associated elements.

CHAPTER 2

THEORETICAL PERSPECTIVES ON AUTISM AND SUPPORT

2.1 INTRODUCTION

In the previous chapter the orientation to this study was provided, followed by an explanation of the auto-ethnographic methodology that was followed. The background and rationale for this study was discussed, and the problem statement identified the gap in existing literature that necessitated this study. An outline of the research design and methods was also presented.

Chapter 2 commences with an explanation of the First Generation Theory (FGT) of Vygotsky (1978) that was used as lens for my literature review and to interpret my data. The two elements emanating from this framework, namely autism and support, are also discussed in detail.

2.2 THEORETICAL FRAMEWORK

The role of theory is to serve as a lens so that the researcher can conduct a particular study (Joubert *et al*, 2016:281). Le Roux (2017:203) adds that a theoretical framework allows the researcher to link his knowledge to an existing theory in order to improve his own research field as well as finding similarities from the research. Engelstrőm (2015:187), on the other hand, emphasises the purpose of theory in research which Okeke and Van Wyk (2016:32) explain as linking theory to reality. For the purpose of my study, I have selected the FGT (Vygotsky, 1978) as theoretical lens to conduct my literature review, and to serve as framework for interpreting my data.

2.2.1 First Generation Theory

In academic literature, researchers tend to make use of triangles to represent the interpersonal and interpersonal development processes which may act as lenses through which they explain their research (Okeke & Van Wyk, 2016:32). The triangle that guided my study is the FGT which emerged from Vygotsky’s theory on cultural mediation (Vygotsky, 1978) (see figure 1.1).

Zittoun, Gillespie, Cornish and Psaltis (2007:1) postulate that the FGT is used as the "most persistent metaphor in cultural and social psychology" as it represents the interrelationship between its three corners, which Vygotsky coined subject, tools and object. These three elements, namely subject, tools and objects, stand in a reciprocal relationship with one another, and function on the basis of stimulus and response (Zittoun, *et al*. 2007:5). Engelstrőm (2001:134) elaborates by referring to each of the three corners as stimuli that affect each other in their own unique way, while Nielson and Wrein (2012:186) suggest that these three corners stress the importance of the stimulation the child receives from the cultural and social environment.

The first corner, namely the subject, may be represented by an individual or group as a separate entity (Gedera, 2016:54). Gedera (2016:54) further states that the subject makes use of mediation in order to achieve a required objective. For the purpose of my study, the subject is represented by myself, a person diagnosed with ASD at the age of four and a half years.

The second corner represents the "tools", which support the subject in reaching his/her goal (object). Roth and Lee (2007:12) note that modelling is an integral part of the tools, and can be understood as the mentorship which caregivers provide in order to achieve a specific goal (object).The subject and object therefore both depend on the tools, which according to Zittoun *et al*. (2007:8), focus on the psychological development of the subject. In this regard Vygotsky (1978) emphasises that the relationship between the subject and tools always involves social and cultural actions.

The last corner is called the object and is the only element that is finite and can be influenced by the other two corners (Zittoun *et al*. 2007:6).To put it differently, the success of the object (in this case the goal or outcome) is dependent on what happens in the subject and tools. In this regard Nielson and Wrein (2012:186) maintain that the object is usually the result of the consistent interaction between the subject and the tools. In other words, in order for the subject (person) to reach an outcome (specific goal or object), certain interventions (by people, cultural artifacts and so on) must be used – and these are referred to as tools (Vygotsky, 1978). On the other hand, it is important to note that Vygotsky's main ideas centered on the impact of additional support on the development of the child's emotional, social and cognitive domains (Engestrőm, 2009:55). Therefore, Fenyhough (2008:3) believes that credit must be given to both the object and tools for the shaping or moulding of the subject.

In my study, the tools are represented by participants, such as my grandmother ,mother, father, brother (my internal support system) and my external support system, which consisted of the occupational therapist, speech therapist and school psychologist and the various devices (therapies, exercises and more) they employed to help me reach my goal (outcome).

The third corner, namely the object, leads to a specific outcome. In this study, through continuous support (tools) I, as a person with ASD (subject), was capable to succeed in school and achieve good marks in order to complete my school career. The outcome (object) that we were all working towards was for me to get university admission to enable me to further my tertiary studies.

Figure 2.1 represents my own understanding of the FGT and how it featured in my life.

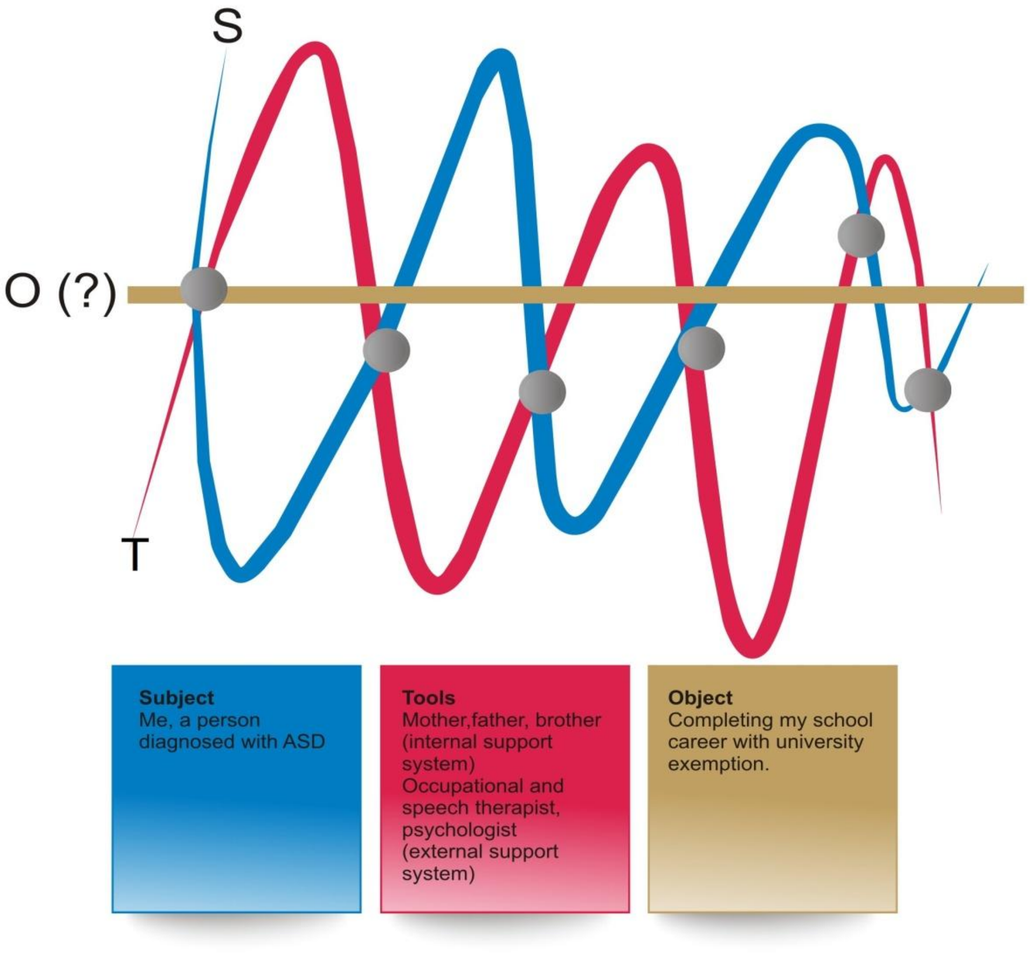


Figure 2.1: My personal adaption of Vygotsky's FGT

My interpretation of the FGT portrays the interrelationship between the three main elements, where the *subject* (I as the person with ASD) and the tools (my internal and external support systems) are represented as spirals. These spirals are wide, which indicates the time that elapsed between the various interventions (grey dots). The lines of the spiral do not run in a neat pattern as regression and stagnation often occurred between the various interventions (grey dots). These grey dots (interventions) depict the support that took place in the different developmental domains (cognitive, social, emotional and physical) during my school career. The outcome (object) for all of us was to enable me to complete my school career and obtain admission to university.

The goal (object) runs in a straight line, like a golden thread throughout the spirals, and represents our (my own and that of my support systems) dream, namely to enable me to finish my school career with university exemption. The end of the golden line (objective) has a question mark, which indicates the endless possibilities that my university exemption generates and may consist of future achievements such as a PhD study and a professional career.

In the following discussion, ASD will be explored in detail, as this disorder defined me as a learner throughout my school career. This will be followed by a discussion on support (tools) and lastly, the journey to reach the outcome (object) will be narrated in Chapter four.

2.3 AUTISM SPECTRUM DISORDER (ASD)

Autism spectrum disorder (ASD) is the most unrecognised and neglected epidemic of all time and is increasingly diagnosed in children till adulthood (Sharma, Gokulchandran, Sane, Biju & Shetty, 2015:3). To illustrate, Wilkinson (2014:4) found that the incidence of ASD has quadrupled from 1.5% to 5.8% throughout the world, and in the United States (US), one out of 68 children is currently diagnosed with ASD. The definition by the American Psychiatric Association (APA) (2013:50) explains that ASD is a neuro-developmental disorder, which could hamper the individual's capabilities to function normally in society (Gaspar de Alba & Bodfish, 2011:30). Sharma *et al*. (2015:9) furthermore explain that autism is a result of the highly complex interaction between the genes, brain and behaviour through the child's developmental period. Jerome Kanner (1943), who can be regarded as the father of ASD, describes this disorder as the child's interest in the same repertoire of fixed behaviours, routines and obsessions (Baumer & Spence, 2018:249). Kanner furthermore maintained that ASD could also be ascribed to a dysfunction in the neurological network of the brain which manifests in the spectrum of autism (Sharma *et al*. 2015:33).

Thibaut (2017:323) explains that diagnosis of ASD usually occurs before the age of three years and can affect the child socially, emotionally and cognitively. Although developmental indicators can be observed before three years of age, most formal diagnoses only take place between four and six years of age (Brooks & Goldstein, 2011:1). Research conducted by Mandell and Salzer (2007:1) indicates that only 30 percent of children diagnosed with ASD are correctly diagnosed; 16 percent are wrongly diagnosed. This 16 percent is due to parents who are unable to afford specialised services and advice whereby the child's deficiency can be directly identified (Mandell & Salzer, 2007:1). According to Wilkinson (2014:18), males are more prone to be diagnosed with ASD than females. This is supported by the Center of Disease Control (CDC) who maintains that autism occurs four times more in boys than in girls (National Institute of Mental Health, 2011:16).

Baumer and Spence (2018:248) indicate numerous questions and speculations regarding the causes of ASD, which include assumptions about genetic transferability or the pregnancy circumstances of the mother. However, Perepa (2013:8) has an interesting theory based on her observations while working with parents and children diagnosed with ASD. She believes that the autism gene is caused by bodily trauma in the mother's womb, which causes damage to the central nervous system which results in "body separateness" and feelings of insecurity and unrest in the mother's womb (Perepa, 2013:8). Tustin (1992) adds that the baby then furthermore experiences feelings of trauma and anxiety after birth and these feelings continue into infanthood which results in a constant feeling of trauma and anxiety throughout the child's life.

The diagnosis of ASD is done according to two categories, namely high functioning autism (HFA) and low functioning autism (LFA) (Gorjy, Fielding & Falkmer, 2017:1490). When comparing the characteristics of HFA and LFA, the APA (2013:55) ascribes the differences as being based on neurological alterations.

2.3.1 High functioning autism (HFA)

High functioning autism (HFA) is a lighter form of ASD as children diagnosed with HFA can function in society despite their inadequate cognitive, verbal and motor skills (Arnott *et al*. 2009). Based on the APA's criteria (2013:52), only six out of 10 000 children are diagnosed with HFA. Crespi (2016) assessed the neurological differences between children diagnosed with low functioning and high functioning autism comparing it with learners which were classified as 'normal', and found that a difference could be detected in a larger brain volume of children with HFA. To put further emphasis on the cognitive abilities of the child, Scahill *et al*. (2015:39) refer to neurological evidence that indicates that these children's intelligence quotient (IQ) is higher than those with low functioning autism (LFA). Children with HFA also present with limited language capabilities and have a mild cognitive delay which manifests in a restriction in basic social, communicative and behavioural activities (Scahill *et al*. 2015:39). Attwood (2013) compared children with HFA with children who are not on the ASD spectrum and noticed that these children learn at a much slower pace. The characteristics of HFA correspond with those of Asperger syndrome and therefore experts classify Asperger syndrome under the high functioning umbrella (Volkmar, Lord, Bailey, Schultz & Klin, 2004). Asperger and HFA symptoms can have the same diagnoses and same behaviour patterns, but the difference presents in a language delay.

Hans Asperger (1906–1980), an Austrian pediatrician who specialised in remedial pedagogy (Schopler, Mesibov & Kunce, 1998:12), conducted a study on four young boys and identified a recurring pattern of behaviour and aptitudes that he termed "autistic psychopath". This term explains the occurrence of abnormality in behaviour and the finest restriction in basic emotion and behaviour in unfamiliar social settings (Attwood, 1997:14). Sharma *et al*. (2015:14) furthermore explain that Asperger syndrome consists of an inability to interact socially with people. It is important to note that children diagnosed with HFA are in general very intelligent and may be able to have a successful career, but need constant encouragement and support (Egilson, Òlafsdóttir, Leŏsdottir & Saemundsen, 2017:134).

2.3.2 Low functioning autism (LFA)

Low functioning autism (LFA) can be recognised by the presence of an intellectual disability (i.e., Intelligence Quotient (IQ) below 70) and is associated with an increased incidence of an acquired or genetically determined biological cause (Rinehart *et al*. 2002:763). Sharma *et al*. (2015:14) explain that LFA involves an inability to communicate effectively and the portraying of stereotype behavioural impairments and social behaviour. These authors also maintain that children with LFA present with “non-social features” such as sensory, feeding and visual-spatial problems (Sharma *et al*. 2015:14).

2.3.3 Characteristics of children with autism spectrum disorder (ASD)

Mazzone, Ruta and Reale (2012), Sikora, Vora, Coury and Rosenberg (2012) and Wilkinson (2014) report on the characteristics of children with ASD, which include poor social communication, short attention span, emotional distress as well as academic and behaviour difficulties. Abrahams and Geschwind’s (2008) research indicates that the brain of children diagnosed with ASD is differently developed than those of neuro-typical children and therefore influences the child’s cognitive, social and emotional functioning. These authors believe that the rapid brain development influences the forming of social relationships, the processing of information and the displaying of inappropriate emotions in certain situations (Abrahams & Geschwind, 2008). Wilkinson (2014:75) believes that these children can experience delays in their cognitive, social and emotional domains, which may have an impact on their academic, social and emotional capabilities. These domains necessitate further discussion.

2.3.3.1 Cognitive domain

Cognition is a broad term that influences a person's (in this case a child's) behaviour patterns and learning abilities and includes the child's working memory, language, attention, processing speed and abstract reasoning (Fombonne, 2005). Sungji, Sohn, Sim and Cheon (2015:1) conducted various MRI scans on children on the ASD spectrum, and found that a dysfunctional activation in different areas of the brain is visible, which affects social communication and emotional impulse control. Courchesne, Redcay and Kennedy (2004:1) also explains that children diagnosed with ASD have a larger brain volume which enables them to recall information more frequently than other children, whereas Weiten (2009:95) postulates that their hippocampus is larger than normal. The hippocampus is the part of the brain which is responsible for the visual, auditive and intellectual development of the child (Nel, Nel & Hugo, 2013:19). Researchers found that their auditive memory is above standard, which is confirmed by Bornman and Rose (2013:197) who add that this aspect is beneficial for academic success. According to Bontinck, Warreyn, Meirsschaut and Roeyers (2017:94), the minority of children on the ASD spectrum (those with LFA) have a below average IQ which contributes to the child's language and learning difficulties.

Furthermore, children on the ASD spectrum, experience numerous sensory and intellectual challenges. Courchesne *et al* (2004) notes that due to the fast growth of the brain, certain abilities increase automatically, such as the sharpness of sensory awareness which includes touch, smell, sight and hearing. This "sharpness" can be painful for the child and can cause inappropriate behaviour. Courchesne *et al* (2004) furthermore asserts that children with ASD are sensitive to visual and auditive stimulation, which enables them to retain large chunks of information which may assist their memory. Williams, Goldstein and Minshew (2006), however, found that children with ASD have difficulty with complex memory tasks based on the limitations in proper planning and organisation skills. Attwood (2013) explains that, although the long term memory of these children is good, there still remains a major question regarding the short term memory of the child. Davis and Carter

(2008:124) postulate that although some of these children's capabilities such as their long-term memory are extraordinary, they are still confronted with numerous challenges that can affect the child's academic performance. In this regard, the child's executive functioning, which is a critical aspect in order to succeed in school, may be compromised. Executive functioning affects basic academic skills such as planning, organisation, impulse control, study methods and general academic support, and originates in the frontal lobe of the brain (Davis & Carter, 2008:124).

Another challenge related to the child's cognition is the theory of mind (Attwood, 2013) which forms part of the social-emotional dimension and effects the perception of the child in challenging situations. Wilkinson (2014:80) mentions that an important aspect of cognition consists of the sharing and portraying of emotions, feelings and knowledge during social situations towards another individual.

2.3.3.2. Social domain

According to the Parental Guide for Autism Spectrum Disorder (2013:6), children with ASD experience numerous social challenges. If one takes into account that the development of certain social skills is seen as a fundamental tool to function in society (Gilliot, 1999), one can understand that the child with ASD experiences hardship. Case-Smith and Bryan (1999:490) found that these children's speech and communication skills are underdeveloped based on the fact that they struggle to produce words and form sentences. Davis and Carter (2008:123) point to the importance of social and communication skills as the fundamental requirements to function and be accepted in society and school. In this regard the APA (2013:50) defines social skills as the ability to communicate effectively and to form reciprocal relationships.

Perepa (2013:47) defines social communication as the ability to communicate effectively, to make use of body gestures and to portray facial expressions, signs and gestures which is required for a specific situation. Davis and Carter (2008:123) note that children diagnosed with ASD struggle to form social relationships, read social cues, identify the intentions of other people and communicate effectively with members from their own peer group. Lombaard (2013:12) observed the behaviour of several children on the ASD spectrum in social situations and noted that the behaviour of these children makes them emotionally vulnerable. They lack the ability to read social cues such as a smile, a wink or general sayings to describe certain situations. Their social interaction is also compromised as they are unable to follow through in conversations, due to the underdevelopment of their expressive language (Nel *et al*. 2013:19) which is aggravated by lack of eye contact and a tendency to babble. Rinehart *et al*. (2002:763) furthermore say that children diagnosed with ASD find it extremely difficult to communicate in big social groups. In addition, these children also tend to indulge in repetitive movement or repetition of certain patterns and interests which can be regarded as socially unacceptable (Hodgson, Grahame, Garland, Lecouturier & Couteur, 2018:165).

Cannon (in Weiten, 2013:544) first referred to the “fight- or flight response” and described it as a “physiological reaction to any form of threat which the autonomic nervous system mobilises the organism for attacking (fight) or fleeing (flight) an enemy”. Cannon further assumed that this reaction is a natural response that an individual experiences when he or she feels threatened or confronted with uncomfortable situations, such as an overcrowded classroom (Weiten, 2013:95). Davis and Carter (2008:123) explain that when a child with ASD decides to fight, the child may choose to confront a situation such as participating in a social activity and being willing to form relationships without showing any sign of fear for social interaction. Social interaction can be problematic as these children lack the ability to understand the rules of social behaviour (APA, 2013:52).The flight response, on the other hand, entails avoiding social interaction and emotional challenging situations. Due to the fact that children diagnosed with ASD are usually fixed to routines, they tend to develop a fear of risk-taking in all aspects of life; the world outside seems to be threatening and disturbing (Hodgson *et al*,2018:165), and the child may experience anxiety when confronted with social situations (David & Cater, 2008:124). According to Davis and Carter (2008:124), these feelings of anxiety and pre-determined fear are aggravated by the inability to pronounce words correctly and language delay. This behaviour trait is visible in the child’s behaviour and can create prejudice and discrimination from class mates and members of society (Davis & Carter, 2008:124).

Another challenge that originates from the child’s cognition is theory of mind (Attwood, 2013), which forms part of the social-emotional dimension. Attwood (2013:12) explains this concept as the ability to acknowledge and appreciate the fact that other individuals have emotions and to show empathy towards their needs, intentions and desires. It is a vital skill that a child needs in order to form friendship and relationships with people. Wilkinson (2014:80) mentions that an important aspect of cognition consists of the sharing and portraying of emotions, feelings and knowledge during social situations towards another individual. Children diagnosed with ASD struggle to read social cues and intentions of other people during socialising. This makes the child on the ASD spectrum emotionally vulnerable (Autism South Africa, 2013:12). Theorists, such as Lev Vygotsky, believed that every child can develop his or her own individual theory of mind skills, which enables them to relate to different situations to make responsible and correct decisions (Fernyhough, 2008:226). Through continuous exposure to different situations, the child's theory of mind can improve (Fernyhough, 2008:227). An important point is that each different situation requires a different behaviour trait and one should modify one's behaviour according to the required situation.

Bauer,Sturm,Carroll and Downs (2013:307) emphasises the importance of support, stating that it takes one special person to invite and make these children feel comfortable and to constantly remind them that there is nothing to be scared of.Gorjy, Fielding and Falkmer (2017:1489) believe that a relationship of trust must first be established in order for the individual/child to feel emotionally safe and to communicate effectively with other children.

2.3.3.3 Emotional domain

Emotions are neurologically controlled by the amygdala, which is the part of the brain that governs emotional behaviour and social response (Weiten, 2013:95). Schumann, Barnes, Lord and Courchesne (2009:12) explain that children diagnosed with ASD have emotional control difficulties due to the overgrowth of the amygdala. This condition takes place before the age of three years and can be associated with other cognitive impairments such as epilepsy and a severe degree of Down's syndrome. Schumann *et al*. (2009:12) furthermore explain that the amygdala has a "well-established role in the production and recognitions in emotions" that affects the child's behaviour in social and unfamiliar situations.

Laghi, Lonigro, Pallini, Bechini, Gradilone, Marziano and Baiocco (2017:795) add that ASD restricts emotional responses, which limits the ability to form human relationships as children with ASD often do not respond, or they display inappropriate or irrelevant emotions in challenging situations. Children with ASD often have emotionless facial expressions, but express physical signs of emotional distress such as hand-flapping gestures (Laghi *et al*. 2017:795). Children on the ASD spectrum cannot read facial expressions, movements and gestures and are prone to anxiety and depression (Baumer & Spence, 2018:250). Due to the inability to handle emotional demanding situations, the child with ASD may struggle to express appropriate emotions for a specific situation. When the child has a choice to confront or to avoid certain problems, the “fight or flight response” is activated (Weiten, 2013:95; see section 2.3.2.2). These children usually struggle to express emotions such anger, distress and affection which are important social cues (David & Carter, 2008). They often are unable to understand emotional expressions of other people and struggle to understand other’s opinions and point of views, therefore making social interaction extremely challenging (Baumer & Spence, 2018:250).

Sharma *et al*. (2015:33) found that when emotional overload occurs, in other words, when the child experiences too many emotions and does not know how to deal with these stimuli, they tend to become aggressive and may bite, scratch, throw objects around, pull hair or play with toys in an irrational aggressive manner.

2.3.3.4 Physical domain

Delays in physical development are one of the most visible characteristics of a child on the ASD spectrum and this can be noted in the decrease of head growth as well as fine and gross motor development (Sharma, *et al*. 2015: 34). Piek and Dyck (2003:5) report that six percent of children diagnosed with HFA between five and 11 years have gross motor problems. Nel *et al*. (2013) maintain that the physical domain comprises of two fundamental aspects, namely motor development and the development of perceptual skills. The development of a child’s perceptual skills includes kinesthetic, spatial, cross-modal and visual development (Piek & Dyck, 2003:5) which are essential for reading and writing and have a prolonged effect throughout the child’s school career (Nel *et al*. 2013:20).

Sharma *et al*. (2015:34) furthermore highlight the sensory challenges which children with ASD experience. This involves sensitivity towards certain smells, textures, sounds and food. This explains why these children often avoid sensory activities such as touching unfamiliar people by shaking hands, hugging or kissing (Sharma *et al*. 2015:34). Children with ASD also tend to display certain vestibular body movements such as rocking body movements, swinging and jumping (Sharma *et al*. 2015:35).

2.3.4 Impact on the family

Raising a child on the ASD spectrum remains a major challenge and requires the whole family to make adjustments to accommodate the child’s needs and abilities (Laghi *et al*. 2017:794). Rezaee, Younesi, Farahbod and Ranjbar (2017:36) note that parents experience fear and confusion when they find out that their child is different from others. A common misconception that parents have is that ASD is a developmental disorder that can be improved throughout the child’s development years and that the child will outgrow the symptoms (Perepa, 2013:18). Barnhill (2014:220) mentions that acceptance begins with the immediate family and it is their choice to either embrace or avoid the diagnoses of ASD. Perepa (2013:16) furthermore asserts that parents need to make peace with the fact that there is no medical cure for ASD, but through continuous support and assistance, the child may improve his or her skills to be able to function in society.

Chan and Lam (2018:45) presents a model which families usually follow and which ranges from dysfunctional to functional. The following figure is a visual representation of this model which represents three elements according to which a family may function. Families function on a continuum, ranging from dysfunctional to highly functional, depending on various factors. The way families function is therefore unique as context determines where functionality is situated on the continuum.

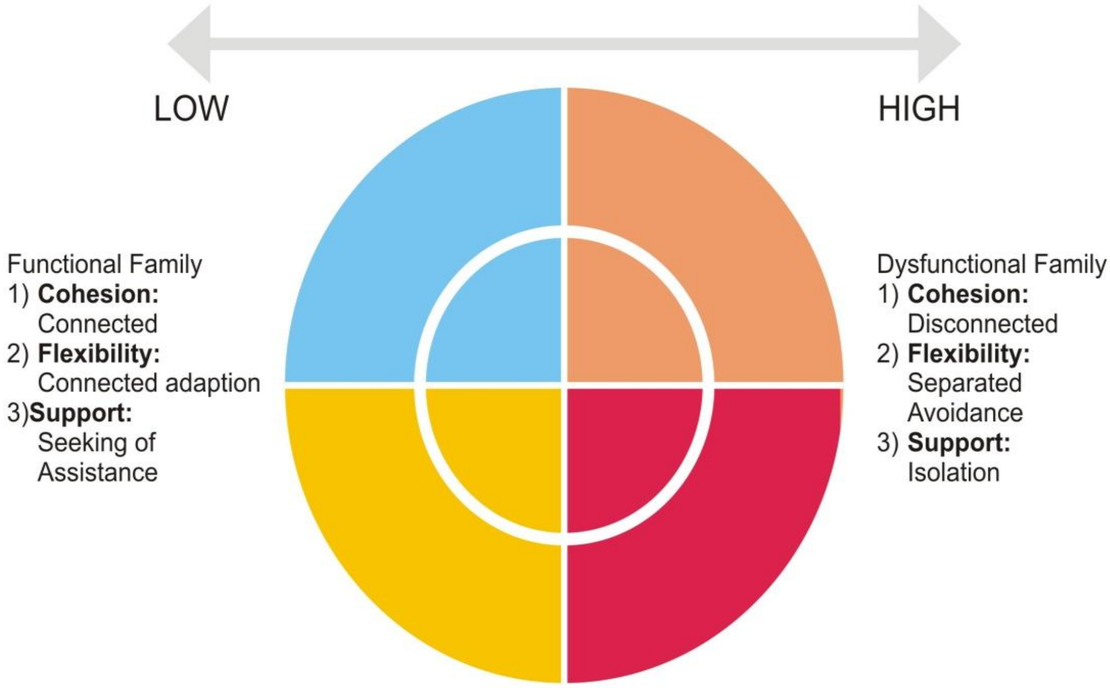


Figure 2.2: The circumplex model (Chan & Lam, 2018:45)

The first element is cohesion which refers to the emotional relationship between family members. Barnhill (2014:219) mentions that in most families the diagnosis of a child with ASD can be disruptive and may have a major impact on the relationship among family members. Zaldman-Zalt *et al*. (2018:1) suggest that parents with children on the ASD spectrum experience more anxiety and stress than any normal household and these feelings influence the relationship among family members. These authors advise that parents should try to remain confident in challenging moments, not to lose hope and to keep trusting their own judgment (Zaldman-Zalt *et al*. 2018:1). Braconnier, Coffman, Kelso and Wolf (2017:2) warn that the relationship between siblings remains the most controversial as siblings usually are “the most critical advocates because of their front row knowledge and experience of living with a sibling on the ASD spectrum”. Braconnier *et al*. (2017:2) notes that siblings are at the receiving end in terms of the inappropriate behaviour that their brother or sister on the ASD spectrum may display. These behaviour problems can cause the sibling to distance him/herself and not to engage in a relationship with the sibling on the ASD spectrum.

The next element in the circumplex model is the ability of the family to be flexible. This element relates to the capacity of parents to accept this child and therefore being willing to adapt their personal life style in order to accommodate the needs of their child. Bontinck *et al*. (2017:91) suggest that not all family members welcome the diagnosis of ASD with open arms; the possibility exists that one parent will find it difficult to adjust and in response may tend to avoid the situation by distancing him/herself from the current household. As the mother usually is the main caregiver, in most cases it is the father who is less involved. Thus, the mother figure is the only prominent one to support the child continuously (Bontinck *et al*. 2017:92).

The third and final element of the model is emotional support. Barnhill (2014:220) highlights that the anxiety following the diagnosis of ASD is enormous and can have a huge impact on the family. Without support from the immediate and extended family, friends and the community, a parent may feel alone and isolated. The community and social groups’ perceptions can also be hurtful. Chan and Lam (2018:45) note that parents are often blamed for the genetic transferability of autism. On the other hand, children with ASD may outwardly appear “normal” and appear physically healthy, but spectators often are unaware of the emotional, social and behavioural challenges that this child may present (Barnhill, 2014:220). Chan and Lam (2018:45) explain that the family is exposed to frequent social criticism based on the child's behaviour. Some parents cannot endure the associated stigma as this may cause feelings of inferiority, shame and helplessness (Chan & Lam, 2018:45).

2.4 EDUCATIONALSUPPORT

ASD is a lifelong disorder that effects the internal family's dynamics (Griffith, walker, Hastings, 2016:59) and without support (which the FGT calls "tools"), both parents and children will not be able to get through life's journey unscathed. Zaldman-Zalt, Szatmari, Duku, Smith, Vaillancourt, Volden, Waddell, Bennett, Zwaigenbaum, Elsabaggh and Georgiades (2018:1) define the term support as a unique quality and admit that each specific challenge with which a child with ASD is confronted requires a specific support service. For young and inexperienced parents, it is a daunting and impossible task to raise a child with autism within a society that favours 'normalcy' (Irene, 2018:1). Depending on the diagnosis of the child, it is critical that members from the child's internal support system work together to make the necessary accommodations to support their child educationally and allow the child to function independently in society (Woodgate, 2008; Irene, 2018:2).

Franz, Hansen and Machalicek (2017:61) explain that the immediate family is the most constant support system the child needs in dealing with ASD. Griffith *et al*. (2013:62) found that some parents are so intensively involved in their child's progress and development that they can be regarded as active activists for autism. Both Gray (2003:4) and Franz, Hansen and Machalicek (2017:61) admit that each parental figure experiences the diagnosis of ASD on a different level and in most cases, the bulk of the responsibility is usually carried by one parent which makes this parent the primary caregiver while the other parent may distance him/herself from the situation.

Parents of young children on the ASD spectrum may experience different emotions such as fear, sadness, doubt and regret after the child's diagnosis and are therefore left with an important decision which could influence the child and the family's personal future forever (Laghi, *et al*. 2017:794). Bontinck *et al*. (2017:94) note that this decision usually results in avoidance and the child is then institutionalised. The other option is that some parents accept the diagnosis and try to find ways in which to accommodate their child's needs.

Nuttall, Coberly and Diesel (2018:2) acknowledge the responsibility of parents to make the right decision based on their specific contexts, and advise that they should weigh the possibilities. The importance of this decision must be carefully considered because all family members and their relationships are influenced due to the sacrifices each must make in order to raise the child (Laghi *et al*. 2017:794).

Should parents decide to venture on the support path, the parents must undertake different roles (Dale, 1996:3; Shepherd, Landon, Taylor & Goedeke, 2018:3). The first role is one of consumer (Dale, 1996:3) which means that the parent will have to take action in order to make the best of the family's situation and to strengthen the family ties. Usually the help/advice of professionals, such as specialists is sought (Shepherd *et al*. 2018:10), which directly links with the tools, in terms of the FGT (Vygotsky, 1978).

The next role the parent undertakes is that of caregiver. Here, parents make use of the advice and knowledge of professionals and try to implement their suggestions in order to accommodate their child's needs (Shepherd *et al*. 2018:4). In this specific stage acceptance and problem solving is in the order of the day and parents try to raise their child to the best of their abilities (Shepherd *et al*. 2018:4).

The third and last category of support is that of clinical supporter, where parents make use of general support systems provided by governments which include mental health facilities (Fänge, Oswald & Clemson, 2012:7). This step depends on the severity of the diagnosis (Fänge, *et al*. 2012:7). Children diagnosed with HFA do not require the services of any mental health facilities as their challenges can be accommodated within the family and the understanding of the community (Klin, Saulnier,Tsatsanis & volkmar,2005:773). In this supportive role the parent passes the responsibility of caregiving into the hands of mental health facilities to provide the child's basic needs. This environment is a protective environment where the child is isolated from any social exposure (Klin *et al*. 2005:773).

This external support system is influential in the holistic development of the child, but Shepherd *et al*. (2018:2) state that without the total involvement and commitment from parents, as well as synergy between parents and external support systems, these children cannot reach their full potential. Mesibov *et al*. (2004) as well as Charman (2012) recommend that the additional support system must work in partnership with the parents to ensure that the child shows progress in the house, school and social environment. To put it differently, parents are in a partnership with the external support systems in order to improve the child’s behaviour. The parent makes use of knowledge from these experts so that they can implement it in their home environment. Mesibov *et al*. (2004) and Charman (2012) highlight that external support is a continuous process and must form part of the household’s lifestyle, but these authors also warn that although the involvement of these professional support systems can assist and may provide reassurance, immediate success is not guaranteed. Marcu, Dey and Kiesler (2010,1) postulate that the seeking of additional support gives parents an ideal opportunity to see the world through their child’s eyes, to gain understanding of their child’s needs and to ensure that consistent stimulation takes place on social and emotional levels.

The role of the parent in supporting the child corresponds with Vygotsky’s theory on support. The concept that is applicable here is the zone of proximal development (ZPD) where the parental approach and the stimulation the child receives on cognitive and emotional level takes center stage (Jarvis & Robinson, 2016:5). The ZPD is a theory that refers to the environment and stimuli the child is exposed to. In order to develop his full potential, the child receives assistance to deal with the challenges he encounters (Levych, 2008:90). Both parties, namely child and parent, must be willing to make sacrifices. A special bond is created between the child and the supporting figure where a special form of interaction is established (Zuckerman, 2007:43

Stadskleiv, Batorowicz, Massaro, van Balkom and von Tetzchner (2018:69) note that children with ASD experience challenges in cognitive, emotional, social and physical domains and therefore these children should receive assistance and support in order to improve the child’s abilities. Bozhovich (2009:50) maintains that parents make use of a variety of methods and specialists in order to support their child’s needs and improves his/her abilities. Therefore, the services of experts such as special education educators, therapists and educational psychologists are of value (Emam & Farrell, 2009; Soto-Chodiman, Pooley, & Taylor ,2012; Yumak & Akgul ,2010).

2.4.1 Cognitive domain

Davis and Carter (2018:124) suggest that a child’s cognitive ability involves his/her working memory and the way in which he/she processes information, thoughts and ideas. They further mention that the study of memory is a complex field which is based on the premise that the cognitive abilities of the child affect the child’s social, emotional and physical capabilities. Children diagnosed with HFA have an extraordinary long term memory, but due to challenges they may face, it is necessary for them to get assistance in basic academic skills such as planning, organisation, study methods and general academic support. These authors emphasise that there is no cure for autism, but that remedial education and therapeutic assistance can assist the child in dealing with challenges associated with this disorder.

Wilkinson (2014:82) note that thirty-nine percent of children diagnosed with ASD have attention problems and that their lack of attention span is noticeable when the child is confronted with complex tasks. Thus, children with ASD should therefore be accommodated in the classroom (Hargreaves, 2003:xi). Teachers should be aware of how these children experience the classroom environment and how they process the curriculum content. Mazzone, Ruta and Reale (2012), Sikora, Vora, Coury and Rosenberg (2012) and Wilkinson (2014:82) corroborate the importance of the role of the teacher in assisting these learners in various ways. Irene (2015:2) specifically mentions the adaptation of the curriculum according to the child's specific needs. Educators can adapt the curriculum by minimising the academic material realistically and by pre- determining the goals in each lesson step by step ('O Rourke-Lang & Bertin, 2018:3).

Nuske, Hassrick, Bronstein, Hauptman, Aponte, Levato, Stahmer, Mandell, Mundy, Kasariand and Smith (2018:4) warn that if the curriculum does not support or accommodate children on the ASD spectrum, there may be at risk of academic under-achievement, school dropout, peer rejection, anxiety and depression. It is therefore important that the needs of the child should be met in the emotional, social and physical domains (Roberts & Simpson, 2016:1086).

Mahn and Steiner (2012:31) believe that the most important aspect in learning and teaching a child with ASD is to build on the child's prior knowledge. In so doing, the competency as well as the confidence levels of the child will be improved. Roberts and Simpson (2016:1086) also advise that children on the ASD spectrum will benefit more if the curriculum is adapted to include non-academic topics such as hygiene, self-care, communication, socialising skills and independent living skills such as how to function in a community. Roberts and Simpson (2016:1086) furthermore point to the emotional bond between the child and supporter which is necessary to improve the child's confidence and abilities. These authors also refer to the importance that parents share relevant information regarding the child to ensure a safe environment, conducive for sound educational outcomes (Roberts & Simpson, 2016:1086). Slabbert, De Kock and Hattingh (2009:34-49) also highlight the importance of a stimulating, comfortable and safe environment where children, with the support from caregivers and specialists, can acquire appropriate skills in order to reach their full potential.

2.4.2 Emotional domain

Children diagnosed with ASD are confronted with different challenges on the emotional level and will struggle to express certain emotions, such as happiness, sadness, shame, guilt, joy and frustration required for a specific situation (Irene, 2015:2). For parents, the emotional behaviour that their child displays seems to be strange and unrealistic and could therefore cause them to worry about their child's emotional wellbeing (Irene, 2015:2).The most common emotional behaviour that can contribute towards the parents' concerns, is the child's tendency towards emotional outbursts and tantrums when confronted with unfamiliar and overcrowded environments (Baumer & Spence, 2018:258). Although there is uncertainty with regard the behavioural trigger, parents are advised to expose the child to environments that are emotionally safe and to avoid sensory over-stimulation. Hodgsen *et al*. (2016:166) note that the more the child gets exposed to different environments, the more skills they will develop. Children on the ASD spectrum perform at their best in a structured environment where rules and structured routines are present. Educational specialists and therapists can advise on rules with inbuilt flexibility and provide visual support material to parents (Hodgsen *et al*. 2016:165).

The emotional behaviour of children with ASD can also be triggered by the emotions of other individuals the child comes into contact with. According to Muller (2009:69), children diagnosed with ASD are sensitive towards any sort of emotion expressed by a close support figure, such as a parent or family member (Roberts & Simpson, 2016:1086). Parents should be alert to behavioural changes and make an effort to avoid negative emotional behaviour that can trigger the emotional outbursts (Roberts & Simpson, 2016:1086). Franz, Hansen and Machalicek (2017:71) indicate that parents can avoid negative emotions by creating a relationship which consists of emotional trust and bonding. When struggling to deal with the child's emotional outbursts, the assistance of trained professionals is required.

Educational psychologists are clinical and trained health professionals who help children and adults with mental health problems as well as emotional and psychological issues (AACAP, 2016:1). Educational psychologists are usually involved in the school and work together with parents in order to improve the child's learning capabilities and emotional, social and interpersonal strengths and difficulties (AACAP, 2016:1). Clinical psychologists are able to perform clinical evaluations, tests, assessments and psychotherapy. The psychologist can help in establishing priorities and plan in collaboration with parents in order to support the child. One of the goals of psychotherapy is to ensure that the child improves his skills in order to function in society (Franz, Hansen & Machalicek, 2017:59). Denne, Hastings and Huges (2017:544) report two types of interventions that psychologists usually employ: applied behaviour analysis (ABA) and developmental individual-difference relationship-based model (DIR).

2.4.2.1 Applied behaviour analysis (ABA)

ABA is a method that aims at reconditioning the child's behaviour. Activities are carefully chosen in order to improve the child's communication, social and vocabulary skills (Fisher, Piazza & Roane, 2011:92).

2.4.2.2 Developmental individual-difference relationship-based model (DIR)

DIR focuses on the improvement of the child's strengths in order to motivate the child and result in improvement of coping skills (Fisher *et al*. 2011:95). Psychologists can help children, parents and families cope with the child's anxiety, moods and depression (Fisher *et al*. 2011:95).

2.4.3 Social domain

In order for a child to adapt in school it is required that he/she must acquire basic social and communication skills. Individuals on the autism spectrum tend to struggle in social situations and to communicate effectively with members from their own peers (Davis & Carter, 2008:123). 'O Rourke-Lang and Bertin (2018:1) indicate that children on the ASD spectrum tend to be more comfortable in the presence of older people rather than members from their own peer group. The underdevelopment of social skills would usually occur in big social groups due to the experience of anxiety. Parents can support their child by learning through mediation to identify the specific emotions by encouraging the child to always make eye contact and never try to avoid the situations. Gory, Fielding and Falkmer (2017:1489) point to the interrelatedness between the emotional and social domain, when mentioning that the flight of fight response has a determining influence on the child's social behaviour.

Another factor influences the child's social behaviour is his/her inability to follow through with conversations and form relationships (Nel *et al*. 2013:19). Children diagnosed with ASD also tend to experience difficulty in expressing themselves verbally, and this can be ascribed to developmental language problems such as echolalia, which involves word pronunciation reversal and the inability to use figurative language (APA, 2013:54). A child on the spectrum is able to communicate effectively, provided he/she feels psychologically safe, but according to the DSM-IV criteria these children lack the ability to understand the rules of the social behaviour (APA, 2013:51-52). Children with ASD cannot avoid big social groups all the time and therefore caregivers can make use of different reinforcement methods to positively reinforce the child's behaviour (Wilkinson, 2014:122). This could motivate the child and make him/her more comfortable to communicate and express social cues such as eye contact and a positive comfortable body posture (Wilkinson, 2014:122).

Children diagnosed with ASD have difficulty to pronounce words and form sentences. This sort of language problem requires specific activities in order to improve the muscles in the child mouth (Patino, 2015:1). By improving the muscles in the child's mouth, oral challenges (eating difficulties, swallowing, drooling) and pitching of the voice will improve (Patino, 2015:1). It is therefore important that parents involve the assistance of a speech therapist who is qualified to help children with specific speech problems and basic language difficulties (Patino, 2015:1). Therapists make use of different interventions to help children with language problems by providing contextual based activities, which are related to the day-to-day functioning of the child. Wilkinson (2014:121) advises that speech therapist must adhere to word learning constructs, such as the making of associations when learning words and nouns.

Parents can support their child by recognising the difficulties in comprehension of abstract language. Expert advice such as that of a psychologist should be sought to inform parents and make them aware of the social difficulties their child experiences ('O Rourke-Lang & Bertin, 2018:1). Psychologists can give parents appropriate guidelines to help their child to develop social skills in different contexts ('O Rourke-Lang & Bertin, 2018:1).

Braconnler, Coffman, Kelso and Wolf (2017:3) advise that parents should teach their child the rules of conversation. Although difficult at first, parents must always try to expose the child as much as possible to different social situations and groups.

The responsibility of a psychologist is to stimulate and improve the children's skills. O'Rourke-Lang and Bertin (2018:1) assert that behaviour therapy is one of the many interventions to stimulate the children socially. The psychologist makes use of the verbal behaviour therapy in order to ensure that the child communicates effectively. The psychologist uses a back-to-basic approach to establish fundamental aspects of learning and verbalisation (i.e.,the use of appropriate words) which will ensure a required response. Psychologists are aware of the underdevelopment of the child's expressive language and suggest that the child improves his/her theory of mind abilities in order to develop basic communication skills (Laghi *et al*. 2017:209).

The research of Vygotsky (1978) suggests that children diagnosed with ASD can improve their theory of mind (i.e., the ability to understand other people's emotions, which ultimately improve the child's social adaptation) through social imaginative play (Wilkinson, 2014:80). Social imaginative play consists of logical and abstract meaning skills. Children diagnosed with ASD find imaginative play enjoyable which leads to inner motivation and inspiration. Wilkinson (2014:80) identifies four stages of social imaginative play:

- *S*ensory motor engagement where the child relates physically to the sensory information. Within this stage the child becomes aware of his/her surrounding;
- Self-exploratory phase in which the child tends to make sense, explore and experiment with the environment and engage with the surroundings;
- Pretended and functional play in which the child becomes more comfortable in his/her surroundings and adapts his/her play style to re-create situations. The ASD child will refer consistently back to his/her imagination in order to improve his/her creativity (Wilkinson, 2014:80).
- Symbolic play, which includes verbal interaction with someone else, the subject or abstract objects (Wilkinson, 2014:80). During this stage, therapists normally suggest that the child be exposed to different social groups.

2.4.4 Physical domain

The physical domain includes the development of the child’s brain, gross and finer motor skills and overall health. Soorya, Carpenter and El-Ghoroury (2013:2) explain that the occupational development is a single, small part of the child’s physical development which focuses on the improvement of strength, muscle tone, mobility and balance. Waller (2015:12) as well as Bourke -Tailor (2011:1) explain that occupational therapy also includes the sensory processing and modulation skills of the child. Children diagnosed with ASD have major deficiencies on occupational level and therefore it is critical for their development to improve their finer motor, perceptual skills and muscle tone (Hetzroni & Shalahevich, 2017:825). Abu-Dahad, Holm, Rogers, Skidmore and Minshew (2013:1) explain that these individuals between the ages 5-21 struggle with strength, coordination and motor speed. According to Afshari (2012:1332), perceptual development is the basic aspect that a child needs to acquire in order to function in overall broader society. These basic skills include the necessary reading and writing skills and the improvement of the child’s attention span. Nel *et al*. (2013:20) further add that the improvement of the child’s perceptual skills is also beneficial for the functioning abilities and the participation in daily activities such as play, self-care and social participation.

Oliveras-Rentas, Kensworthy, Robertson, Martin and Wallace (2011) believe that occupational therapy is more focused on the child’s sensory processing and modulation and can contribute towards the child’s visual and long term memory. According to Sharma *et al*. (2015:49), the occupational therapist will assess and monitor the progress of the child while he/she completes certain activities. Each activity represents a certain perceptual skill that the child may be able to do or may struggle with. One of the main responsibilities of an occupational therapist is to enhance the child’s skill and independency levels. Each task that the child completes involves important skills which can be seen as a small step towards independency. Before the initial therapy process starts, the occupational therapist must conduct certain assessment tests in order to gain information regarding the child’s strengths, challenges and abilities. The learning of skills is process related and works on a trial and error basis such as the learning of receptive and expressive skills (Stadskleiv *et al*. 2018:67).

The development of a child’s perceptual skills is seen as the basis for academic skills such as reading, writing and how information is processed (Abu-Dahad *et al*. 2013:1). Quintin, Bhara, Poissant, Fombonne and Levitin (2013) note that children diagnosed with ASD are confronted with different perceptual challenges on a daily basis, and these can affect them emotionally, socially and physically. Hetzroni and Shalahevich (2017:825) suggest that the following three sub-sections of perceptual development can be beneficial towards the academic progress of the child on the ASD spectrum, namely visual perception, spatial orientation and gross and fine motor skills.

2.4.4.1 Visual perception

Fahnehjelm, Tőrnquist, Olson, Winiarski and Ek (2017:1) explain that visual perpetual skills consist of memory, form consistency and visual sequential memory. Visual perception is the ability where meaning is attached to visual stimuli that are received through the different senses. Visual memory activities include the ability of the child to remember a number of designs from different figures (Fahnehjelm *et al*. 2017). A major strategy to improve perceptual skills is through figure-ground activities, where the child is required to spot pictures and ignore any background disruptions (Fahnehjelm *et al*. 2017). Abu-Dahad *et al*. (2013:1) mention that children's eye-hand coordination can be improved by catching a ball and the following and drawing of different patterns, shapes and pictures on paper.

2.4.4.2 Spatial orientation

Spatial orientation plays a major role in the development of writing and forming of sentences. In this activity the child must form the letters of the alphabet with his/her body (Stadskleiv *et al.* 2018:69). Spatial orientation consists of specific skills where the child must specify the different sides of the body and different directions. Activities consist of mirroring different movements and positions (Stadskleiv *et al*. 2018:69). Spatial coordination can be linked to the development of the child's writing. One of the first steps for a child to learn words as well as forming of sentences is to learn the alphabet and then scaffold from single letters towards the writing of words. Children diagnosed with ASD learn through visual stimulation; through the use of pictures and colour the child's long term memory will be stimulated (Stadskleiv *et al*. 2018:69).

2.4.4.3 Gross and fine motor skills

Houwen, Visser, Van der Putten and Vlaskamp (2016:69) explain that gross and fine motor functioning plays an influential role in the language comprehension and typical physical development of the child. The development of gross motor abilities is a major challenge for a child on the ASD spectrum (Houwen *et al*. 2016:69). Due to their low muscle tone, children diagnosed with ASD will not be able to participate in any physical sport. They will also be unable to make bigger movements such as rolling over or climbing over obstacles without struggle (Botha & Pienaar, 2008:40). The child's gross motor abilities can improve through the participation in activities, which include jumping, running, the throwing and catching of objects. The more exposure the child receives in these activities, the better the child's muscles will get (Botha & Pienaar, 2008:40).

Fine motor abilities include the ability of the child to portray finer and smaller movements with their hands, fingers, toes and wrists (Sharma, Woolfson & Hunter, 2011:465). These small activities are seen as very important skills that contribute towards the first steps of independency and form part of everyday life such as dressing, writing with a pencil, clapping and walking on toes (Botha & Pienaar, 2008:44).The occupational therapist can improve the child's finer motor skills by giving the child small activities to complete in order to improve the finer motor muscles, such as building puzzles, buttoning and unbuttoning objects and using scissors to cut objects and shapes from a piece of paper (Botha & Pienaar, 2008:40).

Although children on the autism spectrum experience different challenges in the above mentioned domains, these children's capabilities are endless, provided there is adequate support and an objective (outcome) in mind, which is represented by the third corner of the FGT model. The objective is the long term goal that has an achievable outcome. This final element is dependent on the success of the synergy between the subject and tools. Through continuous exposure and stimulation to different situations and scenarios, the child's functioning abilities and skills in numerous environments will improve (Howling, 1997:1).

2.5 CONCLUDING REMARKS

The lens through which I conducted this study is based on Vygotsky's FGT, which emphasises the interrelationship between all three corners of his triangular model, namely the subject, tools and object. According to the theory, all three elements must work together to achieve the specified object or outcome. Each element such as the subject, tools and object, has its own unique purpose, but if there is no collaboration among all three elements, the required outcome will not be achieved. The diagnosis of ASD is made according to two functioning modes, namely high functioning autism (HFA) and low functioning autism (LFA). The manner of the achieved objective is dependent on the abilities and willingness from both subject (child on the ASD spectrum) and the tools (support systems) to overcome daily challenges and to reach the outcome (object).

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

In the previous chapter, the two elements of FGT, namely ASD and educational support, were discussed. This chapter explains the research methodology followed to gather information to address the third element of the FGT, namely the outcome. Thus, to reach the outcome (i.e., to complete my schooling and thus enable me to obtain access to higher education), support was needed. Participants, consisting of my internal and external support systems, were therefore probed about their experiences in this process and simultaneously my experiences were added to give a complete picture of the challenges experienced as well as support received in the different domains.

3.2 RESEARCH METHODOLOGY

Whichler, Philbin and Aronson (2018:2) view a research methodology as a method or plan according to which the researcher works. In the same vein McMillan and Schumacher (2010:15) explain research methodology as the plan used for solving the problem that the researcher identified in the research. According to Maree (2012:15), the research methodology is incomplete without the different techniques and methods that are used to answer the research question; these are discussed in the following sections, namely research design , research methods, data analysis and presentation.

3.2.1 Research design

Bryman (2004:542) explains that a research design is a framework that a researcher uses to analyse and collect the data. Creswell (2015:3) refers to this framework as a “control center” where the researcher can choose which design he/she desires to follow. He further notes that the required design is influenced by the researcher’s worldview, paradigm and belief system (Creswell, 2015:3). Buzetto, Luijkx, Calciolari, Ortiz and Vrijhoef (2017:3) and, in an earlier version, Creswell (2014:12) define a research design as a process where the researcher finds meaning between the different variables.

Kothari (2004:7) believes that the purpose of a research design is for the researcher to provide evidence to solve the problem. From a different point of view, Ketchen, Graicheid and Cheng (2018:17) note that the success of the researcher's research design is dependent on two variables, such as casualty (the ability to seek connections between variables) and generalisation (the search of validity between findings (Bryman, 2004:537-540). Maree (2012:17) advises that during the process of constructing the research design, the researcher must answer unanswered questions such as the initial reason why the researcher wants to conduct research which I have done by justifying the paradigm in which my study was situated, the approach I followed and type of research I used in this study.

3.2.1.1 Research paradigm

Mack (2010:5) defines a paradigm as "a loose collection of logically related assumptions, concepts or propositions that orient thinking and research". Chilisa and Kawulichon (2013:1) explain that a paradigm is a representation of the researcher's commitments, beliefs, outlooks and values. Walsham (1993:295) sees a paradigm as an in-depth examination of the phenomenon of interest. My study was situated within the interpretivist paradigm as I believe that experiences are an outcome of interpreted perceptions and I wanted to establish my participants' experiences (or interpretation thereof) in the process of supporting me. I also shared my subjective experiences as an individual on the spectrum.

Tuli (2010:100) explains that the interpretive perspective is a form of qualitative research that sees the world as a modern construction that forms conclusions from interactions and social systems. Chilisa and Kawulich (2013:3) argue that in order to define the role of a paradigm, one needs to discover the knowledge systems from an ontological and epistemological viewpoint.

(i) Ontology

Ontology holds that reality consists of assumptions and how these assumptions interact with each other (Gontier, 2018:32). Individual interpretation explains that reality is constructed based on individual subjective interpretations (TerreBlanche & Durrheim, 1999:292). This knowledge system accepts the premise that multiple realities exist (Gontier, 2018:32) and that these realities must be mined by analysing and reading relevant research studies. Referring to this study, all the information about ASD was studied by reviewing different academic sources. Referring to my personal experiences, I am convinced that children diagnosed with ASD has the potential to succeed in a formal school system and to develop to their fullest potential with the assistance from both their parents and service providers.

(ii) Epistemology

Epistemology assumes that reality and meaning are created through social interaction and communication (Brooks, 2018:14). The researcher adopts the role of an inquirer through social interaction, listening to people or reading related work (Maxwell, 2006). During my data collection process I conducted semi-structured interviews with members of my support system who supported me throughout my school career.

(iii) Methodology

Peffers, Tuunanen, Rothenberger and Chatterjee (2008:4) explain that the methodology consists of the principles and procedures that the researcher follows. From a methodological point of view, data can be collected through interviews, reflection sessions or any written documentation (TerreBlanche & Durrheim, 1999:292). Goldkuhl (2012:2) explains that the quality of the data which is gathered is totally dependent on the participants, who, for the purpose of my study, consisted of me as main participant and my internal support system (mother, father, brother and grandmother) as well as my external support system (occupational and speech therapists and school psychologist).

3.2.1.2 Qualitative approach

Levitt, Creswell, Josselson, Bamberg, Frost and Suárez-Orozco (2018:27) define qualitative research as a method where the researcher analyses the data through verbal expression and explaining experiences through interviews with selected participants. Chang and Yoon (2011:27) add that the data are gathered through the use of limited sources, but the quality of the data is rich and fully contextualized. The data of my study were gathered by the contribution of my own as well as my mother’s experiences, as well as other people who supported me throughout my school career. This information yielded a saturated data set, which explained the value of support to reach a specific outcome.

Levitt *et al*. (2018:28) argue that the most prominent technique the researcher uses to gather data, is through open ended discovery and not from sources that provide the opposite, such as contradictory or problematic views. These authors furthermore believe that qualitative methods provide the researcher with opportunities to compare and analyse data and to relate it to cultural and social contexts. This is in line with the philosophy that undergirds auto-ethnography, which holds that reality is culturally constructed and through the writing of an auto-ethnography, the researcher engages with the phenomenon in a cultural context (Hannigan, 2014:4).In this regard, Joubert *et al*. (2016:10) emphasise that qualitative research methods are socially constructed. In the case of my study, the participants were specifically chosen based on their contribution in supporting me during the different phases of my school career – they were part of my reality during this developmental phase in my life.

3.2.1.3 Research type: self-study

Crowe, Creswell, Robertson, Huby, Avery and Sheikh (2011) explain that self-study is a research method which represents reality from the researcher's point of view. These authors furthermore believe that self-studies are unique because they are an "in-depth appreciation" of the specific field of study (Crowe *et al*. 2011:1).Creswell (2014:13) notes that self-studies can be identified as individualistic approaches where the researcher is a main participant and which give the reader an insider perspective. McMillan and Schumacher (2014:31) mentions that in such studies, the researcher shares a deeper understanding and gives a rather subjective overview of a targeted theme. These authors also mention that the writing style usually occurs in first person and presents multiple perspectives and views of a specific situation which provides the researcher with a voice and leads to personal growth and understanding (McMillan & Schumacher: 2014:30). I agree with these authors, as this study allowed me to arrive at self-understanding through introspection and certain events that occurred were viewed from a different perspective. In this regard, McMillan and Schumacher (2014:270) postulate that introspection can assist the researcher in relating to social ills and problems in society. Similarly, this study enabled me to draw specific conclusions and to present recommendations that were stated in the final chapter.

3.2.1.4 Auto-ethnography

Drabble (2018:6) explains that auto-ethnography is “self-reflective and connects auto-biography and the experience within broader social and cultural contexts”. In other words the writing is written in two genres that represent personal and scientific formats. In the case of my study, I made use of my personal experiences as well as the experiences of my support system, which represented “social and cultural contexts”. Wall (2008:38) furthermore states that the researcher is the main attraction and therefore this platform allows him/her to share personal experiences and do introspection into broader society. I agree as my personal experiences were shared and therefore I was able to assess the attitudes towards children on the spectrum of the school community and society in general. Ellis, Adams and Bochner (2011:3) rightfully maintain that auto-ethnography creates a platform which allows the researcher to have a voice and to understand cultural and sociological ideologies. Anderson (2006:373) explains that the features of an auto-ethnographic study include the ability of the researcher to tell his/her personal story in order to educate.

Drabble (2018:5) further explains that an auto-ethnographic dissertation includes personal stories, data gained from informal interviews and the viewing of historic documentation. Ellis *et al*. (2011:3) furthermore add that an auto-ethnographic study is usually written as a narrative and in first person with characters and a plot line. My study met these authors’ criteria in that my dissertation dealt with my personal experience with autism throughout my school career and was informed by the support that I received from my internal and external support system. I made use of historic documentation which included school report cards as well as reports by teachers, therapists and the educational psychologist. Ellis *et al*. (2011) furthermore mention that the personal story, the characters and the different roles that they play represent society and lead to sociological understanding. Once again I can vouch for this, as my account of what took place during my school years, represents the attitude of role players in mainstream schools as well as society in general.

Belbase, Luitel and Taylor (2008:88) believe that auto-ethnography is a professional academic writing style with the purpose to conduct research. Wall (2008:39) adds that auto-ethnography allows the researcher to link concepts from the literature to personal experiences. Similarly, although dissertation reflects my personal story, in-depth research into relevant literature was conducted to explain ASD and its impact on the person’s developmental domains as well as the impact on the family. Brock, Borti, Frahm, Howe, Khasilova and Ventura-Kalen (2017:119) see the function of auto-ethnography as a "vehicle of interrogating one's own experiences". Chang *et al*. (2013:18) view this methodology as a unique emotional venture where meaning can be gathered through the writing of personal stories (Chang *et al*. 2013:18). Sandelowski and Leeman (2012:1404) distinguish between a traditional study and an auto-ethnographic study in terms of the data analysis; with the latter the researcher is enabled to present his/her findings in a unique manner, such as in narrative format which involves a story which is chronologically told in first-person style. In my study, the analysis of my data involved the telling of my story with the help of my participants (Chapter 4).

Criticism of auto-ethnography includes the objectivity, data quality, legitimacy and ethics of this methodology (Wall, 2008). These aspects were addressed in my justification of the trustworthiness of my study (see sections 3.4) as well as in the section dealing with ethical considerations (see section 3.5). Chang's (2008:5) critique relates to the personal nature of an auto-ethnographic study as she maintains that auto-ethnography seems to focus on the personal narrative, rather than the broader culture. In other words, she believes that a personal account cannot be generalised to broader society. I argue that my personal story, to some extent, reflects the experiences of many other people with some sort of disability and awareness is created of their plight and how the school can adapt to meet the needs of these learners. Chang's (2008:5) second point of critique revolves around the notion that auto-ethnography tends to focus more on the researcher's personal memory rather than existing accredited literature. To address this, I conducted a rigorous review of literature on autism and this has been included in the interpretation of the data to verify the validity of subjective experiences.

3.2.2 Research methods

Williams, Kolek, Saunders and Remaly (2018:10) postulate that research methods involve the ability to use a research procedure as guideline, which Joubert *et a*l. (2016:196) explain as the different strategies that a researcher uses to conduct the empirical study. Furman (2018:4) adds that the research methods provide a solid foundation and automatically provide a platform where new observations and knowledge can be generated. In explaining my research methods, references were made to my role, the participants who were involved in my study, as well as the data collection methods I used to gather information.

3.2.2.1 My role as researcher

The researcher takes center stage in the initial research process and is the main instrument to investigate a specific phenomenon. In auto-ethnographic studies, the researcher fulfils the role of narrator whose expresses his/her personal voice (Creswell & Pott, 2018:70). Mendez (2014:280) describes the role of an auto-ethnographer as an insider-outsider, which means that the researcher shares personal information (role of insider), but also has the responsibility of sharing academic knowledge from relevant literature sources (role of outsider). In this study I shared my personal account as an individual with ASD and how support helped me to achieve my educational goals. As McMillan and Schumacher (2014:31) assert, the researcher must position him/herself in a front and back row position to gain a broader experience of the studied phenomenon. Applied to my study, it meant that I shared my own experiences through the telling of my story, but I also took the back seat to look at the broader picture. I did this by consulting numerous literature sources and taking into account my participants' perspectives.

As researcher I also had to take responsibility for information given by my participants as I had to guide them by asking the right questions to elicit the required response (Gay, Mills & Airasian, 2011:381).It was also my responsibility as researcher to make the participants as conformable as possible by providing them with background information regarding my study and why their contributions were regarded as valuable. According to Anderson and Austin (2011:132), auto-ethnography is an evocative exercise and therefore I needed to confront past experiences even if the memories were hurtful. As researcher it was also my responsibility to evaluate the research findings and if there was a lack of information or if anything was unclear, I had to consult a second time with the participant to ensure that my research was complete and accurate.

3.2.2.2 Participants and research site

As this study focuses on the support that I received as a person with ASD, great emphasis focused on the assistance I received from my internal and external support systems. The identified participants were selected based on their involvement in my journey during the different time frames of my school career.

My internal support system consisted of members from my internal and external family who played some or other role during my developmental stages. Each member's role was different and unique, and even if it seems insignificant, their contribution cannot be ignored. The participants and the reasons for selection were as follows:

(i) Mother as participant

My mother was the key figure in my developmental journey and supported me cognitively, emotionally, socially and physically throughout my school career. The conversations with my mother, as well as insights from the book she wrote, provided a subjective perspective on how she experienced mothering a child with ASD and what drove her in supporting me.

(ii) Father as participant

Although my father was not directly involved in my emotional and social development, he was always willing to support me financially by involving therapists and psychologists. Through conversations with him, I gleaned insight into his experiences and perceptions.

(iii) Brother as participant

My brother was a participant as I needed his perspective on how he experienced the fact that I, his sibling, had ASD.

(iv) Grandmother as participant

My grandmother was specifically involved as support figure during my pre-primary school years as she looked after me during the day while my parents were at work. I interviewed her to gain insight into her experiences with me as a child. The interview also provided insight on the challenges I encountered as toddler that led to my diagnosis.

Members from my external support system consisted of service providers who assisted me throughout early intervention and during my primary and high school years. It was a difficult process to include these participants as they are professional people with their own practices. I however managed to secure appointments with all of them which were handled in a professional way. I had to make an appointment and pay a consultation fee, as any other client would have to do. The following participants entailed my external support system.

(v) Occupational therapist as participant

The occupational therapist was an important role player in my physical development as she helped me to develop my different perceptual skills. By interviewing her, I obtained her professional insights into my case.

(vi) Speech therapist as participant

The speech therapist helped me to develop different skills in order to improve the ability to communicate and the correct pronunciation of words. Different skills were developed to improve the muscles in my mouth. I included her as participant to gain her perspectives about her professional relationship with me.

(vii) School psychologist as participant

The school psychologist, who was an educational psychologist, was a supporting figure during my high school years and assisted me with basic communication and socialising skills. I interviewed her to gain her experiences on how she accommodated my academic challenges.

3.2.2.3 Data collection methods

Data collection methods consist of the researcher's ability to use a variety of methods to gather information. Creswell and Pott (2018:147) believes that the data collection process involves much more than merely conducting interviews or doing observations, but also selecting the participant, collecting data simultaneously and making field notes. To conduct my research, I made use of interviews as well as conversations, consulted my mother's unpublished book and included my school performance reports as well as therapist and psychologist's reports to support the written text.

(i) Interviews and conversations

Creswell and Pott (2018:162) defines an interview as a social activity where conversations take place between the participant and researcher in an informal manner. Both members from my internal and external support systems were interviewed in a similar way, as I also followed an informal style. Due to the sensitivity of the content and the manner in which the diagnoses of ASD affected my family, a conversational method was followed. Feldman (2015:4) notes that the conversation method is a more relaxed and comfortable data collection method where the platform is created for the participant to share true personal experiences and to be able to make a much deeper connection with the researcher on specific topic. The conversations took place in an unstructured manner at convenient times during the day.

Semi-structured interviews were conducted with members from my external support system, namely the speech and occupational therapists and the school psychologist. McMillan and Schumacher (2014:386) mention that semi-structured interviews are more passive and the participants are free to express their emotions and true feelings. The interview questions were pre-planned as each participant requested a copy of the questions a week prior to the scheduled interview appointment in order to prepare.

During the interviews, open-ended questions were asked, which McMillan and Schumacher (2014:387) explain as consisting of the ability of the researcher to share true and honest opinions about a certain phenomenon. The structure of the questions was set up from general to specific and the questions were asked in a specific manner to refresh the memory of the participants. Participants were granted an opportunity to share their experiences and perspectives on how they experienced me and the accommodations they made to accommodate my needs.

(ii) My mother’s unpublished manuscript

My mother’s book is a biography in which she documented my challenges and her experiences with ASD during my school career. The book was written in first person and gave me background information regarding my mother’s personal experiences in raising me. The book was written in the form of a journal that kept track with my development since birth to the time that I entered university. Both the interviews with my mother and her book corresponded with each other and formed the basis of my data analysis.

(iii) School performance cards

The school performance cards are historical documents with sentimental value (McMillan & Schumacher, 2014:361) that gave evidence of personal challenges, achievements and triumphs over the years. These documents contributed towards the credibility of this study and as it provided evidence of the academic challenges I encountered in school. The school performance cards include the viewpoints of my teachers during the different phases of my school career.

(iv) Psychological and therapist reports

The psychological and therapists' reports which were included in the study are original documentation that serve as evidence of the challenges I encountered on cognitive, emotional, social and physical levels. These reports attested to the progress I made during the different phases of my school career. The reports were included in the analysis of the data and supported the written text.

3.2.3 Data analysis and presentation

According to Silverman (2005:183), data analysis is an umbrella term to explain how the researcher makes sense of the data that was gathered and relates the findings to the broader culture. Gibbs (2012:4) believes that data analysis actually occurs before the data is analysed and is a method that the researcher uses to find patterns and connections to explain content. In my research I made use of both deductive and inductive approaches, as two processes were involved during the analysis phase. My novella was written by using the four developmental domains as guidelines in so doing, I made use of a deductive approach, which Creswell and Pott (2018:182) explains as consisting of a theory to test the hypothesis. In other words, it relates to the use of predetermined themes or categories by which the collected data are discussed (for the purpose of this study, in the form of a novella). Gibbs (2012:6) describes this approach as referrals that are first made to reality that do or do not confirm the further investigation of a certain research topic.

The second phase of the data analysis process involved the analysis of my novella and here the inductive approach was used. Theron (2015:5) explains this approach as a method that is used when a researcher conducts research before making any observations or generalisations. Gibbs (2012:6) writes that the inductive approach paves the way to generate appropriate new theories and to generate new observations based on data gathered. Applied to my study, this process can be referred to as interpretation where several sub-categories emerged from the analysis of the novella, which directed the second stage of the analysis process.

3.3 TRUSTWORTHINESS

Bryman (2004:26) maintains that trustworthiness is used as criterion to assess the quality of any type of research, in other words, establishing trustworthiness is necessary to determine how good the study actually is. Trustworthiness works according to quality criteria where the researcher asks the question to identify if the research findings can be trusted and if it is as true as can be (Korstjens & Moser, 2018:121). Korstjens and Moser (2018:121) indicate that trustworthiness consists of different elements such as conformability, validity, credibility, and transferability. Firstly, verisimilitude will be discussed as this is an important element in any form of narrative writing (Weller, 2017:9).

3.3.1 Verisimilitude

The word verisimilitude is a term that is broadly acknowledged as a concept that challenges theories to the nearest truth and accuracy (Kuipers, 2017:3). Merriam-Webster (2017:1) explains that the word “verisimilitude” entails the correspondence and similarity of findings. In auto-ethnographic studies, it is important that historic events and experiences as accounted for by the researcher and participants are related to each other (Merriam-Webster, 2017:1).To ensure that research findings (e.g., the remembering of similar past experiences and events) derived from my recall and the participants were accurate and corresponded with each other, it was appropriate to compare research findings and results with each other to ensure no deviation from the facts recalled. Verisimilitude also acknowledges the contribution of each scientific theory to a specific field of research (Dunn, 2018:3). Valentine, Fleischman and Godkin (2018:285) note that verisimilitude questions the relevance of the theory or findings.

Schwandt (2011:2) furthermore explains that verisimilitude is used as a form of “criterion that the researcher uses to evaluate a narrative”. The findings must be as near to the truth as possible even though narrative enquiry seems to be closer to reality and is emotionally provocative. Shaw and Holland (2017:5) concur that verisimilitude always refers to written texts but also involves the ability of the researcher to make the reader interested by making them believe that the information is realistic and true. The writing style keeps the researcher engaged and interested.

A major critique of an auto-ethnographic study is the issue of how the researcher proves that interviews was conducted and if the participants' views are the true reflection of their personal experiences. The true identity of an auto-ethnography is depicted through the controversy between different viewpoints and therefore I included my participant's true views and opinions in narrative format. Although some of these opinions and views are contradictory with my personal point of view, it still remains a valuable piece of qualitative data that can be regarded as credible. Research findings must be dependable and therefore consistency is established when the findings, the researcher's interpretations and conclusions are the same (Bryman, 2004:30). It was recognisable through all my interviews with my internal and external support system that some of the behaviour traits I portrayed as a child were known to them all and mentioned consistently.

A number of critics criticise the validity and credibility of the participant's observations and opinions in an academic format. Critics also criticise the participation of participants selected therefore evidence must also be available of the complete participation of participants in any form. To avoid any form of conflict, my participants completed a consent letter to explain the proceedings and intentions of their contribution in the study. There is a fine line between fact and opinion and therefore the researcher must provide evidence of each statement through the inclusion of historic artifacts such as observations from specialist and educators (Moran, 2018:1). Each interview conducted with the school psychologist, speech and occupational therapist supported the verifications and were used as guidelines to refresh my participants' memories during their separate interviews.

The following elements of trustworthiness were also used as discussed in the ensuing sections.

3.3.2 Credibility

The term credibility entails the assurance that the research findings are accurate and reliable (White, Wutich,Larson, Gober, Lant & Senneville,2010:236).This process allows the researcher to give factual evidence through a variety of sources such as photographs, journals and academic records (White *et al*, 2010:236).As the main participant I shared my experiences as an individual on the spectrum and how I was supported to overcome each challenge. To ensure that my data were a true reflection of the support I received during my school years, I made use of other participants as well, and did not rely on my own perceptions and experiences as the narrator. This study required the views of multiple participants to ensure that the findings are credible.

3.3.3 Transferability

In an auto-ethnographic writing style it is important to identify the gap in the research findings and therefore the question of transferability comes to the fore. Transferability means that the results and findings from the research can be used in other contexts for future research purposes (Willis, 2007:222).Ellis (2015:13) explains that auto-ethnographic studies entail the sharing of personal experiences in order to achieve a specific goal which entails the sharing of common values, beliefs and experiences for the purpose of giving an insider perspective on the life of the pre-selected culture. As an auto-ethnographic study is personal in nature, it will not be possible to apply the findings to other contexts, but the methodology can be followed in other research studies. The writing of this auto ethnography created a platform for me to share my personal experiences challenges, triumphs as an individual on the autism spectrum throughout the pre-primary, primary and high school years. Through the retelling of my personal story, perceptions about the academic capabilities of individuals on the autism spectrum will change and school systems will make the necessary changes to accommodate more children on the spectrum in mainstream schools on cognitive, emotional, social and physical domains.

3.3.4 Conformability

Conformability is another important element of trustworthiness to which my study had to adhere. Guba and Lincoln (1981) explain that it entails the consistency of results that frequently comes forth. This major step involves the opinions and assistance of outside forces (such as my mother) in order to follow through the history and progression of results. Certain key decisions are made to ensure that consistency in results of both parties is portrayed. These research findings are supported through readings and investigations from similar studies (Ary, Jacobs, Sorensen & Razavieh, 2010:638). Applied to my study, I frequently made reference to the book that my mother wrote and to the contributions of each participant. The data also corresponded with literature findings which meant that I operated within the boundaries of conformability. To illustrate: some of the symptoms I portrayed as child correspond with previous academic case studies about children on the ASD spectrum. In this regard Bryman (2004:30) explain that auto-ethnography is an evocative writing style which requires true and honest opinions and views both from the researcher and participants. In so far as this was the goal that I sought to achieve, I believe this study met the standards of conformability.

3.4 ETHICAL CONSIDERATIONS

Le Roux (2017:196) explains that auto-ethnographers pride themselves on being honest and ethical about the events described, as well as the content of words expressed by all the participants involved. Sanduliak (2016:362) suggests that the general rule pertaining to auto–ethnographic studies is to ensure that no intended harm takes place and that the events must be true and accurate. Mendez (2013:17) maintains that the aim of adhering to ethical principles involves ensuring that the interests of participants are protected. The two major points of concern involving auto-ethnographic studies standing the tests of truth and honesty have been alluded to in the previous section. The other concern is the protection of participants. As I am known to the reader through the disclosure of my name in this dissertation, the anonymity of my family, as my internal support system, could not be guaranteed. I clarified this issue with them beforehand, and they were willing to share their experiences regardless the fact that their identities would be known. I could however protect the identities of my external support system, as their identities were not divulged in any way. The participants agreed and I assured them that no information will be mentioned that might come forth as offensive and personal. Okeke and Van Wyk (2015:285) also suggest that the privacy and space of participants must always be protected and respected and I tried to adhere to this principle by not forcing anybody to share any information that they regarded as sensitive or too personal.

I also had to apply for ethical clearance from the ethics committee of the Faculty of Education, University of Pretoria, which involved a rigorous scrutiny of my application, and where I explained in detail the way I would treat my participants. This also involved a thorough explanation of my research design and the role of my participants in the letters of consent that each had to sign (see Appendix A). It was the participants' prerogative to choose an appropriate date, time and setting where the interviews would be conducted.

3.5 CONCLUSION

This chapter outlined the research methodology that I followed and the steps and processes for conducting this study. I gave an account of the paradigm in which my study was situated as well as the approach I followed. Auto-ethnography was discussed as a research methodology and it was explained how my study met the associated criteria by explaining my role as participant as well as the role and contribution of the other participants. I also addressed concerns regarding this methodology raised by other authors. In the next chapter I present the analysis of my data in two parts: how I analysed the data used to write my novella and my findings in the form of my novella.

CHAPTER 4

NOVELLA

4.1 INTRODUCTION

Chapter 4 represents my personal experiences as an individual with ASD as well as the experiences of my participants (internal and external support systems) who supported me educationally. This data is supplemented by several documents, such as reports, photos and extracts from my mother’s book (unpublished manuscript). My data analysis has been written in narrative format (novella) and each experience has been chronologically presented from early development until high school. The data analysis is divided into the three different time frames/developmental stages, namely pre-primary, primary and high school with the focus on the educational support received. Each time frame/developmental stage presents its own unique learning curves, successes and challenges and can be linked to a specific developmental domain, such as the cognitive, emotional, social and physical, which also forms the framework of this chapter. Each developmental phase is introduced by an autobiographical sketch, representing the specific phase.

4.2 PRE-PRIMARY PHASE

“I knew something was wrong”

My mother had a normal pregnancy and was looking forward to the birth of her first-born. ***“****The gynecologist suggested that I gave birth via a Caesarean. I agreed because the procedure is safe, and I wanted to give birth without stressors. So on the evening of the 17th of February, I was awaiting the birth of my baby boy. It was to be my first operation ever, and I was nervous. On the same evening at 20:15, Emile was born. A moment of perfection when my baby was placed in my arms. I could not believe how beautiful Emile was. He was a brunette baby who weighed 3.2 kg, and his Apgar score was 9/10”.*

Figure 4.1: A few hours after my birth

When my mother got home, postnatal depression set in this lasted for 18 months. My mother recalls: *“Emile struggled to latch, and breastfeeding became a prolonged nightmare. He cried consistently and the pediatrician diagnosed him with colic”.* My mother had to go back to work when I was eight weeks old, and for the next few years, I stayed with my grandmother on my father’s side. She was a strict lady, with a no-nonsense attitude. As her relationship with my mother was strained, there was little communication between the two, and she never told my mother about her opinions related to my behaviour. According to my grandmother she never noticed any unusual behaviour from my side. During our interview, she revealed: *“I looked after you during the day while your parents were at work. Although you shared your days with nine other children, I noticed that you never was part of them and did not play with them”.*

My mother became concerned when I was around three months old. She remembers: "*I knew something was wrong when Emile did not respond as babies usually do. I waited in vain for gurgling sounds, shrieks of happiness, and smiles"*. She became quite worried when I didn't show any response to interaction: She continues: "*My husband and I interacted with him by talking to him, playing with him, but he did not respond*". My father, who was an inexperienced new dad, thought that my behaviour was quite normal: He remembered a crying baby, but never thought something could be wrong**.** He recalls: "*I never realised that something could be wrong with Emile. I thought the behaviour that he portrayed, was quite normal".* With time my mother became aware of my a social behaviour. She remembers: "*When we visited people, Emile was shy and withdrawn, and cried in a new environment. Even when my mother came to visit, Emile did not even look at her. He turned his face away when she spoke to him*". Even when trying to stimulate me by exposing me to other environments, my parents could see that I did not respond as young children normally did. My mother adds: "*We always exposed Emile to different learning environments, but he was scared and unsure of himself in unfamiliar places. I noticed that he refused to feed small animals like rabbits, and he absolutely refused to touch animals*".

My mother became really worried when, as a toddler, I still did not speak. Then my brother was born. *She recalls:*

"The age difference between Emile and Ruan is three years. Emile was involved with Ruan in the sense that when I gave Emile instructions to assist, he listened. Emile was never moody or disobedient". It however became obvious to my mother that in this situation, there was also a lack of real interaction. She remembers: "I noticed that Emile wouldn't try to teach his little brother something, or help him; nor did he play spontaneously with his brother".

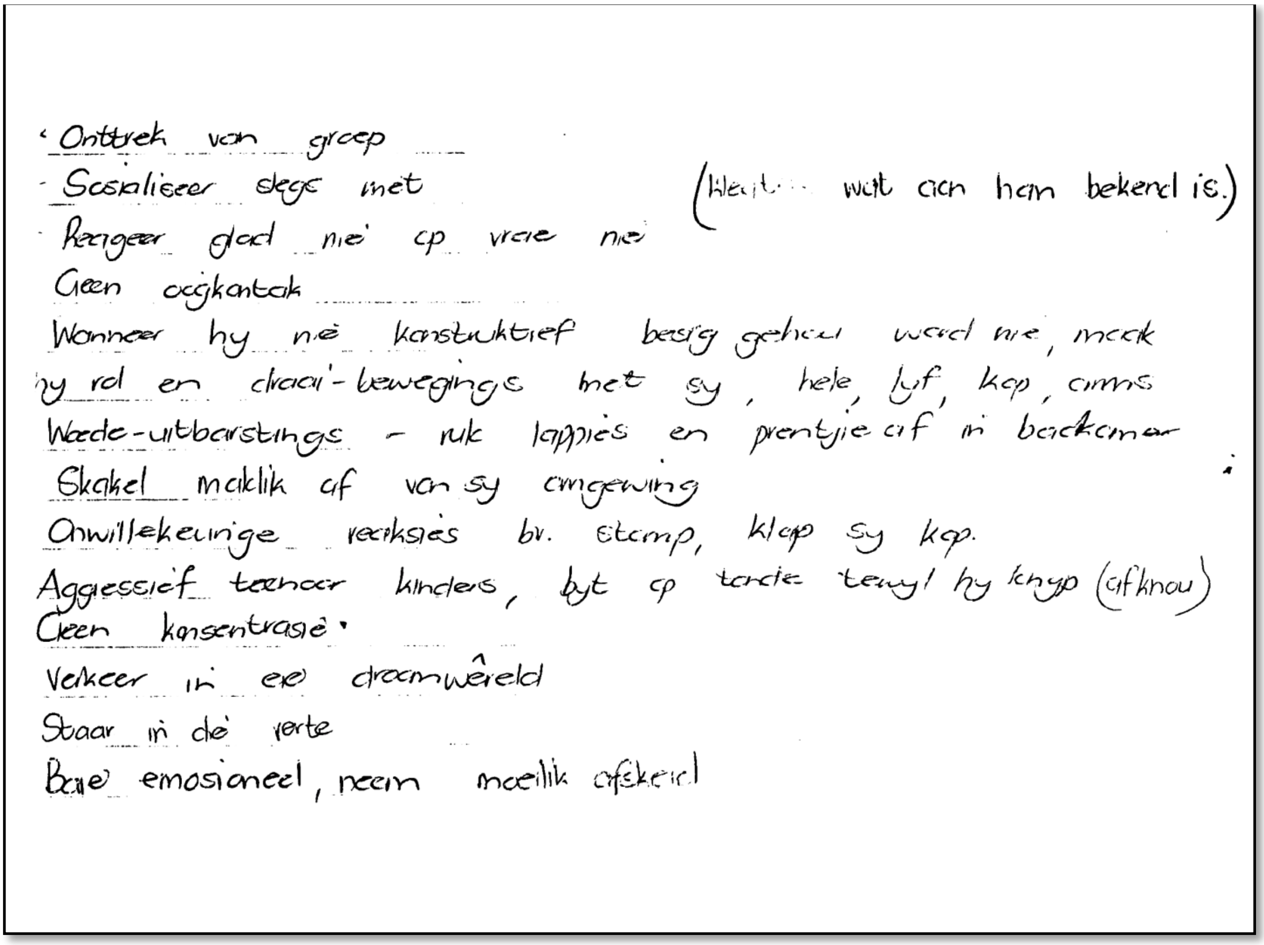
Figure 4.2: My baby brother Ruan, and I

Figure 4.3: An artist's representation of myself at this age. Notice the hooded eyes and open mouth due to low muscle tone

At the age of three years eleven months, my mother enrolled me at a nursery school situated across from my grandmother's house. There were 27 learners in my class. It was a new environment with children with whom I was unfamiliar. Instead of excitement and eagerness, fear and anxiety characterised my emotions and behaviour. I remember being afraid of all the new people and all the children. It was the first time that I was exposed to a new environment with strict routines and rules.

My mother recalls the first day I was enrolled in nursery school: "I *was feeling excited because it was an opportunity for Emile to be stimulated in a new environment and to meet and make friends*". My mother remembers that I was emotional that day and that I cried a lot on the way to school.

Very soon red lights started to flicker. My teacher noticed that I experienced challenges with language and communication, social interaction, flexibility in thinking and sensory perception. In her report (see Figure 4.4), she specifically referred to matters such as: "*He withdraws from group activities, doesn't react when questioned, makes no eye contact, resort to funny movements with his body*". She also referred to "*eruptions of rage, aggressive behaviour towards other children – biting his teeth while bullying them, no concentration, lives in his own world, very emotional, battles with separation anxiety"*. She conveyed to my parents that she identified tendencies related to autism. She advised my parents to have me assessed, and that was the start of a long and uphill road of my life's journey.

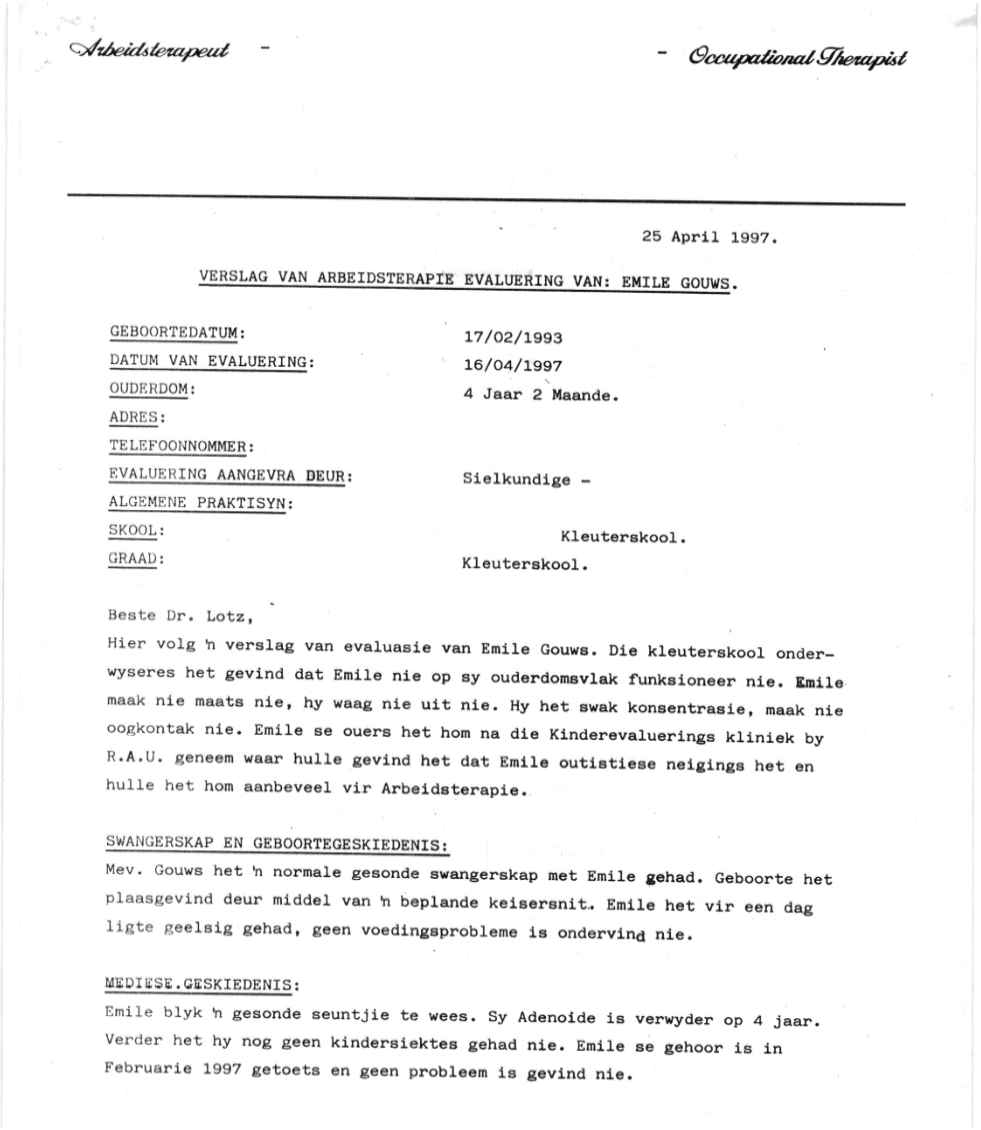


Onttrek van groep
Sosialiseer slegs met (kleuters wat aan hom bekend is.)
Reageer glad nie op vrae nie
Geen oogkontak
Wanneer hy nie konstruktief besig gehou word nie, maak
hy rol en draai-bewegings met sy, hele, lyf, kop, arms
Woede-uitbarstings – ruk lappies en prentjie af in badkamer
Skakel maklik af van sy omgewing
Onwillekeurige reaksies bv. stamp, klap sy kop.
Aggressief teenoor kinders, byt op tande terwyl hy knyp (afknou)
Geen konsentrasie.
Verkeer in eie droomwêreld
Staar in die verte
Baie emosioneel, neem moeilik afskeid

Figure 4.4: Report from class teacher

The teacher's observations came as a shock to my parents. My mother recalls: *"I was nervous; I knew something was wrong, but never expected to hear that Emile portrayed ASD tendencies".* My father was also shocked: "*Deep down I suspected that something was wrong, but hearing from a teacher that something is wrong with your child, was very difficult".*

The teacher discussed my situation with the principal, who referred my parents' to the former Johannesburg University, namely Rand Afrikaans University (RAU). An occupational therapist conducted an in-depth evaluation. She observed my actions and behaviour and confirmed that I revealed ASD tendencies. During consultation my parents had to answer many questions about my behaviour that included; social play, social interest in other people, joint attention, and motor development (see Figure 4.5). Through the asking of questions the occupational therapist gathered enough information to compile the report. In this report the therapist specifically mentioned that I do not function on my age level, that I don't make friends, and that I don't explore my environment. She also referred to my lack of eye contact and concentration. She referred to the tests done at Rand Afrikaans University where it was found that I was on the spectrum of ASD.



Arbeidsterapeut - - *Occupational Therapist*

25 April 1997.

VERSLAG VAN ARBEIDSTERAPIE EVALUERING VAN: EMILE GOUWS.

GEBOORTEDATUM: 17/02/1993
DATUM VAN EVALUERING: 16/04/1997
OUDERDOM: 4 Jaar 2 Maande.
ADRES:
TELEFOONNOMMER:
EVALUERING AANGEVRA DEUR: Sielkundige -
ALGEMENE PRAKTISYN:
SKOOL: Kleuterskool.
GRAAD: Kleuterskool.

Beste Dr. Lotz,
Hier volg 'n verslag van evaluasie van Emile Gouws. Die kleuterskool onderwyseres het gevind dat Emile nie op sy ouderdomsvlak funksioneer nie. Emile maak nie maats nie, hy waag nie uit nie. Hy het swak konsentrasie, maak nie oogkontak nie. Emile se ouers het hom na die Kinderevaluerings kliniek by R.A.U. geneem waar hulle gevind het dat Emile outistiese neigings het en hulle het hom aanbeveel vir Arbeidsterapie.

SWANGERSKAP EN GEBOORTEGESKIEDENIS:
Mev. Gouws het 'n normale gesonde swangerskap met Emile gehad. Geboorte het plaasgevind deur middel van 'n beplande keisersnit. Emile het vir een dag ligte geelsig gehad, geen voedingsprobleme is ondervind nie.

MEDIESE.GESKIEDENIS:
Emile blyk 'n gesonde seuntjie te wees. Sy Adenoide is verwyder op 4 jaar. Verder het hy nog geen kindersiektes gehad nie. Emile se gehoor is in Februarie 1997 getoets en geen probleem is gevind nie.

Figure 4.5: Report of occupational therapist

A year of occupational therapy followed, but the therapist noted that there was no improvement in my behaviour. I was then referred to a neurologist who performed an electrocardiogram (ECG) together with other tests. He confirmed the delay in my language development. At the age of five years and four months, the occupational therapist recommended that my parents consider placing me in a school for autistic learners in Pretoria.

The following extract from my mother's book (unpublished manuscript), documented her personal memories:

> *When the occupational therapist phoned me to discuss the possible enrollment of Emile at a school for autistic learners, I was very upset that this option was even considered. The reality that my child was on the autistic spectrum and the recommendation that my child should be educated in such an institution, was traumatic. I then decided to visit the school, and to possibly reconsider my options. On our way to the school, my husband and I decided to discuss our feelings with the multi-discipline team that awaited us. I will never forget the empty school ground, with no learner playing around, when we entered the premises. When I entered the office, two different therapists waited for us together with the principal. I felt comfortable in their presence; because I knew that we would consult with experts, who would be able to make the best recommendations towards Emile's development. After our discussion the principal took me to the different classrooms and discussed the curriculum that the children follow. I was shocked to see that the children learn through visualization, which implied that they would remain practically illiterate. In the hallway I told the principal that I won't consider placing Emile in the school. I wanted to give Emile a reasonable chance in life and would reconsider only when he does not make any progress with my methods. I shared my decision with the rest of the team and we agreed that we must continue with therapy and that Emile must be placed in a mainstream preschool and should receive multi-disciplinary therapy by an occupational therapist, a speech therapist as well as a psychologist.*

My parents appointed another occupational therapist, as they believed the previous one was too negative. I received long-term occupational and speech therapy as well as regular sessions with a psychologist. I was also placed in a new pre-primary school, which was in the vicinity of our home and in the feeding area of the primary school. It was the first step towards my school career that reflected my developmental progress in the different developmental domains.

4.2.1 Cognitive domain

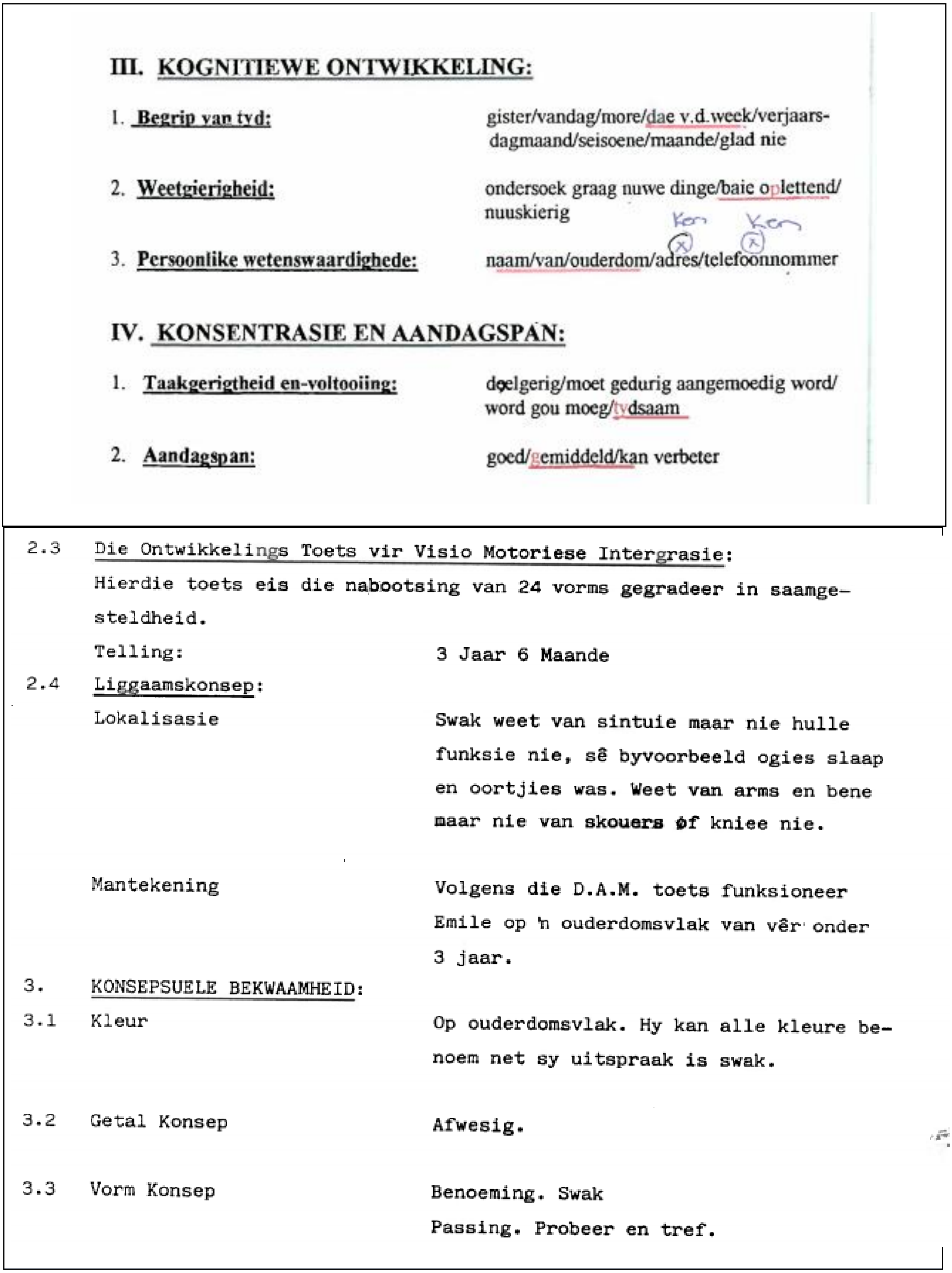
I remember the unfamiliar surroundings at the pre-primary school. Routine was very important to me, and the change from my grandmother's house to a pre-primary school was traumatic. It was extremely difficult to readapt when my routine changed and or I was exposed to unfamiliar people and situations. I found it complicated to formulate sentences, and I struggled to answer questions in front of other children. It became part of my behaviour to distance myself, and to play only with Kaylee and Tertia, the two children whom my grandmother also looked after. If they played with other children on the playground, I distanced myself from them, and played alone in a corner, keeping myself occupied with hand gestures.

My mother remembers that I never told her anything about my day at my grandmother's, nor discussed any school-related experiences. *"Emile did not speak to me and I assumed that it was because he was an introvert and because he is a boy, he took longer to talk. He never questioned anything around him. It was important for me to talk to him daily, but he refrained from discussing any experiences with me, and never gave me feedback, or reasoned with me. It was as if people and experiences did not exist in his life. I got used to having a monologue as Emile never responded to my attempts to communicate with him".* It was only much later that my mother made the connection: "*I eventually came to the conclusion that Emile withdrew physically and psychologically after a day at school, as that was his way to unwind. He would rather go to his room, get a toy and made movements with this toy between his fingers".*

My mother attributed my lack of response at the preschool to the fact that I was frightened and disconnected and therefore chose not to be involved.

The primary school was next to the pre-primary school. I could see the children playing, and I remember that the noise levels were totally overwhelming. My senses were overdeveloped and extremely sensitive, because my senses were reacting strongly to the impulses it received. It was as if my sensory wires got tangled up when I was in a strange environment and I struggled to make sense of what was happening. I did not know how to communicate my distress to my teacher or my parents, and it manifested in aggressive behaviour. “*I was very upset when the teacher called me one day to complain about the fact that Emile was disobedient*”, my mother recalls. “*Hearing that my sweet little boy bit the other children, and that he ripped the pictures from the bathroom wall at the preschool, came as a terrible shock. I could not associate this behaviour with my child”.* My mother was convinced that one of the other children was framing me, and it was only years later that I admitted to her that I was really the culprit.

My auditory memory was excellent, so I had no problem taking in information that was presented orally. I was well aware of what happened in class, but I found it extremely difficult to follow instructions. During classroom activities my attention was divided, and to focus was difficult due to all the sensory stimulation. The following two reports from my teacher during the first semester (Figure 4.6) depict the cognitive challenges that I experienced. Although I was already four years and several months, one test indicated my developmental age at three years and six months; while the Draw-a-Person test (DAP) indicated that I functioned way beyond three years of age. The purpose of this test was to evaluate my intelligence levels by drawing three separate pictures of a man, woman and myself. The report further indicates that I wasn’t able to name any body parts, nor attribute any function to them; I couldn’t count, had no concept of numbers and did not know any shapes. Although I knew the days of the week, I did not have any concept of time, my completion time of an assignment was very slow, and according to my teacher I had an average attention span.



III. KOGNITIEWE ONTWIKKELING:

1. **Begrip van tyd:**	gister/vandag/more/dae v.d.week/verjaarsdagmaand/seisoene/maande/glad nie
2. **Weetgierigheid:**	ondersoek graag nuwe dinge/baie oplettend/ nuuskierig
3. **Persoonlike wetenswaardighede:**	Kon ⓧ Kon ⓧ naam/van/ouderdom/adres/telefoonnommer

IV. KONSENTRASIE EN AANDAGSPAN:

1. **Taakgerigtheid en-voltooiing:**	doelgerig/moet gedurig aangemoedig word/ word gou moeg/tydsaam
2. **Aandagspan:**	goed/gemiddeld/kan verbeter

2.3 Die Ontwikkelings Toets vir Visio Motoriese Intergrasie:

Hierdie toets eis die nabootsing van 24 vorms gegradeer in saamgesteldheid.

	Telling:	3 Jaar 6 Maande
2.4	Liggaamskonsep:	
	Lokalisasie	Swak weet van sintuie maar nie hulle funksie nie, sê byvoorbeeld ogies slaap en oortjies was. Weet van arms en bene maar nie van skouers of kniee nie.
	Mantekening	Volgens die D.A.M. toets funksioneer Emile op 'n ouderdomsvlak van vêr onder 3 jaar.
3.	KONSEPSUELE BEKWAAMHEID:	
3.1	Kleur	Op ouderdomsvlak. Hy kan alle kleure benoem net sy uitspraak is swak.
3.2	Getal Konsep	Afwesig.
3.3	Vorm Konsep	Benoeming. Swak Passing. Probeer en tref.

Figure 4.6:Report relating to my cognitive status at three years and six months

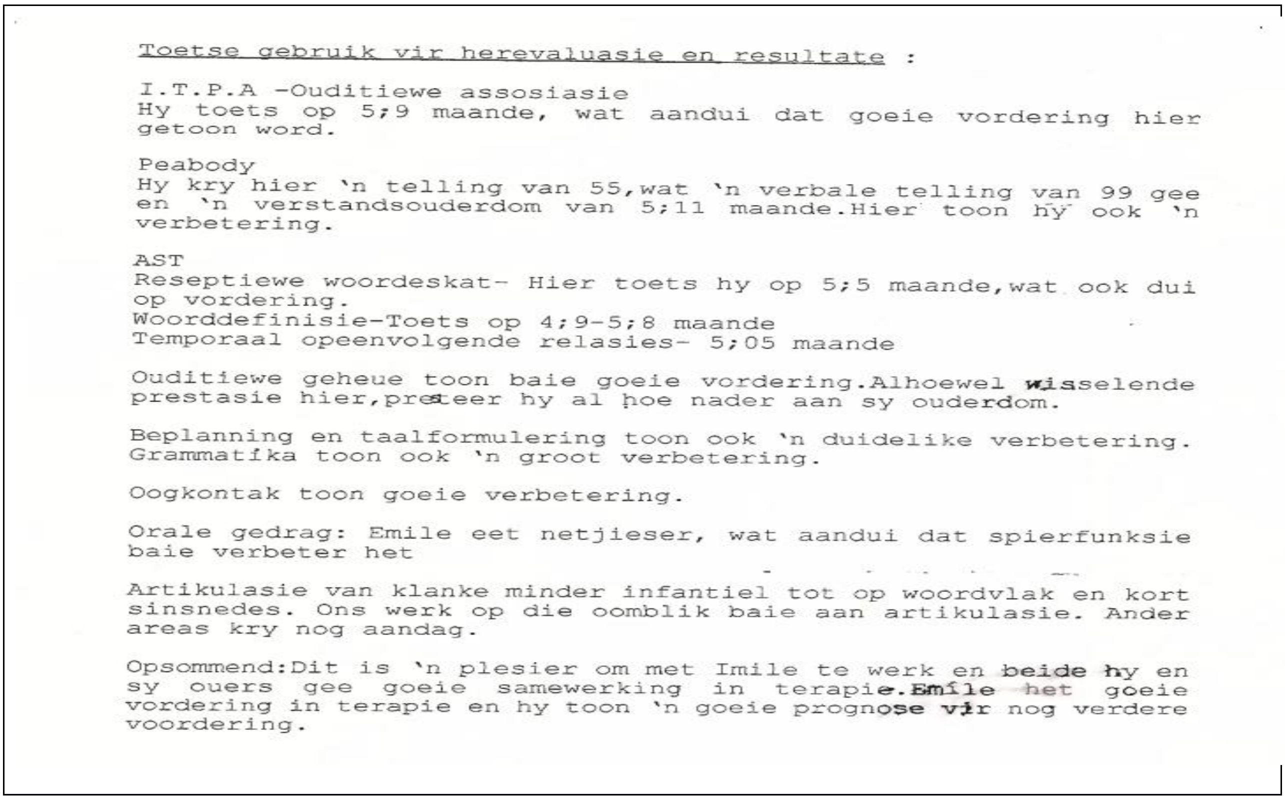
This first school report came as a tremendous shock to my mother as she was totally unprepared: She recalls: "*In the more than four years of his development Emile's grandmother never mentioned any inappropriate or delayed behaviour. She was his caretaker during the day, and she should have told me that my child's behaviour was different from the other children. When I confronted her with the report, she said that the report was a fabrication, as it did not reflect Emile's abilities. I was so confused, but as a mother I wanted the truth. We consulted the occupational therapist, and when I received the results I knew that I needed to support Emile. I decided to resign and dedicate my time to get involved in Emile's development".*

Thinking back, I know that my mother's unselfish decision put my life onto a different trajectory – her sacrifice paved the way to enable an autistic little boy to complete his school career with university exemption.

My mother's life started revolving around mine. She describes: "*I bought products from Smiley Kids and we did exercises to improve his memory processing skills. The repetitions of activities were vital, and it took up much time because his working speed was so slow. Emile's muscle tone was low and it took him longer to complete exercises. I got to know that patience is a virtue and it enabled me to assist Emile in completing the activities that the therapists prescribed. It was always important to explain work to Emile so that he could process the information and understand what the expectations were all about. He completed the exercises and did all the repetitions without complaining or asking why it should be done".* My father also commented on the amount of time my mother spent with me, and the effort that she put in. He recalls: "*I remember that your mother played meta music (used for people with brain injuries) at night while you slept, to improve the brainwaves".* According to my father, the music helped me to be more alert when I woke up in the mornings. He also remembers that my mother used to play music during the day while we were busy doing homework. "*Meta music made you feel relaxed",* my father recalls.

At the age five years my mother taught me to read as she thought this would ease my adjustment to primary school. Learning to read was not an easy process because I struggled to fixate, my word production and pronunciation was inadequate due to the thickening of my tongue and the weak muscles in my mouth.

She bought a computer program, the Aquino’s program that consists of developing perceptual skills and we spent most of our time learning. In the interview with the speech therapist, she revealed: “*It was a major advantage that you could read before the age of six years. The constant stimulation and exposure to different perceptual activities contributed towards your capabilities to read easily. Speech therapy had a major influence on your speech development and reading abilities”.* In the following report from the speech therapist, at the age of 5 years and 8 months, she indicates the various tests conducted, which gave evidence of improvements in various areas: auditive association which indicated good progress, the Peabody test which measured my verbal ability and school readiness capabilities included several activities such as my receptive vocabulary, auditive memory, planning and language formation as well as pronunciation of various sounds. She concludes that the prognosis for further progress is very good, and that both my parents and I collaborated with her and contributed to the good progress I made.



Toetse gebruik vir herevaluasie en resultate :

I.T.P.A -Ouditiewe assosiasie
Hy toets op 5;9 maande, wat aandui dat goeie vordering hier getoon word.

Peabody
Hy kry hier ‘n telling van 55,wat ‘n verbale telling van 99 gee en ‘n verstandsouderdom van 5;11 maande.Hier toon hy ook ‘n verbetering.

AST
Reseptiewe woordeskat- Hier toets hy op 5;5 maande,wat ook dui op vordering.
Woorddefinisie-Toets op 4;9-5;8 maande
Temporaal opeenvolgende relasies- 5;05 maande

Ouditiewe geheue toon baie goeie vordering.Alhoewel wisselende prestasie hier,presteer hy al hoe nader aan sy ouderdom.

Beplanning en taalformulering toon ook ‘n duidelike verbetering. Grammatika toon ook ‘n groot verbetering.

Oogkontak toon goeie verbetering.

Orale gedrag: Emile eet netjieser, wat aandui dat spierfunksie baie verbeter het

Artikulasie van klanke minder infantiel tot op woordvlak en kort sinsnedes. Ons werk op die oomblik baie aan artikulasie. Ander areas kry nog aandag.

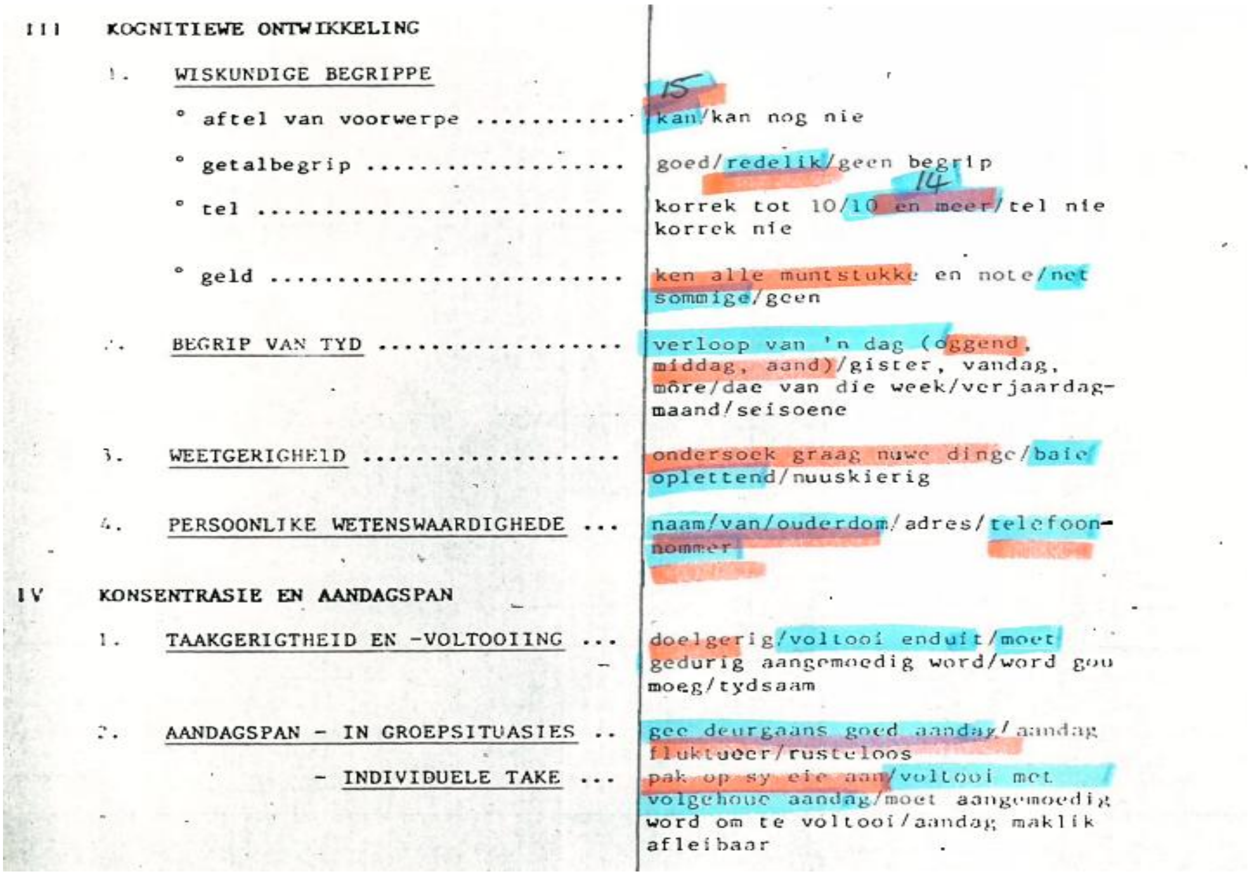
Opsommend:Dit is ‘n plesier om met Imile te werk en beide hy en sy ouers gee goeie samewerking in terapie.Emile het goeie vordering in terapie en hy toon ‘n goeie prognose vir nog verdere voordering.

Figure 4.7: Report from speech therapist at age of 5 years and 8 months

At the age of six years and 2 months I went to another pre-primary school. My enrolment in the new pre-primary school was a major adjustment because I was far away from my grandmother’s house, and it was totally unfamiliar to me. Although challenges remained with my numerical and writing abilities, there were signs of improvement due to the therapy

I received and the additional activities that improved my perceptual development. Every afternoon my mother would assist me with homework, and slowly but surely my cognitive abilities improved.

The new teacher had a positive attitude, and the learning experiences were broader. My anxiety levels decreased, and I changed into a toddler who explored his surroundings. I was aware of time management and the routine in the day. Although I was familiar with different seasons, I struggled to wear the correct clothing due to sensory sensitivity and preferred not to wear knitted woolen clothes in the winter. Due to activities that I found interesting, my attention span increased, and I learned more. In the mornings and afternoons, I went to school and weekends I received therapy. Late afternoons and evenings consisted of completing homework that I received from the therapists and additional work. The following report (Figure 4.8), attests to the fact that my mother's support started to paid off. With mathematical concepts, I could count objects, and count up to fourteen. I had an average concept of numbers and also of time and was quite alert in class. I also knew my name, surname and our telephone number.



III	**KOGNITIEWE ONTWIKKELING**	
1.	WISKUNDIGE BEGRIPPE	
	° aftel van voorwerpe	15 kan/kan nog nie
	° getalbegrip	goed/redelik/geen begrip
	° tel	14 korrek tot 10/10 en meer/tel nie korrek nie
	° geld	ken alle muntstukke en note/net sommige/geen
2.	BEGRIP VAN TYD	verloop van 'n dag (oggend, middag, aand)/gister, vandag, môre/dae van die week/verjaardag-maand/seisoene
3.	WEETGERIGHEID	ondersoek graag nuwe dinge/baie oplettend/nuuskierig
4.	PERSOONLIKE WETENSWAARDIGHEDE ...	naam/van/ouderdom/adres/telefoon-nommer
IV	**KONSENTRASIE EN AANDAGSPAN**	
1.	TAAKGERIGTHEID EN -VOLTOOIING ...	doelgerig/voltooi enduit/moet gedurig aangemoedig word/word gou moeg/tydsaam
2.	AANDAGSPAN - IN GROEPSITUASIES ..	gee deurgaans goed aandag/aandag fluktueer/rusteloos
	- INDIVIDUELE TAKE ...	pak op sy eie aan/voltooi met volgehoue aandag/moet aangemoedig word om te voltooi/aandag maklik afleibaar

Figure 4.8: Report from my classroom teacher at the new preprimary school

My parents appointed a private multi-disciplinary team operating in various educational fields. They devised activities which I had to complete in my leisure time to improve my gross and fine motor skills. Coaches assisted me with ball play, swimming, pottery classes, tennis, and chess. Myself-confidence grew, because I received occupational, speech and psychological therapy. I was able to recall the days of the week and months of the year, but it remained a challenge to name and write the four different seasons in a timeline. It was difficult to organise and plan the seasons in the different time frames.

My mother admits that I struggled to complete some activities and said, "*Occupational therapy was exhausting for Emile, and to complete activities took time".* Mathematics always remained a problem and it was difficult for me to grasp the concepts. At the age of three years, I could complete complicated jigsaw puzzles, even when the pieces were facing downwards. I would build the puzzle by noticing the shape of the pieces, and not by recognising the pictures. To improve pronunciation, the speech therapist helped me to improve my receptive and expressive language.

My mother used to play music to develop verbalisation. She bought programs which focused on children's music, poems, and rhymes to help me memorise. When she fetched me from school, she used to play songs in the car. I couldn't sing along, and struggled to speak, although my parents strongly encouraged me to communicate.

Through occupational therapy my perceptual skills, visual classification and association skills improved. When the therapist saw my progress, she decided to see me twice a week, instead of only once. My auditive memory also improved tremendously, because I was able to follow and complete instructions. I was able to recall information. Repetition of work, visual discrimination, visual perception, visual sequencing, auditive perception and auditive classification enhanced my long-term memory. During the interview, the speech therapist commented on her therapeutic role in my development: *"I strengthened your memory through association, recalling of words, sounds, the reading of sentences from stories, and through visual sequencing of memory. After I read a story, you had to answer questions. 'Can you remember the story about the rabbit and the turtle'? Some questions were easy, and some not. Your memory was also strengthened when you had to put* *pictures in sequence. Memory activities also included the remembering of telephone numbers and at the age of five years, you needed to remember five numbers"*

Although I received speech therapy, I remained non-verbal. My mother tried various techniques: the first and basic step was to ensure that I could read and write the alphabet. Through the learning of the alphabet, I could associate the letters with the sound, or a visual picture. Taking small words into consideration, she made sure that I pronounced the word letter by letter. The word was then associated with a specific picture on a flash card. My mother made use of modelling in spelling, where she pronounced the word firstly and I followed afterwards. She remembers these individual sessions: *"You learned to read visually and not auditively. Basic planning and organisation of words and sentences was problematic, and therefore you took you longer to speak".* She also explained other techniques: "*Visual classification was used instead of spelling the word to enable you to memorise words by looking at a picture. Flashcards were made to form words and plastic-modelled words were used to build sight words*". I learned phonics as well, and I was continuously stimulated aurally through listening to jingles and children's sing-along songs. I was also stimulated with fables and nursery rhymes. Our lives consisted of learning.

My mother's efforts were rewarded by seeing the weekly progress that I made. She used to sit in the therapy room and observed the sessions. I only needed more time to do things independently. I used to get twelve A3 sheets of homework a week. It took us several hours a day to improve my fine motor development. Sometimes she thought we did not have enough time to complete activities. One day my mom asked the occupational therapist: *"Armanda, please tell me: will Emile be able to reach his milestones, physically and cognitively?"* She replied, *"Yes, he will, but it will just take longer.* Her words encouraged my mom, and gave her hope.

Cognitive support was relatively easy, in the sense that my mother knew what needed to be done to strengthen a skill; emotional support was more challenging.

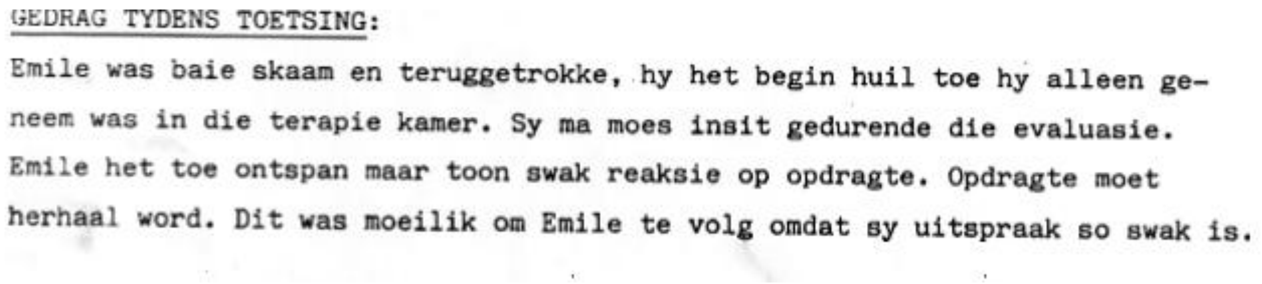
4.2.2 Emotional domain

As any young mother with her first-born, my mother liked to take me places – to shopping centers, visiting friends, family or places of interest like the Johannesburg Zoo. My mother recalls that very early in my life, she could detect that my behaviour changed in unfamiliar environments. *"You would just start crying and would be crying all the time while in a* *strange environment. I remember telling my sister that you were different than other babies when visiting people. Only after you were diagnosed with ASD, I realised that your behaviour could be ascribed to ASD ".*

Social change led to anxiety and nervousness. I was shy and withdrawn and it took my mother some time to realise that confronting me with unfamiliar places and crowds of people, was very upsetting for me. If I visited unfamiliar places, I experienced complex processing problems and could not respond to verbal questions. If I was put on a spot, I froze, and could not respond. It was emotionally exhausting for me when my mother exposed me to unfamiliar people or places.

Although my mother realised that I found social exposure emotionally demanding, she believed that it was the only way for me to learn to respond differently and acquire coping mechanisms. If I was in a crowd I tended to be so anxious that my mom had to take my hand. When we entered shopping centers, she walked next to me, and constantly reminded me that the feeling of fear would subside. Although I did not verbalise my fear, she quickly learned that my emotional distress manifested through hand gestures, which other people found strange and socially unacceptable. The autistic rigid hand positions are called mosaic movements. It is a tense, frozen position, very often in both hands, similar to the claws of an eagle. She learned to communicate with me when the mosaic movements appeared and tried to draw me out of the world that I had created. She never punished me for making these hand movements, because she realised that it was my emotional outlet. She therefore tried to avoid situations which I could experience as emotionally taxing: She told me: "*I made a point of assuring you constantly of my proximity and that everything will be all right and that you are safe".*

After the diagnosis, my parents made an appointment with the principal to discuss my behaviour and within two weeks they consulted an occupational therapist to assess me. The following remark (Figure 4.9) reflects my emotional response during the assessment. In this report, the occupational therapist noticed that I am very shy and withdrawn, and that I started crying when I was left on my own. My mother had to be present during the assessment.

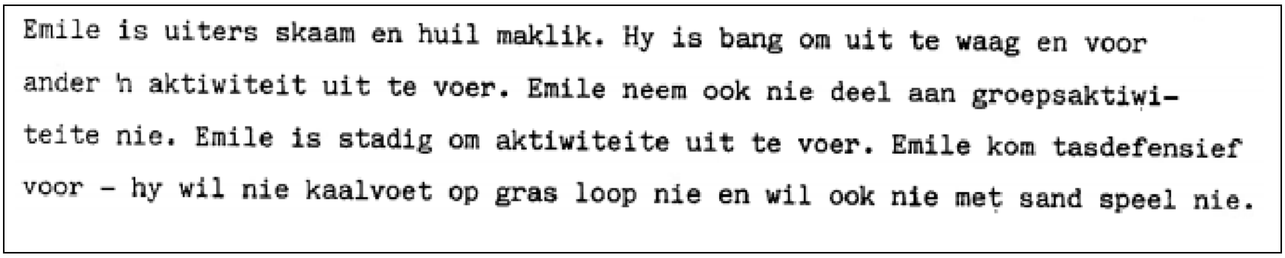


GEDRAG TYDENS TOETSING:

Emile was baie skaam en teruggetrokke, hy het begin huil toe hy alleen geneem was in die terapie kamer. Sy ma moes insit gedurende die evaluasie. Emile het toe ontspan maar toon swak reaksie op opdragte. Opdragte moet herhaal word. Dit was moeilik om Emile te volg omdat sy uitspraak so swak is.

Figure 4.9: Assessment of my behaviour during occupational therapy

My mother agrees: “*When you went to pre-primary school, you suffered from separation anxiety”.* The following report from my teacher (Figure 4.10) gives evidence that I was a very shy child who cried easily in front of strange people. The report also mentions that was scared to explore and to complete an activity in front of other children. It also indicated my lack of collaboration in group activities.

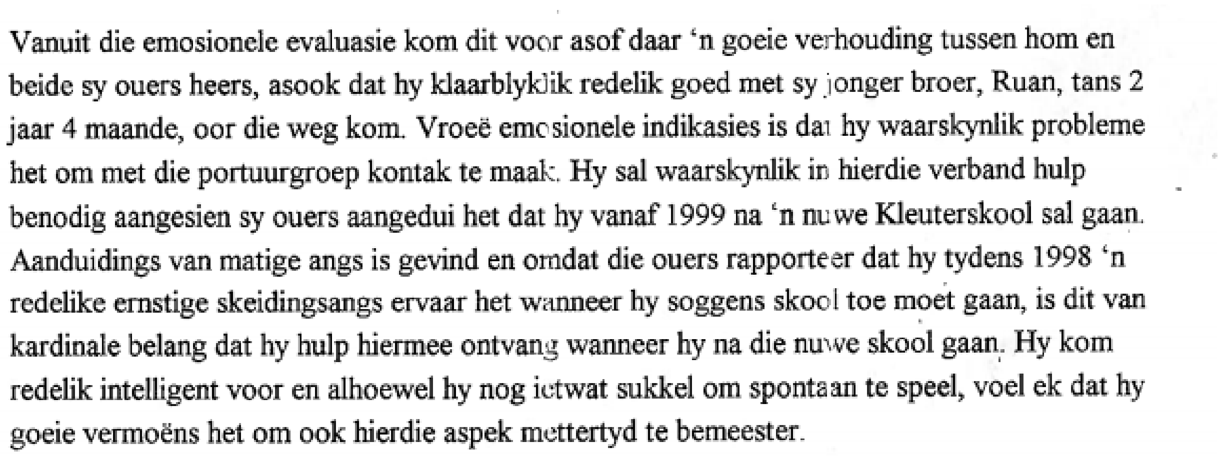


Emile is uiters skaam en huil maklik. Hy is bang om uit te waag en voor ander 'n aktiwiteit uit te voer. Emile neem ook nie deel aan groepsaktiwiteite nie. Emile is stadig om aktiwiteite uit te voer. Emile kom tasdefensief voor – hy wil nie kaalvoet op gras loop nie en wil ook nie met sand speel nie.

Figure 4.10: Report from pre-primary school

After receiving this report, my parents decided to have me evaluated by an educational psychologist. During our first couple of appointments, I could not see Mr Williams’s face. We also realised later in life, that this ‘blindness’, was a form of an emotional defence mechanism. It was only after our fourth meeting, that I could see his face, as I felt more relaxed in his presence. What I appreciated about Mr. Williams was that he remained positive, even when I struggled during therapeutic sessions. He also informed my mother about my progress and advised her on what measures to take to improve my holistic development.

In the conclusion of the following report (Figure 4.11) that was conducted by Mr. Williams, he noted that I had a very good emotional relationship with my internal family members which included my parents and brother, but that I struggled emotionally to relate to children from my own age group.



Vanuit die emosionele evaluasie kom dit voor asof daar 'n goeie verhouding tussen hom en beide sy ouers heers, asook dat hy klaarblyklik redelik goed met sy jonger broer, Ruan, tans 2 jaar 4 maande, oor die weg kom. Vroeë emosionele indikasies is dat hy waarskynlik probleme het om met die portuurgroep kontak te maak. Hy sal waarskynlik in hierdie verband hulp benodig aangesien sy ouers aangedui het dat hy vanaf 1999 na 'n nuwe Kleuterskool sal gaan. Aanduidings van matige angs is gevind en omdat die ouers rapporteer dat hy tydens 1998 'n redelike ernstige skeidingsangs ervaar het wanneer hy soggens skool toe moet gaan, is dit van kardinale belang dat hy hulp hiermee ontvang wanneer hy na die nuwe skool gaan. Hy kom redelik intelligent voor en alhoewel hy nog ietwat sukkel om spontaan te speel, voel ek dat hy goeie vermoëns het om ook hierdie aspek mettertyd te bemeester.

Figure 4.11: Report from the educational psychologist

Through constant therapy sessions my self-confidence grew, and I was able to follow instructions. Nobody monitored my progress in a social environment and my mother was the only person who could see improvement in my behaviour. My mother noted in her book: "*Emile will listen to a conversation and observe from a distance. But the moment he becomes emotionally upset he will have a meltdown and the hand gestures will increase".* My mother also specifically remembers that I hardly ever cried when I was a toddler, as if I wanted to avoid the attention that my crying would have elicited. She also found it extremely difficult to teach me about different emotions - it was as if I just couldn't distinguish between happiness, sadness and so on.

She also found it upsetting that I did not respond to other people's expressions of emotions and felt that I was "*emotionally blunted*". She also remarked, "*Emile will accept demonstrations of love, such as hugging and kissing, but struggles to express his love in the same way".*

My mother also found it strange that I never came home and remarked about other children's emotional responses. The teacher reported that when another child engaged in screaming, crying or any emotional outburst, I would remove myself physically and resort to hand gestures. Both teachers in preschools X and Y resorted to screaming at the children when they were at wits' end. Consequently, I isolated myself from everyone, as all the loud noised caused anxiety. Only when I removed myself from the busy environment, my anxiety levels subsided. To comfort myself, I created imaginary friends, and by thinking about them, I would forget about reality. These thinking patterns would usually appear during breaks and play times, when I removed myself physically from the rest of the children.

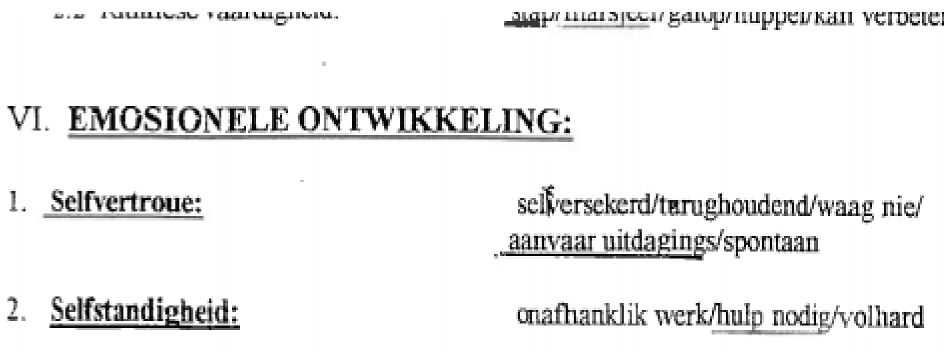
Funnily enough, my grandmother was never present when I portrayed hand gestures and was quite adamant when saying that she never saw me expressing any emotion – only once when I was hospitalised at the age of two years – then I was ‘angry’.

Figures 4.12: Photos of me resorting to hand gestures

My mother never even knew about my temporary blindness: “*Emile never explained to me that he experiences sensory blindness. He only mentioned it to me at the age of 24 years. I was shocked to realise that the associated symptoms of ASD affected also his life on a visual level”.* I tried to explain to my mother that with this blindness, I was unable to see the facial expressions of people and could therefore not read the emotions on their faces.

That explains why I refrained from making eye contact. While interviewing my mother she confessed, it “*saddens me to know that I have exposed you to environments that caused so much stress that you could not see people’s faces. Had I known, I would be much more careful to what I would have exposed you to”.*

This blindness remained a challenge, as I could also not see the facial expressions of the children at pre-school. At the age of six years when I went to my second pre-primary school, I struggled to adapt. I was now also a big brother, as my brother Ruan, was also enrolled in the same school. Although I still struggled to express myself, my self-confidence increased due to therapy, as well as participation in different activities like swimming, pottery classes, karate and tennis lessons. The following school report (Figure 4.13) notes the improvement in my emotional development. Reference is made to the fact that I now accept challenges, but still need assistance to complete independent assignments.



2.2 Ritmiese vaardigheid: stap/marsjeer/galop/huppel/kan verbeter

VI. **EMOSIONELE ONTWIKKELING:**

1. **Selfvertroue:** selfversekerd/terughoudend/waag nie/ aanvaar uitdagings/spontaan

2. **Selfstandigheid:** onafhanklik werk/hulp nodig/volhard

Figure 4.13: Report from second pre-primary school

My emotional responses were interlinked with how I experienced my social exposure, as the following section will indicate.

4.2.3 Social domain

One of the first indicators that I was different from other babies was the way I responded in social situations. Although my mother was inexperienced, she noticed that I was different from other babies. When we visited my grandmother Lily, my maternal grandmother once a month, I used to cry in her presence. When all the cousins were together, the crying was worse; when my parents went home, the crying would stop. My mother also noted that I hardly expressed my needs in a social environment, as I hardly ever expressed any emotions such as laughing or crying.

At the age of eight weeks, my mother had to go back to work and I had to stay with my paternal grandmother. As she was looking after other children as well, my parents felt “*It was comforting to know that Emile was in a safe environment and where he would get exposure to other children as well”.*

According to my parents I was a happy toddler while in the secure environment of our own home, but as soon as they exposed me to an unfamiliar environment, my behaviour would change: I did not express my emotions when somebody communicated with me, nor did I respond, or laugh when people interacted with me. Even when my cousin, Lillian, was visiting, I would not play with her, even though we were the same age. My parents ascribed my behaviour to being an introvert, and believed that social interaction would develop in time. When family visited us on weekends, my mom noticed that I isolated myself. I would go to my room and play alone with my toys.

I was a serious little boy who preferred his own company and tended to escape to his own world where there was no eye contact and no communication. My father agrees when recalling:*”You were a serious toddler who rarely smiled”.*

My mother soon became aware that an unfamiliar environment and that people, especially a group of people, had a disturbing effect on me. In her book my mother wrote:”At *Church a women once made a remark that Emile is an unstable toddler. I know that was because she noticed that Emile preferred his own company when there were other people around. When Emile was two years old we went to a Christmas function. All the children would get on a train that drove them around on the premises. I told Emile that he can take a ride on the train while I waited for him. He got on the train, but once it started moving, he jumped off, irrespective of the fact that he could get hurt”.* All the other children enjoyed the ride, but my mother realised that the unfamiliar surroundings made me fearful and anxious.

My mother recalls how she had a day off at work and decided to spend it at my grandmother’s house. “*It was disturbing to see that Emile sat on his own in front of the television set while the other children were playing”*. When my mom noticed that I was alone, she would always fetch me and encourage me to play with the children. *“I always encouraged Emile to play with the other children. It was not healthy for Emile to distance* *him from children and to play alone".* The following photo (Figure 4.14) is an example of the behaviour I portrayed in front of family members. I am sitting in the second row on the right in front, and it is clear that I am looking away from the camera, while the other children all looked at the camera smiling.

Figure 4.14: Family photo that portrays my lack of social skills

At my grandmother's home I was getting accustomed to a one-on-one situation and relaxed in the company of my cousins, Elsa and John, who also stayed at my grandmother's place. My mother soon noted that I was submissive in their presence and that I did not express my emotions or needs in front of them. She also noticed that I preferred to communicate with the younger children, Caylee and Tersia, as I felt that they accepted me and always played with me. According to my mother I never complained about how Elsa and John treated me: "*From the look of the eye you communicated and socialised normally".*

My grandmother who observed my behaviour in the afternoons was aware that I did not form part of the play group. During our interview, she mentioned:*"You preferred to distance yourself from the group whereby you played with your fingers, or you would prefer to watch*

TV on your own". She also recalls that I did not communicate. *"If I asked you a question, you did not answer. You did not communicate spontaneously. If I did not make the effort to communicate with you, you wouldn't speak at all".* During our interview, my grandmother remarked that she now realises that, as a toddler, I never communicated with my grandfather.

Attendance of the pre-primary school at the age four years was the first time that I was exposed to a strange environment. Here I was placed in a class with 17 other children. The strange faces, noise and activities had a huge impact on me. As I was unable to verbalise my emotions, I withdrew myself into an imaginary world where I communicated with hand gestures. I would only portray the non-verbal hand gestures, if I felt frustrated. I decided to keep my distance, because I did not understand the social cues of the children; in my own world. I escaped reality by using my imagination, which was extremely stressful.

When the teacher tried to understand my behaviour, I could not verbalise my frustration and distress as my vocabulary was limited and my sentence construction and pronunciation were poor. She was shocked when I expressed my distress by aggressive behaviour whereby I pulled down the pictures from the bathroom walls and bit the children.

My anxiety levels became a barrier to social interaction, because I avoided playing and communicating with my peers. My perception was that I was placed in an unfriendly, noisy and strange environment and in order to survive, I had to block my ears to avoid hearing all the noise. It was therefore difficult for me to develop social contact and skills as I preferred to isolate myself from the noise.

The children noticed my behaviour was strange, and after a while, they stopped making any effort to play with me. The teacher observed my behaviour, but because of her lack of knowledge and experience, she did not know how to cope with me. Two weeks after enrolment, she discussed my behaviour with my parents. It was only then that my parents realised that in comparison with other children, my behaviour was not on par with my peers. I was then diagnosed with ASD and was placed in another pre-primary school at the age of six years.

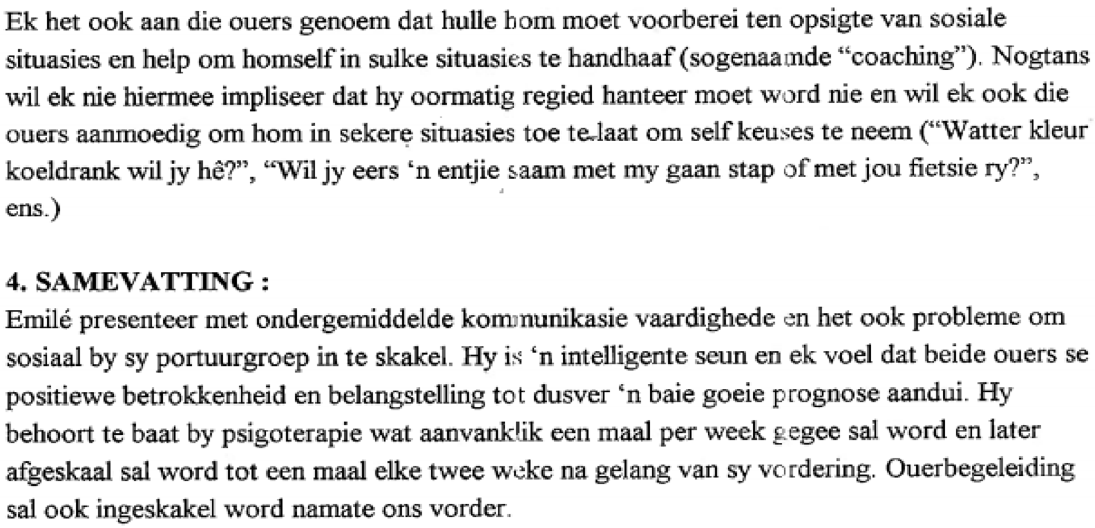
My mother was very concerned about my social development and immediately played open cards with the teacher. She wrote: "*When I enrolled Emile at pre-primary school Y, I explained to the teacher that Emile was diagnosed with ASD. She assured me that the* *school is ASD friendly and promised to monitor Emile's behaviour. When I visited the school one day, she assured me that the children accepted Emile and that his behaviour was acceptable".*

Attending this school meant that I could not go to my grandmother in the afternoons, as the school was far from her house. At first the adjustment was difficult and I found it difficult to get used to the new children. The same feelings returned – I experienced sensory overload on the first day when I walked into the classroom, and I wanted to flee to a safe place where I could be alone.

Although I had received therapy, my sensory processing did not improve, and it remained one of my greatest challenges. Although I was in a classroom with children my age, they did not understand that my brain responded differently to sensory information. It was difficult to concentrate in classes and to focus on tasks.

To speak and express myself remained a challenge and continued to have an impact on my social relationships and acceptance. My mother was aware that I never formed any friendships and that I never invited friends over: In her book, she narrated*: "Emile was never invited to birthday parties. He never introduced any children at school to me and never mentioned that he had friends at school. Although I arranged big birthday parties at my mother- in-law's house for Emile, it was only the children that she looked after during the day that attended."*

The following extract from the report of the psychologist (Figure 4.15) indicates my struggle in social situations. Here the psychologist mentions that my parents should guide me in standing my ground in social situations (coaching), and that they must allow me to make my own choices – even if it is about the choice of a cold drink or whether I prefer to ride my bike or walk. In his conclusion he mentions that I present with sub-normal communication skills and that I struggle to for part of my peer group.



Ek het ook aan die ouers genoem dat hulle hom moet voorberei ten opsigte van sosiale situasies en help om homself in sulke situasies te handhaaf (sogenaamde "coaching"). Nogtans wil ek nie hiermee impliseer dat hy oormatig regied hanteer moet word nie en wil ek ook die ouers aanmoedig om hom in sekere situasies toe te laat om self keuses te neem ("Watter kleur koeldrank wil jy hê?", "Wil jy eers 'n entjie saam met my gaan stap of met jou fietsie ry?", ens.)

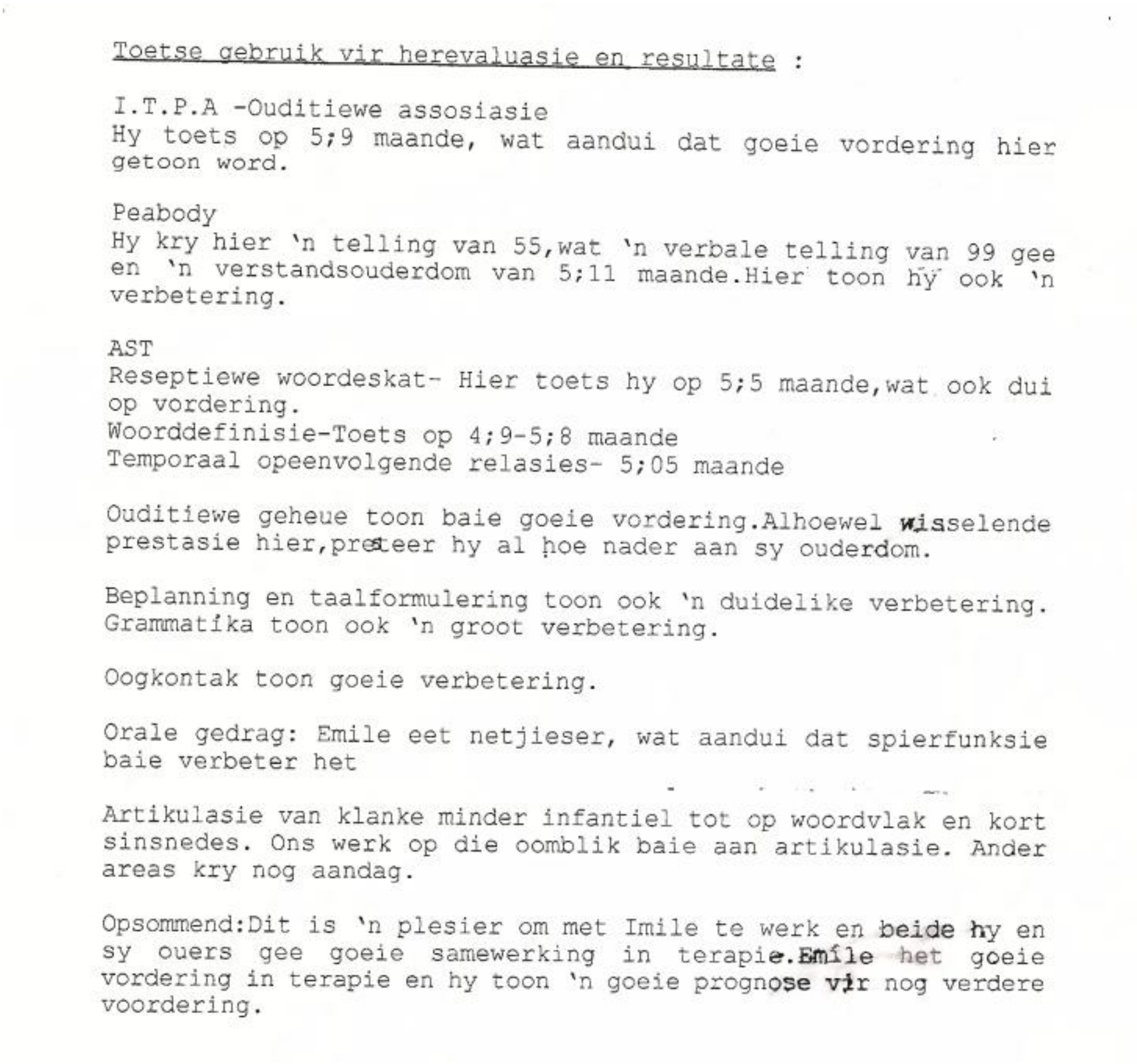
4. SAMEVATTING :

Emilé presenteer met ondergemiddelde kommunikasie vaardighede en het ook probleme om sosiaal by sy portuurgroep in te skakel. Hy is 'n intelligente seun en ek voel dat beide ouers se positiewe betrokkenheid en belangstelling tot dusver 'n baie goeie prognose aandui. Hy behoort te baat by psigoterapie wat aanvanklik een maal per week gegee sal word en later afgeskaal sal word tot een maal elke twee weke na gelang van sy vordering. Ouerbegeleiding sal ook ingeskakel word namate ons vorder.

Figure 4.15: Report from the psychologist

The educational psychologist was furthermore concerned because I struggled to 'read' and adapt to different social situations. He realised that my word pronunciation was not established. Symptoms of echolalia (the unintended repetition of words and sentences) were present when I spoke, and therefore Mr Williams referred me to Miss Sandy, a speech therapist in 1998. She noticed that my communication levels were below par and that I failed to make eye contact. My mouth muscles were weak and therefore I tended to spit while communicating. To pronounce the R-sound was difficult; therefore she used creative methods to improve the pronunciation of sounds, such as the sucking of ice, to strengthen the tongue muscles. Through repetition and the commitment of my mother who took me regularly to the speech therapist and practicing the exercises, I was eventually able to pronounce the R-sound.

Evaluation by the speech therapist, (Figure 4.16) took place, when I was five years nine months old. The Illinois Test of Psycholinguistic Abilities (I.T.P.A.) and Peabody tests indicated a major improvement. In this report, she mentions improvement in the following areas: The auditive association test showed that I was on a 5.9 months level, and progress was noted. On the Peabody test I scored 55, which was also an indication of my progress. My vocabulary tested on a score of 99 which showed a mental age of 5 years and 11 months, and positive progress was noted. The testing of my receptive vocabulary showed that I tested on a 5.5-month level. On word definition I improved from a 4.9 to a 5.8-month level. I tested on temporal sequence on a 5.5-month level. My auditive memory showed great progress and was tested close to the level of my peer group. The therapist was still concerned because inconsistent results were noted. My grammar improved, as well as planning, language formulation, and eye contact. During therapy my eating improved, which showed that the muscle tone in my mouth had improved. Articulation of sounds was less infantile, and more to a word level. My sentences remained short and work was in progress. To conclude, the speech therapist mentioned that my progress was satisfactory, and she noted that my co-operation and future prognosis was positive.



Toetse gebruik vir herevaluasie en resultate :

I.T.P.A -Ouditiewe assosiasie
Hy toets op 5;9 maande, wat aandui dat goeie vordering hier getoon word.

Peabody
Hy kry hier 'n telling van 55,wat 'n verbale telling van 99 gee en 'n verstandsouderdom van 5;11 maande.Hier toon hy ook 'n verbetering.

AST
Reseptiewe woordeskat- Hier toets hy op 5;5 maande,wat ook dui op vordering.
Woorddefinisie-Toets op 4;9-5;8 maande
Temporaal opeenvolgende relasies- 5;05 maande

Ouditiewe geheue toon baie goeie vordering.Alhoewel wisselende prestasie hier,presteer hy al hoe nader aan sy ouderdom.

Beplanning en taalformulering toon ook 'n duidelike verbetering.
Grammatika toon ook 'n groot verbetering.

Oogkontak toon goeie verbetering.

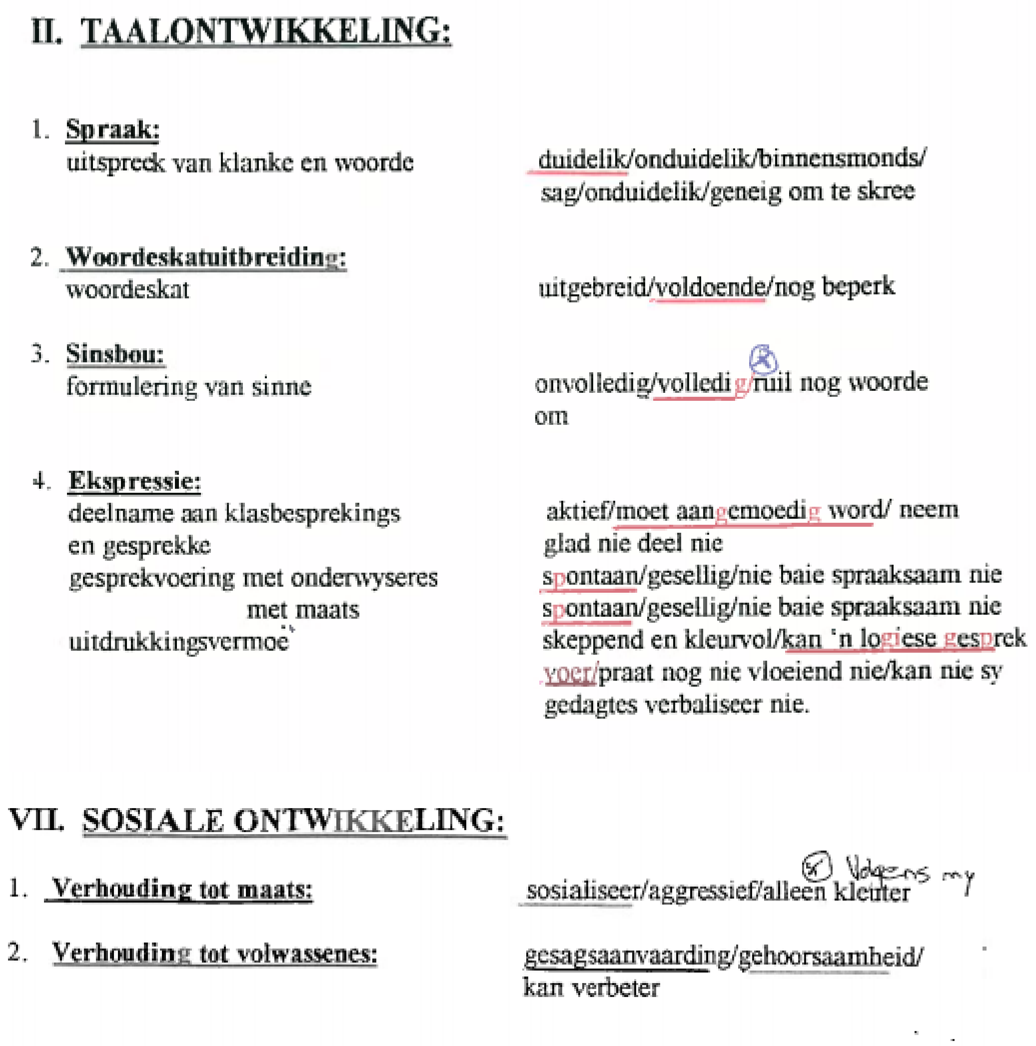
Orale gedrag: Emile eet netjieser, wat aandui dat spierfunksie baie verbeter het

Artikulasie van klanke minder infantiel tot op woordvlak en kort sinsnedes. Ons werk op die oomblik baie aan artikulasie. Ander areas kry nog aandag.

Opsommend:Dit is 'n plesier om met Imile te werk en beide hy en sy ouers gee goeie samewerking in terapie.Emile het goeie vordering in terapie en hy toon 'n goeie prognose vir nog verdere voordering.

Figure 4.16: Progress report from evaluation that speech therapist conducted

Also, in school, my progress was noticeable, and it was clear that slowly but surely my mother's sacrifices began to pay off. The following report (Figure 4.17) indicates that my pronunciation of words are clear, that my formulation of sentences is complete, that my vocabulary is sufficient, but that I still need to be encouraged to participate in classroom discussions. The teacher also notes that I do socialize and that I accept authority.



II. TAALONTWIKKELING:

1. **Spraak:** uitspreek van klanke en woorde	duidelik/onduidelik/binnensmonds/ sag/onduidelik/geneig om te skree
2. **Woordeskatuitbreiding:** woordeskat	uitgebreid/voldoende/nog beperk
3. **Sinsbou:** formulering van sinne	onvolledig/volledig/ruil nog woorde om
4. **Ekspressie:** deelname aan klasbesprekings en gesprekke gesprekvoering met onderwyseres met maats uitdrukkingsvermoë	aktief/moet aangemoedig word/ neem glad nie deel nie spontaan/gesellig/nie baie spraaksaam nie spontaan/gesellig/nie baie spraaksaam nie skeppend en kleurvol/kan 'n logiese gesprek voer/praat nog nie vloeiend nie/kan nie sy gedagtes verbaliseer nie.

VII. SOSIALE ONTWIKKELING:

1. **Verhouding tot maats:**	sosialiseer/aggressief/alleen kleuter ⊗ Volgens my
2. **Verhouding tot volwassenes:**	gesagsaanvaarding/gehoorsaamheid/ kan verbeter

Figure 4.17: Progress report from educator to improvement in social skills improved

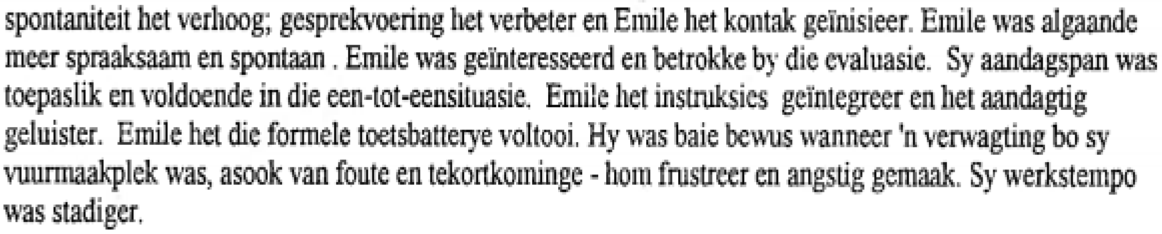
The occupational therapist realised the importance of positive reinforcement and social exposure during her therapeutic sessions. She therefore advised my parents that my therapy should be done in pairs to stimulate social interaction, and a boy, Wesley, also joined the sessions. Wesley was diagnosed with ADHD and he joined me with fine and gross motor activities. The occupational therapist guided us individually but supported us together with activities. During her interview she noted, *“Both of you learned from each other”.*

The occupational therapist also realised that although Wesley and I both had our unique challenges, we performed on the same level with working memory tasks. We also motivated each other to succeed during each therapeutic session.

When I was six years old the occupational therapist advised my mother regarding my social development and, according to her, she always knew that I had the capabilities to communicate and socialise. The occupational therapist said,*" I believed that you have improved your social skills through exposure. At first it was extremely difficult, but I knew the more you would be exposed, the more your social skills would improve over a period of time".*

My mother shared her opinion about my communication skills and documented it as follows*:" Emile only started to truly communicate his experiences and feelings with me when he was 14 years old. When he was younger it was so difficult for him to give his own opinion. He imitated me, but he never expressed his emotions or feelings".*

The following progress report (Figure 4.18) is an example of my social development during period of the occupational therapy I received. In this report the occupational therapist noted my behaviour during assessment: I was reserved at first and did not communicate in full sentences; I responded to yes/no questions; I did not portray any sign of eye contact and tended to avoid contact by turning my body away from people; and I was uncomfortable with physical contact. However, the more I got used to the same environment, my behaviour traits changed notably. I became more relaxed and comfortable. My communication improved and I answered questions spontaneously. My attention span improved during the individual evaluation. I was self-aware in the sense that I knew when activities were too difficult for me to complete, which made me feel anxious. I also knew that my work tempo was slower than other children's. Though constant therapy my behaviour changed and my communication skills improved.



Emile het gemaklik geskei en sy samewerking was goed. Hy was aanvanklik baie stil en pogings om gesprek uit te lok en net ja/nee response ontlok .Oogkontak aanvanklik vermy en ander vermydingsresponse is waargeneem - fisies self dwars gedraai om kontak te vermy . Hy was ongemaklik met fisiese kontak Hierdie gedrag het egter met die verloop van die evaluasie merkbaar verander - spontaniteit het verhoog; gesprekvoering het verbeter en Emile het kontak geïnisieer. Emile was algaande meer spraaksaam en spontaan . Emile was geïnteresseerd en betrokke by die evaluasie. Sy aandagspan was toepaslik en voldoende in die een-tot-eensituasie. Emile het instruksies geïntegreer en het aandagtig geluister. Emile het die formele toetsbatterye voltooi. Hy was baie bewus wanneer 'n verwagting bo sy vuurmaakplek was, asook van foute en tekortkominge - hom frustreer en angstig gemaak. Sy werkstempo was stadiger.

Figure 4.18: Report from occupational therapist

After the therapy that I received, social interaction still remained a challenge where I struggled to verbalise my feelings, emotions and needs, but the more I was exposed to the environment, the more my self-confidence grew.

My mother remembers the exposure to various social activities as emotionally exhausting*: "It was my responsibility to reassure him that it is okay to walk in a crowd. I failed to reassure Emile that it is safe to feel secure in an insecure environment when sensory sensitivity occurred, because he did not feel safe".* My mother understood the importance of exposure despite the sensory challenges I experienced. She wrote the following in her book:"*It was my responsibility to expose Emile daily to places, people and animals where sensory sensitivity would occur. It broke my heart to see how he struggled and how other people reacted to his odd behaviour, but I chose not to surrender. I knew it would be the easy way out not to expose Emile to social situations, but then he was at risk to live an isolated life. It took Emile years to realise that by exposing him socially, it was emotionally so difficult for me".* Eventually I got used to the different environment and my social skills developed slowly but surely. Through social exposure I have learned to adapt to social environments. I became aware of which social situations made me uncomfortable and learned strategies to cope. I got to know what triggered anxiety or what events could be potential stressors and I learned to take 'time out 'when I became over-stimulated in any environment.

The physical manifestation of ASD was particularly striking and I think this is the area in which I struggled the most. This is illustrated in the ensuing section.

4.2.4 Physical domain

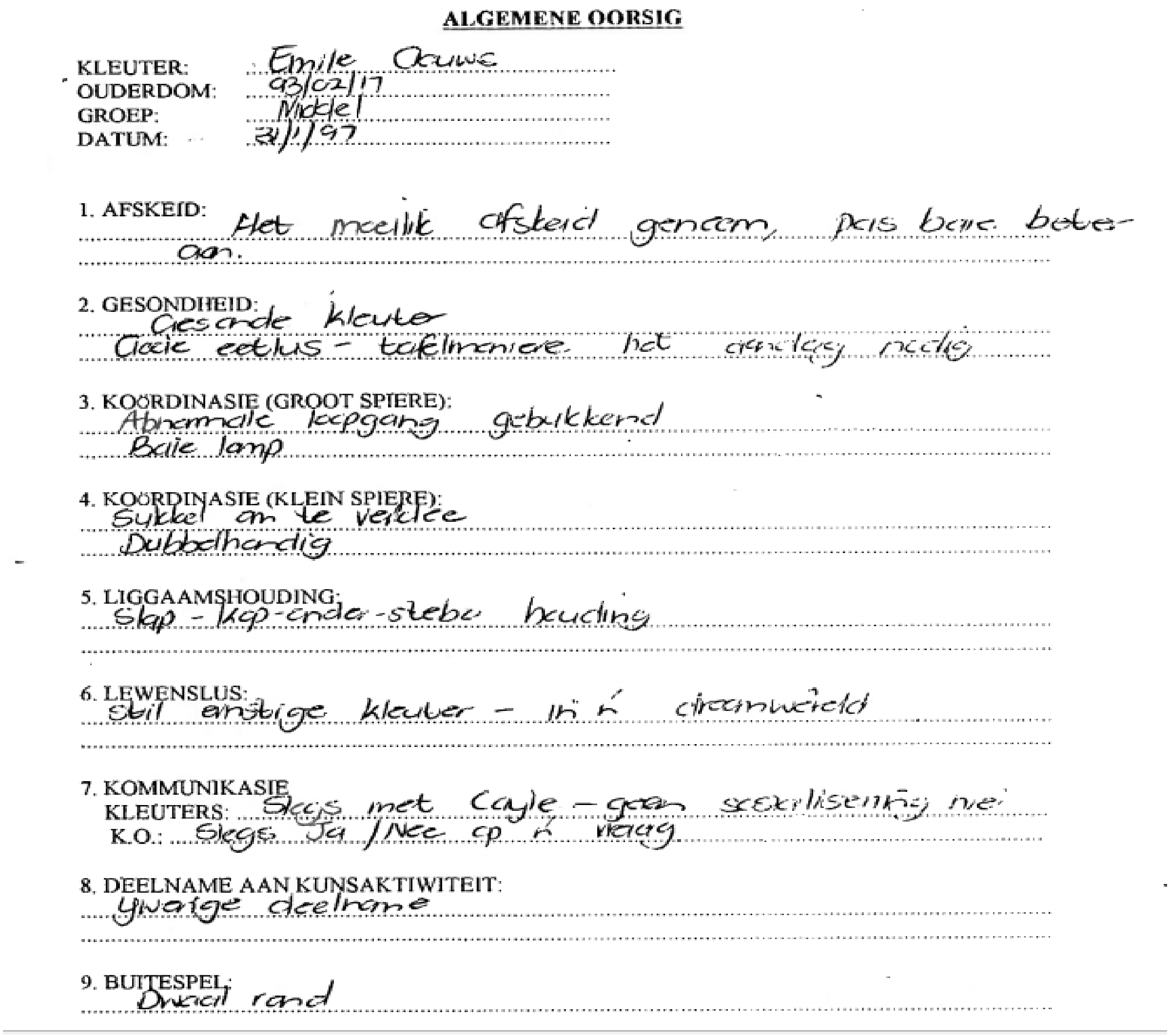
This photograph (Figure 4.19) depicts a normal, happy baby, aged seven months.

Figure 4.19: Photo of me with my mother

However, my mother paints a different picture: *“After the caesarean, I had to cope with the pain, and learn how to breast feed my newborn baby. When I started to breastfeed, Emile struggled to latch, because the muscles in his mouth were weak. My first night at home degenerated into a nightmare because Emile cried continuously. I called the paediatrician at 2:30 in the morning and told him that my baby cried all the time, and he doesn’t latch to the breast. He suggested that we visit him the next morning for an examination. After the examination he told me that Emile has colic. We went home, and the following weeks were characterised by sleeplessness. The battle to feed him and to endure the crying was horrific. Emile only slept two hours at a time, and when he woke up I battled with breastfeeding. When Emile slept during the day, I also tried to doze off. When Emile was seven weeks old I decided to wean of the breast, because I had to go back to work. A positive change occurred when I started to feed Emile soya milk. The milk fed my baby, and he started to sleep longer hours”.*

This strange sleeping pattern continued. My mother recalls:*”Emile was awake at night and I used to go to work tired the next morning”. At my mother-in-law’s place, Emile slept sometimes for four hours in the morning and then four hours in the afternoon. It was difficult to get Emile in a normal sleeping pattern at night. I had to get use to less sleep, and to stay awake at night. Due to little activity in the day Emile became a chubby baby”.*

Comparing my physical development with other children my age, my mother noticed my motor skills were weak. She recalls: *“When Emile started to crawl at 7.8 months, his muscles were weak and he was a slow crawler. When I wanted to show people that my baby crawled, but he refused to crawl as there were strange people around”.* I started walking when I was 14 months old, struggled to keep my balance and therefore often fell down. This clumsiness continued and the following report from my classroom teacher (Figure 4.20), at the age of four years, clearly mentions that I walked abnormally (hunching) and that I was very clumsy. My physical frame was also limp; I struggled to change clothes and was ambidextrous. During this time, I started with occupational therapy, and the therapist’s report (Figure 4.21) also refers to my inability to balance and the fact that I cannot walk on my toes.



ALGEMENE OORSIG

KLEUTER: Emile Oouws
OUDERDOM: 93/02/17
GROEP: Middel
DATUM: 31/1/97

1. AFSKEID: Het moeilik afskeid geneem, pas baie beter-aan.

2. GESONDHEID: Gesonde kleuter
Goeie eetlus - tafelmaniere het aandag nodig

3. KOÖRDINASIE (GROOT SPIERE): Abnormale loopgang gebukkend
Baie lomp

4. KOÖRDINASIE (KLEIN SPIERE): Sukkel om te verklee
Dubbelhandig

5. LIGGAAMSHOUDING: Slap - kop-onder-stebo houding

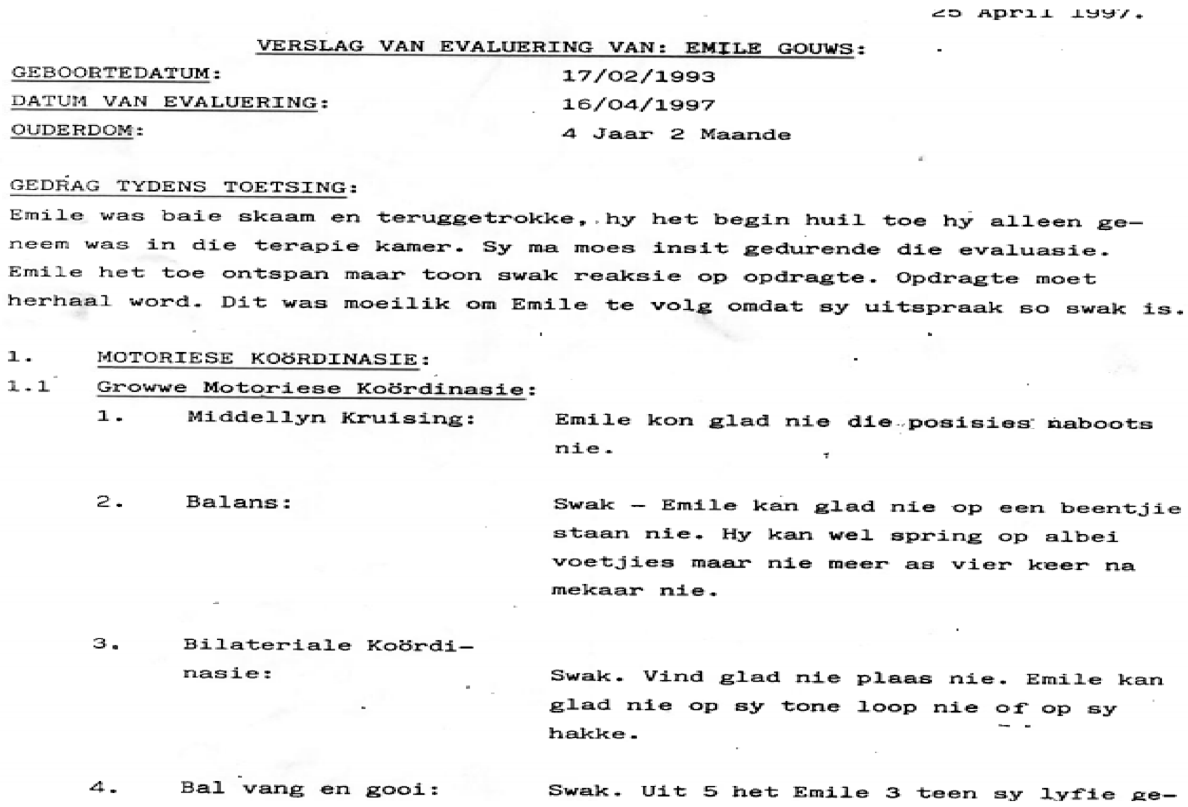
6. LEWENSLUS: Stil ernstige kleuter - in 'n droomwereld

7. KOMMUNIKASIE
KLEUTERS: Slegs met Cayle - geen sosialisering nie
K.O.: Slegs Ja / Nee op 'n vraag

8. DEELNAME AAN KUNSAKTIWITEIT: Ywerige deelname

9. BUITESPEL: Draai rand

Figure 4.20: School report



25 April 1997.

VERSLAG VAN EVALUERING VAN: EMILE GOUWS:

GEBOORTEDATUM: 17/02/1993
DATUM VAN EVALUERING: 16/04/1997
OUDERDOM: 4 Jaar 2 Maande

GEDRAG TYDENS TOETSING:

Emile was baie skaam en teruggetrokke, hy het begin huil toe hy alleen geneem was in die terapie kamer. Sy ma moes insit gedurende die evaluasie. Emile het toe ontspan maar toon swak reaksie op opdragte. Opdragte moet herhaal word. Dit was moeilik om Emile te volg omdat sy uitspraak so swak is.

1. MOTORIESE KOÖRDINASIE:
1.1 Growwe Motoriese Koördinasie:
1. Middellyn Kruising: Emile kon glad nie die posisies naboots nie.
2. Balans: Swak – Emile kan glad nie op een beentjie staan nie. Hy kan wel spring op albei voetjies maar nie meer as vier keer na mekaar nie.
3. Bilateriale Koördinasie: Swak. Vind glad nie plaas nie. Emile kan glad nie op sy tone loop nie of op sy hakke.
4. Bal vang en gooi: Swak. Uit 5 het Emile 3 teen sy lyfie ge-

Figure 4.21: Report from the occupational therapist

The occupational therapist focused on balancing exercises. One of the first activities we did was to walk on a wooden balancing beam. My core muscles in my stomach were not strong enough and I always needed assistance from her when I tried to balance. There wasn't a session that went by during which I didn't struggle with balancing. At home, we did exercises to improve my low muscle tone and balance. My mother bought a jungle gym, and to be honest, I was scared to climb on the gym. I always needed support to climb on it. I struggled to climb over structures and it seemed so difficult for me to lift my leg over in order to climb on and off physical structures. My mother recalls: "*When Emile was four years old, I bought a jungle gym, and asked my mother- in- law if I could leave it on her premises so that the children could play on it. The day after it was delivered she asked us to remove the gym. I was disappointed because Emile would then only get the opportunity to play on it during weekends".*

My mother remembers how I struggled with fine and gross motor activities:"*You responded slowly with regard to fine and gross motor skill activities. We repeated activities numerous times, but you took time to execute any form of activity".* Numerous perceptual activities proved to be difficult, such as borderline crossing. It was a challenge to climb on playground equipment like a slide or jungle gym. Climbing stairs or an incline was difficult

-

and I was apprehensive to walk or crawl. I tended to be clumsy when I walked, and had to concentrate not to fall. I hardly jumped from a jungle gym, because I did not like taking risks.

Both my parents remember that I reacted in a strange way when walking on certain surfaces. My father recalls*: "When you were nine month old, we took you to Durban. You did not like to walk barefoot on the sand. I knew you disliked walking on grass, but now it was sand as well".* The following picture clearly shows my dislike for touching the sand (Figure 4.22).

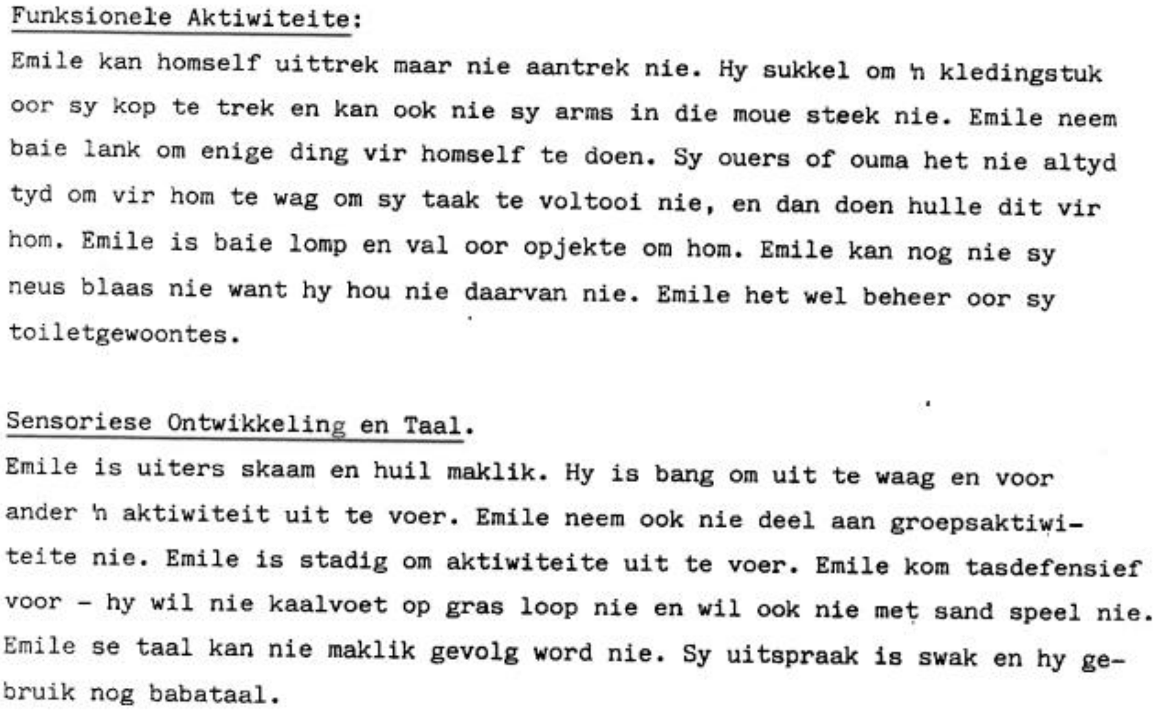
Figure 4.22: Picture of me as a nine month old baby walking on sand

I was also touch-sensitive. To touch the texture of dough and sand was dreadful. When the teacher took play-dough out at school, all the children were excited, but I refused to touch the dough. My father further recalls that I refused to eat certain food such as soup or to touch rice. I preferred to eat solid food and disliked the sensation of the liquid soup in my mouth. My grandmother did not notice any strange behaviour patterns and denied that I avoided certain food textures. When asking my grandmother whether she could recall that I refused to eat certain food, she said*: "I can't recall that you did not like different food structures". You ate the soup I made, and you never told me that you disliked any of the food I make".* When my mother bathed me, I did not like the texture of the cloth, sponge or a brush. I disliked the texture of certain clothes as well. For example, I did not want to wear wool and therefore disliked a jersey even in cold weather. Combing my hair was another challenge, and it still is something I cannot tolerate. My father recalls, “*I insisted that we must comb your hair lightly”.* Clipping my nails was another challenge as I could not stand someone approaching me with a nail clipper. My mother had to guide me a step at a time in order to manage clipping my nails.

Although I attended various activities, my fine and gross motor skill remained problematic. My eye-hand co-ordination was weak, and it was a strain to complete fine motor activities. During the completion of these activities, I always worked overtime to complete work, due to my slow working tempo. It was difficult to change clothes. It was very difficult to grasp scissors with my fingers and cutting pictures took time because I did not have the muscle strength to use the scissors and work fast. I also struggled to colour in pictures and coloured outside the lines. My grandmother was aware of the different challenges I was confronted with*.* She remembers:”Your *gross motor skills were problematic, and it was difficult for you to keep your balance. You were off balance and struggled to walk or run. Your fine motor skills were problematic as well, and it took you time to tie your shoelaces”.* My mother bought various perceptual educational toys from Smiley Kids to improve my fine motor development and memory. Every afternoon after school we engaged in activities that we received from the occupational therapist. My mother knew the different areas I struggled with*:”Tying shoe laces were difficult” as* the muscles in my hands and fingers were not strong enough to tie the laces.

What my parents also found strange was that I loved any form of spinning around. I liked to take rides on objects that spun, such as the merry-go-round. My parents were not aware that this was an indication of ASD tendencies. I always struggled to keep my balance; however, on the merry go-round I did not have a problem to keep my balance and posture and therefore could just enjoy the speed and the movement.

The report from the occupational therapist (Figure 4.23) mentions my various physical challenges. She refers to my inability to dress myself, to put my arms in sleeves and how slow I was to complete activities. She also refers to my clumsiness and that I stumble over objects. She also mentions that I cannot blow my nose, as I do not like it. She also refers to the fact that I do not like walking barefoot, and that I clearly experience tactile sensitivity.



Funksionele Aktiwiteite:

Emile kan homself uittrek maar nie aantrek nie. Hy sukkel om 'n kledingstuk oor sy kop te trek en kan ook nie sy arms in die moue steek nie. Emile neem baie lank om enige ding vir homself te doen. Sy ouers of ouma het nie altyd tyd om vir hom te wag om sy taak te voltooi nie, en dan doen hulle dit vir hom. Emile is baie lomp en val oor opjekte om hom. Emile kan nog nie sy neus blaas nie want hy hou nie daarvan nie. Emile het wel beheer oor sy toiletgewoontes.

Sensoriese Ontwikkeling en Taal.

Emile is uiters skaam en huil maklik. Hy is bang om uit te waag en voor ander 'n aktiwiteit uit te voer. Emile neem ook nie deel aan groepsaktiwiteite nie. Emile is stadig om aktiwiteite uit te voer. Emile kom tasdefensief voor - hy wil nie kaalvoet op gras loop nie en wil ook nie met sand speel nie. Emile se taal kan nie maklik gevolg word nie. Sy uitspraak is swak en hy gebruik nog babataal.

Figure 4.23: Report from the occupational therapist

When I was four years old, I started learn to swim. All the children went for swimming lessons at my day-care and my grandmother suggested that I should learn to swim as she knew that swimming would be beneficial for my muscle development. During the interview my grandmother said: "*The children swam on Thursday and Saturday afternoons, and I encouraged your parents to take you for swimming lessons".* Swimming was one of the few activities that I really enjoyed. Although I loved swimming, the water had to be the right temperature – not cold at all. My swimming lessons started in a heated pool at the age of three and a half years and continued until I was seven years old. My swimming coach, Beth, only worked with four children in a group, which suited me. Before the swimming lesson would start, she was already in the water, and waited for me. She first made me feel comfortable and discussed the purpose of the lesson. My first lessons consisted of breath control and body control in the water. Whilst I swam, my anxiety levels reduced and eventually my self-confidence improved.

Beth strengthened my muscle tone in the water. Swimming improved my co-ordination and strengthened my muscles. My body was lighter in water, I experienced freedom of movement, and this also led to an improvement in my motor development. The following certificate that I obtained (Figure 4.24) attests to my physical fitness levels, speed, endurance and strength which improved with every lesson.

Marcia's
SWIM
SCHOOL

Certificate

awarded to

EMILE GOUWS

on completion of the following courses

CROCODILE
Gold, Silver and Bronze
Jump into the water from the side of the pool, turn around and hold the pool edge
Swim 5 metres on tummy, using arms and legs
Pick up objects from bottom of pool
Leave pool unaided

SEAHORSE
Pick up object with open eyes, or;
Do a starfloat
Crocodile with face in the water and kick
Fall-and-turn technique

DOLPHIN
Glide and float
Swim 2-3 metres
Backfloat on the steps
Jump in shallow end
Sit on bottom and let water push you up

TADPOLE
Crawl kick with board
Swim 5-6 metres with breathing
Swim, turn on back and float
Tread water
Sitting dive
Jump off board, dressed

Date: MARCH 2001

ETSCTA

Figure 4.24: Certificate for completion of swimming courses

My mother was present at swimming lessons and noticed that I enjoyed it. She documented: “*Emile was like a fish in the water. Emile learned to swim at an early age and enjoyed swimming in hot water”.*

As my mother was a national athlete, she knew that my gross motor skills and balance would improve if I participated in sport activities. When I was old enough, she let me take tennis lessons and at the age of six, these lessons started.

My eye-hand co-ordination was under-developed when I played tennis. It was always a problem to catch the ball when the coach threw the ball to me. My muscles responded slowly; by the time I should have closed my hands to catch the ball, it had passed me. It was difficult to hold the racket firmly. I also attended play ball activities and through exposure my reaction time to catch a ball improved, but to follow the ball was a challenge. My concentration was intense when I followed the movement of the ball as it approached me. Today I know that my right eye is weaker than the left eye, and I could not see the ball approaching me from afar. I attended pottery classes to improve sensory sensitivity, as well as to strengthen the muscles in my hands and in my fingers. Pre-school presented compulsory pottery classes once a week and I was enrolled for lessons to improve the right brain activity.

When I was seven years old, my parents taught me how to ride a bicycle which had side balancing wheels in a relaxed atmosphere, where nobody observed my learning experience. They knew I would fall off the bike, and would not want spectators to observe, because I would feel embarrassed and would stop the learning experience if somebody looked at me. I had low muscle tone, and lacked the strength to ride a bicycle. But I could only strengthen my muscles if I did gross motor exercises. At first, I struggled to keep my balance on the bike and to keep pedalling the bike was problematic.

My mom kept explaining to me how to pedal and to keep my body posture straight whilst I was on the bike. I realised that if my posture was not straight, I would be off balance and I would fall. To keep direction and the handles of the bike straight was complicated. My mother explained to me if I kept the handles straight, the wheels would stay straight. It was not easy to sit straight on the bike, because when I started to pedal, I had to concentrate and it was a strain to keep my posture, concentrate on balancing, ride the bike and keep aware of the role my posture played. To learn to ride a bicycle took time. My parents took time to explain the components of the bicycle to me so that I could understand what the bike could do and what was expected of me. For some reason I could not see the big picture and it was vital to teach me step by step. Eventually I learned to ride a bicycle without side wheels.

CERTIFICATE

Little Potters

This certificate is awarded to :

Emile

for excellent participation during the

1999

Little Potters Course.

M. Steyn for Little Potters
Member of The Association of Potters of South Africa

Instructor Adele Kokt

Date 23/10/99

playball

CERTIFICATE OF ACCOMPLISHMENT

Awarded to

Emile Gouws

PLAYBALL is pleased and proud to award the PLAYBALLER this certificate in recognition for having accomplished the required ball skills.

HEAD COACH

PREPS

Hall
COACH

Figures 4.25 and 4.26: Certificates of my participation in pottery and playball

Another physical problem that I presented with was that my mouth always hung open, especially when I was focused on something. The speech therapist told my parents that some muscle problems are neurologically related and cannot be improved through speech therapy. My mother could never understand why my mouth was always open, while doing other activities. She remembers: "*Emile's mouth was always open. I constantly had to remind him to close his mouth. I always believed that through speech therapy, Emile's muscles in his mouth will become stronger and he will be able to close his mouth".* She further shared that children diagnosed with ASD disorder cannot focus on multiple tasks at the same time. To illustrate, she explained:" When *you were aware that your mouth was open, you were able to keep it closed because you were concentrating, but when you got distracted; your mouth will automatically open."* These weak muscles also influenced word production and pronunciation. The speech therapist remembers: *"The muscles in your mouth were not strong enough because of a neurological disorder. You were not able to close your mouth when you pronounced sounds such as 'R' because the muscles in your mouth were not strong enough to pronounce the letter".* The weak muscles in my mouth also resulted in bad eating habits. In order for the occupational therapist to identify this problem, she invited me to share a baked cookie with her. While I was eating, she continuously watched my jaw movements. I was never embarrassed to eat in front of her because she was such a kind lady. To strengthen these muscles, the speech therapist gave me exercises, such as drinking through a straw and sucking ice cubes. The occupational therapist also had to work on strengthening the muscles in my body. She recalls: *"It was extremely difficult for you to lift your arms, and to undress or to take off your jersey. I needed to strengthen your muscles so that you could be strong enough to perform these basic activities".*

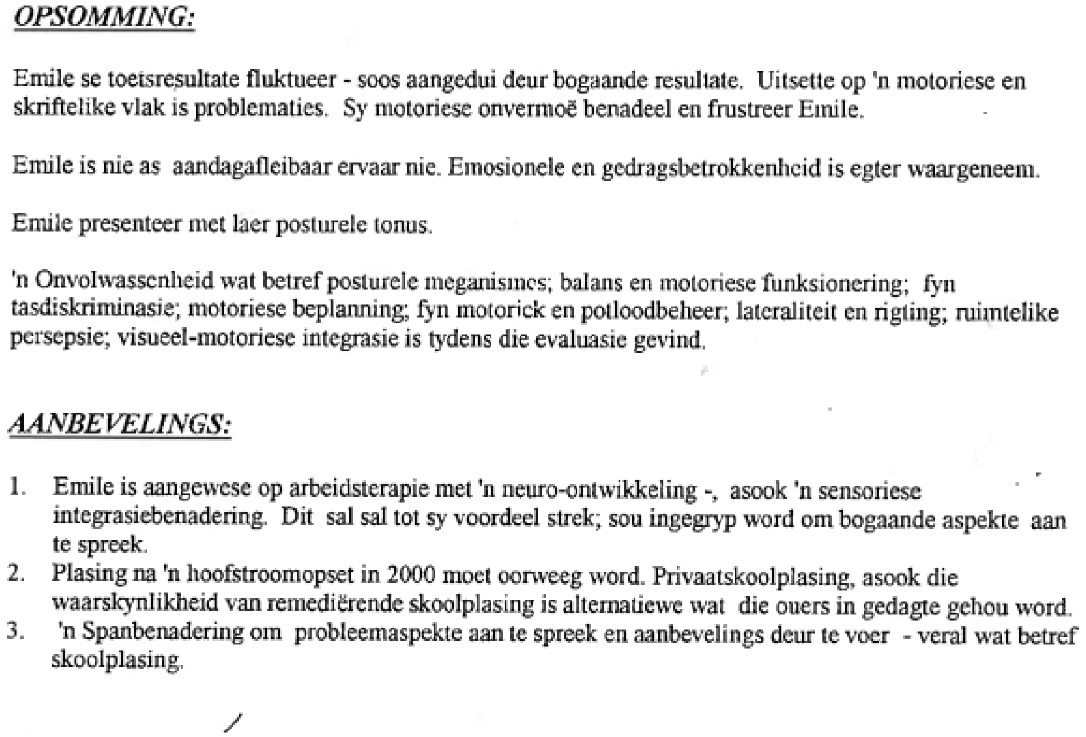
As my mother took me for therapy sessions, she was always present. She was involved in the therapy, as she had to do the prescribed exercises and activities with me at home. She remembers: "*I used to sit in the therapist room whilst she showed me what skills Emile acquired.* To strengthen my core, the occupational therapist assisted me when performing certain activities such as crawling and turning somersaults. My mother recalls her emotional experiences: *"I got tears in my eyes when Emile climbed in the air to slide down the 'foefie-slide', because I was told in the past that Emile will not be able to learn, and now a therapist proved that through exposure, it is possible for Emile to participate in activities. We proved the critics wrong".*

During therapy sessions, the occupational therapist did basic activities in a big therapy room to improve fine motor and gross motor skills. Activities consisted of catching and throwing bean bags or gym balls and I struggled to keep my balance. To improve my fine motor skills, the occupational therapist conducted activities to improve my low muscle tone. She was aware that my tempo was slow and I struggled to complete activities. During our interview she recalled: *"You received homework to improve your fine motor development. Living with ASD will always remain a challenge, but therapy taught you that you can improve your motor skills through exercises".*

During these sessions Miss Armanda, the occupational therapist, helped me to deal with sensory overloading in the classroom. After every therapeutic session with the occupational therapist, my self-esteem and self-confidence improved.

My parents tried their utmost to prepare me for primary school. Although the delay in my development was neurological, they believed in my abilities to learn and to improve my capabilities. Based on the following report from the occupational therapist (Figure 4.27) they decided to enroll me in a mainstream school. In this report the therapist lists all my challenges: immature postural mechanisms, balance and motor functioning, fine tactile discrimination, fine motor and pencil control, laterality and direction, special perception and visual-motor integration.

She then advised that I should go for occupational therapy with a neuro-development and a sensory-integration approach. At that stage she penned the magic words: *"Placement in a mainstream setup in 2000 should be considered".*



OPSOMMING:

Emile se toetsresultate fluktueer - soos aangedui deur bogaande resultate. Uitsette op 'n motoriese en skriftelike vlak is problematies. Sy motoriese onvermoë benadeel en frustreer Emile.

Emile is nie as aandagafleibaar ervaar nie. Emosionele en gedragsbetrokkenheid is egter waargeneem.

Emile presenteer met laer posturele tonus.

'n Onvolwassenheid wat betref posturele meganismes; balans en motoriese funksionering; fyn tasdiskriminasie; motoriese beplanning; fyn motoriek en potloodbeheer; lateraliteit en rigting; ruimtelike persepsie; visueel-motoriese integrasie is tydens die evaluasie gevind.

AANBEVELINGS:

1. Emile is aangewese op arbeidsterapie met 'n neuro-ontwikkeling -, asook 'n sensoriese integrasiebenadering. Dit sal sal tot sy voordeel strek; sou ingegryp word om bogaande aspekte aan te spreek.
2. Plasing na 'n hoofstroomopset in 2000 moet oorweeg word. Privaatskoolplasing, asook die waarskynlikheid van remediërende skoolplasing is alternatiewe wat die ouers in gedagte gehou word.
3. 'n Spanbenadering om probleemaspekte aan te spreek en aanbevelings deur te voer - veral wat betref skoolplasing.

Figure 4.27: Occupational therapist's report

My mother remembers: "*I knew it would be a risk to enroll you in a mainstream primary school, but I believed that this would be the place where you would be able to reach your full potential. I went to the library and took out a book: 'Remedial teaching in the primary school' written by M.C. Grove and H.M.A.M. Hauptfleisch. The two of us sat whenever I had a minute to spare and completed most of the perceptual exercises. Based on this information that was used and the Aquinas program, I prepared you for primary school".*

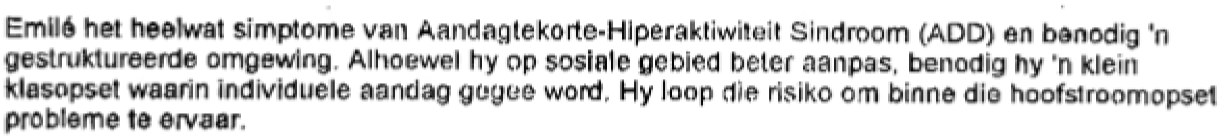
The next phase of my journey started – I was in primary school!

4.3 PRIMARY SCHOOL

"Your mother was your main supporter during your primary school years. Wasn't it for her, you would not have made it. She gave her life for you" (My grandmother).

At the age of six years, it was time for my parents to place me in primary school. A multi-disciplinary team conducted private comprehensive evaluation and therapy to prepare me for school. My mother documented her thoughts: "The *integration with broader society in a mainstream school will be a challenge for Emile but I believe that he will benefit from the learning experiences. My only concern is that Emile would be the only child on the autism spectrum".*

The psychologist, speech therapist and occupational therapist advised caution with school placement in a mainstream school. At an early age, certain warning signs flickered which suggested I would struggle in a mainstream setup. All the therapists agreed that the best would be placement in a small structured class setting where I could benefit from individual attention. An extract from a report (Figure 4.28) indicates their reservations.



Emilé het heelwat simptome van Aandagtekorte-Hiperaktiwiteit Sindroom (ADD) en benodig 'n gestruktureerde omgewing. Alhoewel hy op sosiale gebied beter aanpas, benodig hy 'n klein klasopset waarin individuele aandag gegee word. Hy loop die risiko om binne die hoofstroomopset probleme te ervaar.

Figure 4.28: An extract from a joint report by the therapists

My mother recalls:*"The risk of failing in a mainstream school was undeniable without support. When we enrolled you, I knew this would be a rough ride and that your success would be determined by the support you got. I knew homework would take time, because you were a slow worker, and you needed time to finish his work. As you were diagnosed with low muscle tone, writing would take longer. Expressing your thoughts would be a challenge but eventually you would arrive at the same understanding as other children".*

During our interview, my father related: *"I was relieved that we made the decision to place you in a mainstream school as I knew you had the potential to succeed and that the placement in the autism school would change your future forever. It was a risk to place you in a mainstream school, but it was worth taking because your support structures were strong".*

My mother knew that this decision would demand great sacrifice from her. She recalls: "*I was aware that the teachers wouldn't be able to modify the curriculum to meet your unique needs, but I decided to fill the gaps and to devote all my time to support you".*

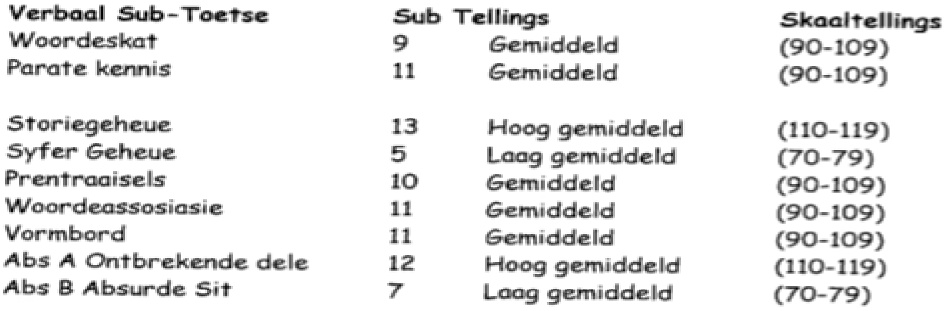
Notwithstanding the risk of mainstream schooling and the possible challenges I might experience within the different domains, the decision was made to afford me the same opportunities as neuro-typical children by giving the necessary educational support.

4.3.1 Cognitive domain

My parents decided to place me in a prominent mainstream school in our neighbourhood. On 14 January 2000, I joined the school with an enrolment of 800 children. My mother informed the teachers beforehand about my diagnosis and asked my class teacher to monitor my progress daily.

There were 22 children in the class, which I found overwhelming. I sat alone and I did not know how to interact with the children, who were all strangers.

On 11 July 2000 after six months in Grade 1, Mr. Williams the educational psychologist, conducted a Junior South African Individual Scales (JSAIS) as well as an Intelligence Quotient (IQ) to determine my cognitive abilities (Figure 4.29). In his subsequent report, he explained: "*One of the first tests that I usually conduct with children on the ASD spectrum is to test their cognitive abilities such as memory thinking and reasoning".* He noted that I faced challenges with mathematics and revealed attention deficit disorder (ADD) tendencies. Positive indicators were my vocabulary, general knowledge, story memory, visual discriminative and word association. The results provided my parents guidelines how to strengthen the weak areas.



Verbaal Sub-Toetse	Sub Tellings		Skaaltellings
Woordeskat	9	Gemiddeld	(90-109)
Parate kennis	11	Gemiddeld	(90-109)
Storiegeheue	13	Hoog gemiddeld	(110-119)
Syfer Geheue	5	Laag gemiddeld	(70-79)
Prentraaisels	10	Gemiddeld	(90-109)
Woordeassosiasie	11	Gemiddeld	(90-109)
Vormbord	11	Gemiddeld	(90-109)
Abs A Ontbrekende dele	12	Hoog gemiddeld	(110-119)
Abs B Absurde Sit	7	Laag gemiddeld	(70-79)

Figure 4.29: IQ test results

My story memory tested high because I had been read numerous stories before I went to school. My vocabulary improved through reading, although it was difficult to speak. When I was in Grade 1, my mother continued to strengthen my reading abilities. When my peers learned to read in class, I could relax as it was a skill I had already mastered with the help of my mother.

During my Grade 1, the multi-disciplinary therapy team decided that it was time to quit the therapy. The occupational therapist felt I had reached a plateau and needed to rest; the speech therapist was satisfied with the improvement in my pronunciation. The educational therapist was satisfied with the support that my mother rendered and felt that I should focus on my school career. My mother was relieved and she recalls*:"I realised that all the different types of therapy took time, and we decided that Emile must spend his time in the afternoon on homework and activities at school like tennis, swimming, playing chess and rugby".*

So every afternoon after my homework was done, my mother and I worked through the Aquinas educational program which stimulated me visually through pictures and aurally through sound. My only challenge was having to read in front of the other children. It made me nervous and I stuttered. In the Grade 2 report card (Figure 4.30) the teacher mentioned that I can construct good sentences and make only a few spelling mistakes. She comments on my good readings skills and how speech therapy contributes to my literacy.

Geletterdheid

Assesseer leerder ten opsigte van sy/haar vaardighede, waardes en kennis	Nog nie bemeester	Gedeeltelik bemeester	Bemeester	Goed	Baie goed
▪ Luister			✓		
▪ Mondelinge kommunikasie				✓	
▪ Skriftelike kommunikasie			✓		
▪ Leesvaardigheid				✓	
▪ Herkenning van klanke			✓		
▪ Spelling			✓		

Opmerkings : Emile kan goeie sinne maak, met min spelfoute. Hy geniet dit om te lees en kan die leesboekies goed lees. Hy ondergaan spraakterapie, wat 'n baie positiewe bydrae lewer tot sy Geletterdheid.

Figure 4.30: Teacher's remark regarding my reading abilities

However**,** my tempo remained a challenge and the same teacher reported on the incompleteness of my working cards and assignments (Figure 4.31).

Gesyferdheid

Assesseer leerder ten opsigte van sy/haar vaardighede, waardes en kennis	Nog nie bemeester	Gedeeltelik bemeester	Bemeester	Goed	Baie goed
▪ Getalbewerking				✓	
▪ Opbreek van getalle				✓	
▪ Rond af tot naaste 10				✓	
▪ Spreikaarte (245 = 200 + 40 + 5)					✓
▪ Woordprobleme				✓	

Opmerkings : Werk steeds stadig en voltooi meestal nie werkkaarte nie. Behaal egter gewoonlik sukses met dit wat hy voltooi

Geletterdheid

Figure 4.31: Grade two teacher's report

In Grade 3 a certificate was awarded to me for the most books read (Figure 4.32).

Sertifikaat van Verdienste

Geletterdheidsweek
16—20 September 2002

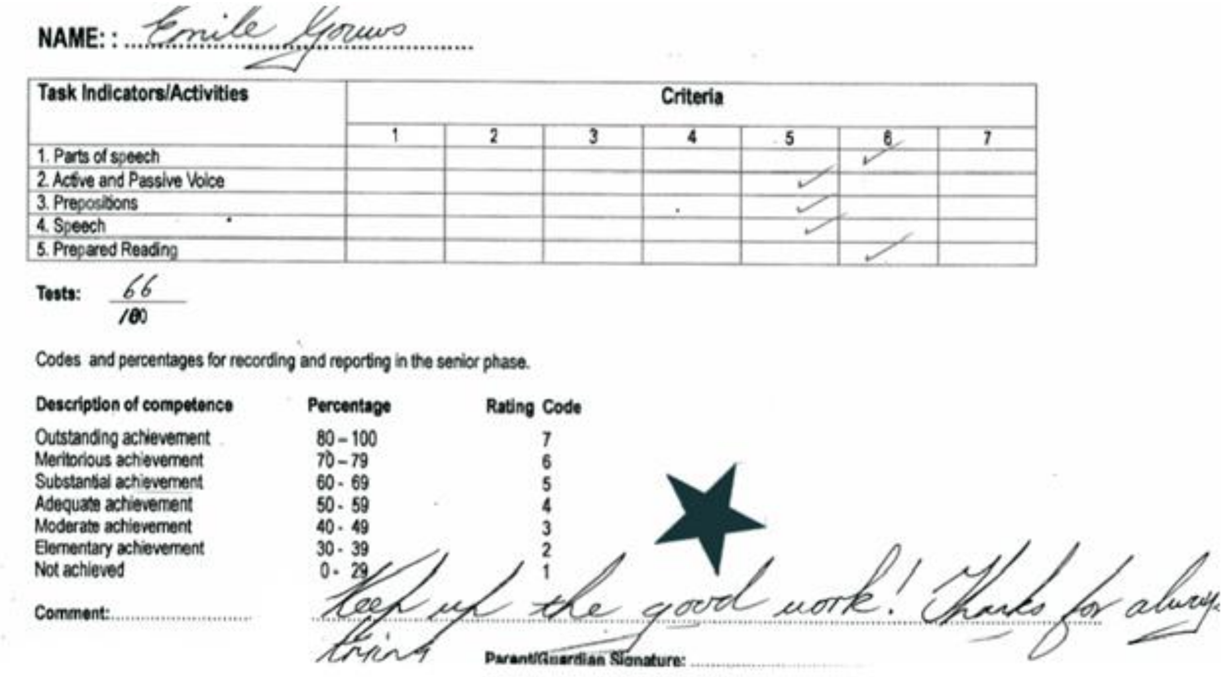
Sertifikaat toegeken aan :

EMILE GOUWS

Vir die meeste boeke gelees in Graad 3.2

Figure 4.32: Certificate for the best performance in literacy and numeracy

In Grade 4, I started reading English books on rugby, as it was my special interest. My mother bought rugby books and magazines and I started to improve my English vocabulary and could read English books with ease. The reading of English books benefitted my academic performance in English first additional language in the intermediate and senior phase, as indicated in the following school report (Figure 4.33):



NAME: : Emile Gouws

Task Indicators/Activities	Criteria						
	1	2	3	4	5	6	7
1. Parts of speech						✓	
2. Active and Passive Voice					✓		
3. Prepositions					✓		
4. Speech					✓		
5. Prepared Reading						✓	

Tests: 66 /100

Codes and percentages for recording and reporting in the senior phase.

Description of competence	Percentage	Rating Code
Outstanding achievement	80 – 100	7
Meritorious achievement	70 – 79	6
Substantial achievement	60 - 69	5
Adequate achievement	50 - 59	4
Moderate achievement	40 - 49	3
Elementary achievement	30 - 39	2
Not achieved	0 - 29	1

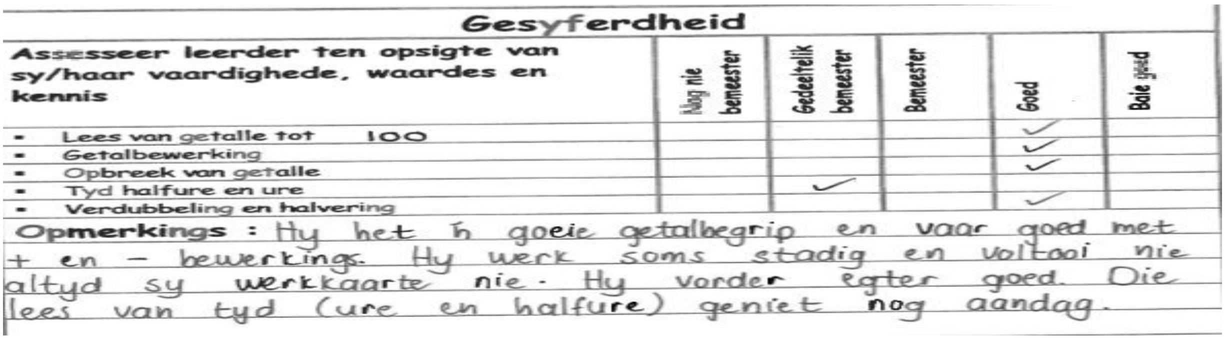
Comment: Keep up the good work! Thanks for always trying

Parent/Guardian Signature:

Figure 4.33: The Grade 7 English teacher acknowledged my good performance in English first additional language

Through reading my general knowledge improved and I enjoyed sharing my insights with my parents. I could also retrieve information accurately and was able to recall various facts quite easily. Yet some challenges remained: my communication skills remained limited. The speech therapist ascribed this my early exposure to more than one language. Code switching occurred when I was staying at my grandmother's as all the other children were English-speaking.

I still needed more time to process information and putting my thoughts on paper was very time consuming as I had to plan and organise information; in other words, my work tempo remained very slow. Because of this problem, mathematics remained problematic, as I could not finish work in time (Figure 4.34 and 4.35) and my mother resorted to extra classes.

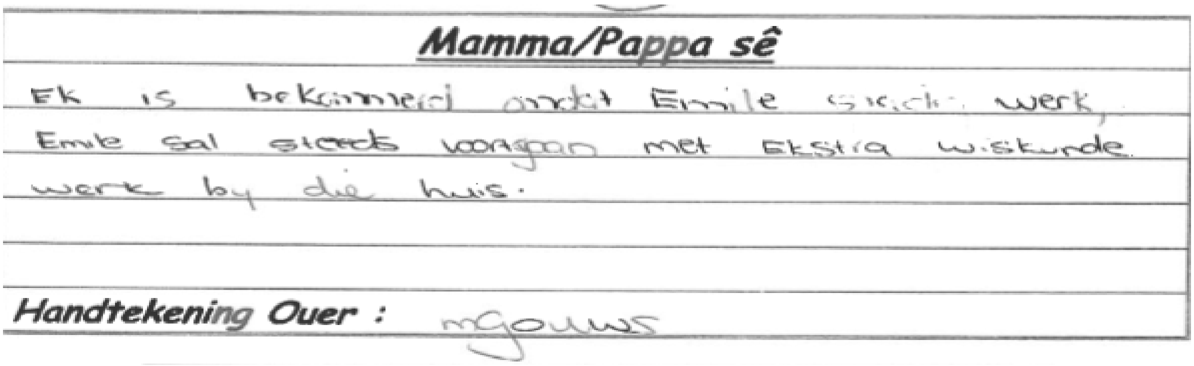


Gesyferdheid

Assesseer leerder ten opsigte van sy/haar vaardighede, waardes en kennis	Nog nie bemeester	Gedeeltelik bemeester	Bemeester	Goed	Baie goed
• Lees van getalle tot 100				✓	
• Getalbewerking				✓	
• Opbreek van getalle				✓	
• Tyd halfure en ure		✓			
• Verdubbeling en halvering				✓	

Opmerkings : Hy het 'n goeie getalbegrip en vaar goed met + en – bewerkings. Hy werk soms stadig en voltooi nie altyd sy werkkaarte nie. Hy vorder egter goed. Die lees van tyd (ure en halfure) geniet nog aandag.

Figure 4.34: The teacher's remark about my slow working tempo and lack of task completion



Mamma/Pappa sê

Ek is bekommerd omdat Emile stadig werk, Emile sal steeds voortgaan met ekstra wiskunde werk by die huis.

Handtekening Ouer : mGouws

Figure 4.35: My mother's comment about my slow tempo and assurance of the continuance of extra math's lessons

My cousin (Grade 12) offered to assist me with mathematic lessons, but this did not last as he was very strict and did not grasp my challenges. A private maths teacher was appointed to assist me.

As from Grade 4, I began to struggle academically. The teachers did not have time to repeat the work in class anymore and we started to write tests. My mother could not apply for extra time to complete work during examinations, because it was not offered in mainstream schooling. I did not have enough time to finish my tests and was penalised. During examinations while we studied and when both my mother and I were tired, a spark of hope would suddenly occur when I would recall work stored in my long-term memory.

I learned best when I could visualise my work, because my brain processed information faster when I saw pictures. Although I knew my work while writing a test, during examinations I would finish last in class. I was concerned that I could not even finish a simple exam paper even if I was properly prepared. I discovered that I did not break information down and wrote everything down that I had learned. I was never unprepared for a test. I just found it a challenge to narrow the required information down and to present the essence.

In Grade 5,I experienced difficulties in coping with the workload and processing information. In the afternoons my mother invested time to explain work to me in different ways. She ensured that I completed the work we did in the class, and redid incorrect work. During these difficult times my mom was the only person who communicated with me daily about the challenges I faced in the classroom. My mother assisted me through visual stimulation, while the teachers focused on auditive methods. Although two different learning styles were used, I managed to learn from both.

These afternoon sessions were time-consuming. While the teachers presented the big picture in class, my mother broke down the work in segments and together we then tried to put the pieces together again so that I could understand the bigger picture.

From Grade 5 to 7, I felt I was drowning in activities. Due to overstimulation at home and in the classroom, I could not pay attention in class. I was unable to give my mother the correct information regarding school work and assignments I needed to do. My attention span was fragmented and I struggled to follow instructions. My marks decreased due to the difficulty and volume of home and class work.

We also then started with more advanced projects and had to visit the library as some homework needed research. My mother devised a very helpful working schedule. With every project she made sure that an evaluation sheet was produced that explained how the work will be assessed and planned our schedule accordingly. She overcame the overload of homework by consistently planning and organising my suitcase and diary daily. She had faith in me and knew that I had the potential to do something if I understood the expectations. I just needed enough time to prepare assignments, class work and tests. My routine in the afternoon led to sustainability of schoolwork. The discipline gave me emotionally security, and I learned to do problem solving in a structured environment.

My mother was forced to make appointments with the teachers in order to find out what homework I received. She always discussed my progress with the teachers in class. She remembers:"*I visited the school daily because your academic success depended on the collaboration of the teachers and on the support in the afternoons".*

My mother furthermore explains her involvement: *"It was tiring to assist you on an individual basis in the afternoons, as our sessions were very intensive. I had to repeat information numerous times, and never corrected you, and did not educate you through* *correction".* Thus, she avoided arguments by showing me what was wrong; instead she followed an approach where she presented the mistake as a problem that had to be solved. Her aim was to support me so that I could learn to solve problems independently.

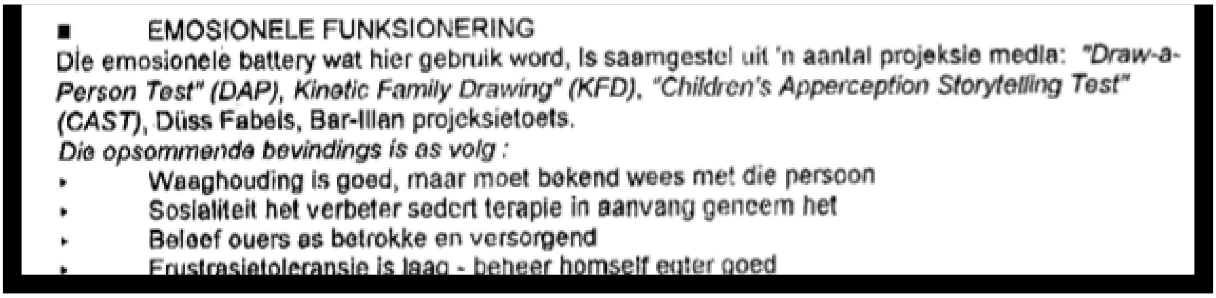
For my mother it was a difficult path. She wrote in her book*: "I was always the only one who did the talking, and I told myself that even though he did not verbally respond, at least he listened. Emile never complained – although he worked hard during the day at school, his afternoons were also packed with learning activities, and he never let me, or himself down'.*

My mother devoted all her free time to me. My father did not really feature in my life during this stage. He remembers: *"I was not involved during this specific time frame. I knew your mother would assist you in the afternoons and evenings". I trusted your mother to be there for you."*My brother was always present as a silent observer during these learning experiences. In this way he also learned and mastered some key content which benefitted him academically. During our interview he admitted*: "I could not believe that you struggled with homework that seemed so easy".* My brother knew that I needed assistance with basic planning and breaking work into easier pieces. He ended our one conversation with the comment: *"Mom devoted her life to assist you".*

Hard work became a life style and my mother studied with me and made sure that I could reach all the outcomes. We studied late at nights or even early in the morning. My mother added:*"A critical point of view will be that my child was supposed to play and not to do homework day in and day out".* The overcrowded classrooms and the inability of the educators to give me individual attention remained a challenge during my primary school years and greatly impacted my emotional experiences.

4.3.2 Emotional domain

Before commencing with my school career, the educational psychologist, Mr Williams, evaluated me once again by making use of the Draw-a-Person test (DAP), the Kinetic Family Drawing (KFD) and the Children's Apperception Storytelling Test (CAST). His report (Figure 4.36) mentions that I tend to explore when knowing the person, my social skills have improved since the start of therapy, and that my self-control is good, even though my frustration tolerance is low. He also remarked that my parents are involved and caring. In the second part of the report (Figure 4.37), regarding my emotional disposition, Mr Williams remarks that I am at ease and get quite excited. He also mentioned my tendency to be impulsive and to interrupt myself.



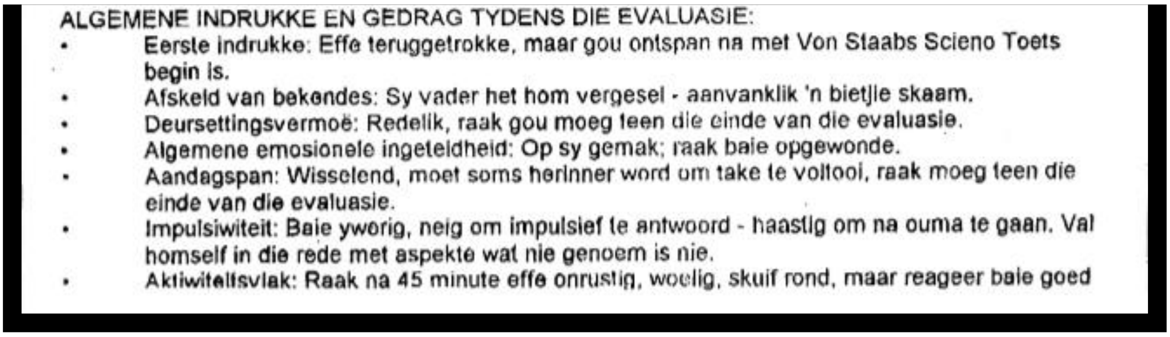
■ EMOSIONELE FUNKSIONERING

Die emosionele battery wat hier gebruik word, is saamgestel uit 'n aantal projeksie media: *"Draw-a-Person Test" (DAP), Kinetic Family Drawing" (KFD), "Children's Apperception Storytelling Test" (CAST)*, Düss Fabels, Bar-Illan projeksietoets.

Die opsommende bevindings is as volg :

- Waaghouding is goed, maar moet bekend wees met die persoon
- Sosialiteit het verbeter sedert terapie in aanvang geneem het
- Beleef ouers as betrokke en versorgend
- Frustrasietoleransie is laag - beheer homself egter goed

Figure 4.36: Findings from the educational psychologist regarding my emotional functioning



ALGEMENE INDRUKKE EN GEDRAG TYDENS DIE EVALUASIE:

- Eerste indrukke: Effe teruggetrokke, maar gou ontspan na met Von Staabs Scieno Toets begin is.
- Afskeid van bekendes: Sy vader het hom vergesel - aanvanklik 'n bietjie skaam.
- Deursettingsvermoë: Redelik, raak gou moeg teen die einde van die evaluasie.
- Algemene emosionele ingesteldheid: Op sy gemak; raak baie opgewonde.
- Aandagspan: Wisselend, moet soms herinner word om take te voltooi, raak moeg teen die einde van die evaluasie.
- Impulsiwiteit: Baie ywerig, neig om impulsief te antwoord - haastig om na ouma te gaan. Val homself in die rede met aspekte wat nie genoem is nie.
- Aktiwiteitsvlak: Raak na 45 minute effe onrustig, woelig, skuif rond, maar reageer baie goed

Figure 4.37: Educational psychologist’s general impressions regarding my behaviour

This report indicated to my parents where I still needed help. My mother remembers: *“This report confirmed that I was making the right decision to enroll you in a main stream school. I believed that you had to be exposed to more challenging environments as I had faith in your ability to adapt to any environment, notwithstanding your diagnosis”.* My mother also specifically mentioned that she always told herself that she would remove me from a situation if I indicated that I could not cope or was unhappy.

But determining my emotional wellbeing was difficult. My mother recalls:”*After your first day at school I asked you about your day and I was concerned when you only showed me the drawings that you made in class. Emotionless you sat in the car, and could not tell me about your day. Your behaviour saddened me, and I once again realised our journey would be different from other families with neuro-typical children”.*

The first three months at school were emotionally challenging. In the classroom the learners realised my behaviour was odd and did not want to associate with me. I kept to myself and tried to blend in. I was quiet in class and stayed out of trouble. From Grade 1 to 3 the school made use of a demerit system that rewarded learners with merits for good behaviour and demerits for unacceptable behaviour. In Grade 4 I benefited from the merit system as shown in Figure 4.38 whereby I was rewarded for my good behaviour in the classroom.

Toegeken aan :

Emile Gouws

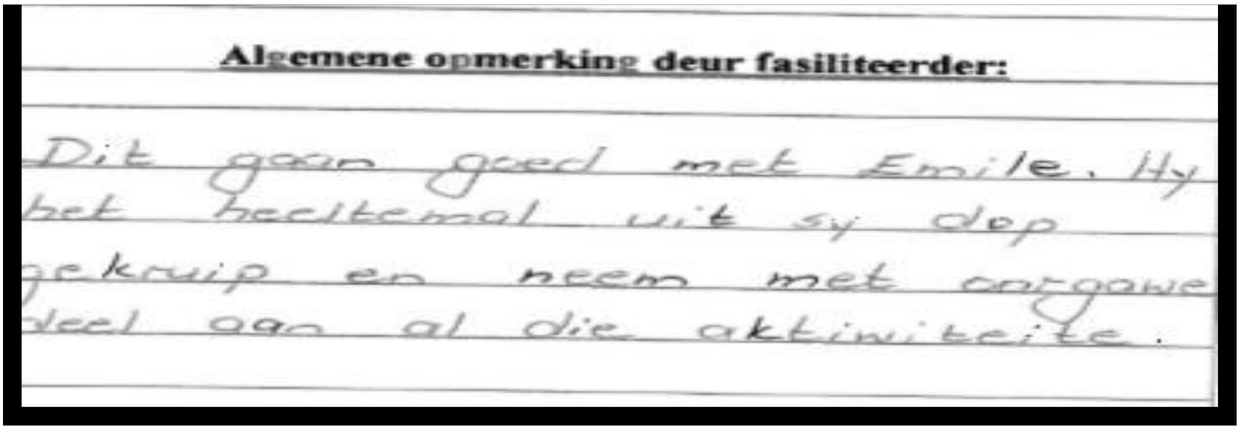
Vyfster Leerder

Vir : 50 Merietes

29/8/03
Datum :

Figure 4.38: Certificate for achieving 50 merits

Due to exposure my behaviour changed at school. The Grade 4 teacher (Figure 4.39) mentioned that I was not so shy and withdrawn anymore and that I wholeheartedly participated in all the activities. This feedback also encouraged my mother and she wrote: “*When I received positive feedback from the teacher, it gave me strength to keep Emile in a mainstream school”.*

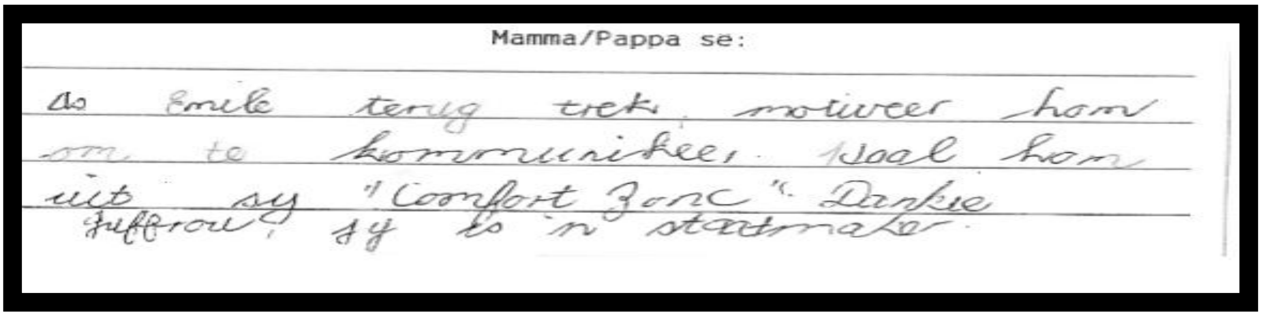


Algemene opmerking deur fasiliteerder:

Dit gaan goed met Emile. Hy het heeltemal uit sy dop gekruip en neem met oorgawe deel aan al die aktiwiteite.

Figure 4.39: Grade 4 report

Being aware that I was the only autistic learner in the school, my mother was always concerned about my emotional wellbeing. She documented her concerns:"*In a mainstream setup the teachers do not promote ASD awareness. Emile was placed in a school system that is not autism friendly. Children from different backgrounds attend the school and they do not know that Emile is on the spectrum, they don't even know what the word autism means. It was my responsibility to make sure that even the teachers were aware of the possible stressors that can affect Emile's behaviour".* My mother constantly reminded the teachers to encourage me to participate and draw me out of my comfort zone (Figure 4. 40).



Mamma/Pappa se:

As Emile terug trek, motiveer hom
om te kommunikeer. Haal hom
uit sy "Comfort Zone". Dankie
Juffrou! Sy is 'n staatmaker.

Figure 4.40: My mother's advice to the Grade 3 teacher

Autism did not only affect my behaviour negatively, but also how I responded to challenges. In Grade 5, due to the increase in workload, I retaliated by withholding important information from my mother, such as submission dates of assignments and tests. My mother had to rely on information from the teachers to prepare me in time.

My mother expressed her frustration as follows: *"When Emile withheld the test dates, or didn't tell me about homework, it affected our time management. During these times we had to work in the evenings to catch up. It made me angry, as I felt this was all Emile's fault - he could have prevented it. Emile on the other hand believed that I was unreasonable when we had to work late".*

In the classroom I struggled with work. Easy practical activities which had to be done in class were difficult to complete. I felt I was in a wormhole and I needed to escape. I needed to do something in order to decrease the pressure. My coping skills collapsed, and I tried to avoid class work. The only solution that I thought of was to throw my books away. I also decided not to answer any questions anymore, and only responded by an outright 'yes' or 'no'. In the process I did not bring homework home, because there were no books.

I told my mother that my books were at school; after a while my mother decided to investigate and when contacting the teachers, they told her that the books were with me. My mother was devastated, as she felt that her hard work and sacrifice were in vain. She documented: *“I was shocked when I discovered that Emile rebelled against any form of school work. Although we have established a predictable and stable learning routine in the afternoons and some evenings, I found it so sad that our system of learning had now collapsed and Emile chose to shut it down. I suppose it was just a matter of time for him to rebel against homework because the pressure was too much. As a result, his marks deteriorated and he was at risk to fail Grade 5”.*

My mother then realised that the demands of a mainstream school were too severe and she knew it was time to place me in a remedial school. It is important to note she had already applied for remedial placement when I was in Grade 1, since she did not know whether I would cope in the mainstream school. Placement was denied every year and I was on a “waiting list”. When she became desperate and approached the headmaster of the remedial school once again for placement, he recommended that she applied for application at a school in another district. My mother then decided that I had to remain in the mainstream school and adapted her approach. She went to the school daily to collect homework. When she spoke to the headmaster and deputy headmaster about my marks, they assured her that I was not at risk because with my overall marks would enable me to pass. She then realised that she couldn’t rely on me to give her the necessary information anymore and took the responsibility for my progress in school.

My father could not comprehend why I threw my books away and why I refused to work anymore. When he interrogated me, I could not explain my reasons to him. It was always difficult to explain or talk to him about my challenges as he never was involved in my academic career. He remembers: *“I was shocked when I heard that you threw your books away. You had no reason to do that, because you had the support from your mother. She was always there for you, assisting you in the afternoons and evenings – and then you did this!”*

Due to the stressors at school and the fact that I did not cope, my hand gestures increased. Although I tried to restrict this socially unacceptable behaviour, I found it impossible. This was my way of unwinding and it helped me to feel better and more relaxed. I knew that the children were talking behind my back and staring at me all the time, so in order to avoid further discrimination, I would isolate myself and could then resort to the hand flapping movements. My mother wrote in her book: *“At first I did not understand Emile’s hand gestures but in time I realised this ritual won’t stop, and I must try to understand why he portrays this behaviour. It is only my child in the family that behaved in this way, and I told him that people do not understand his nonverbal behaviour and he must not display it in public”.*

In the classroom, when I wanted to release the pressure, I would play with any object, such as a pen. I tried to control my movements, so the hand movements were not so obvious, and the teachers did not notice anything peculiar. This ‘mosaic’ hand movements represented my emotional state. My mother understood the implications of my behaviour. In her book, she related:”*Emile learned to cope with stress by venturing into his own world. I know the longer he stayed there, the more he lags behind. During these rituals he misses out on learning experiences. If only Emile would replace hand gestures with communication because I don’t completely understand what he wants to express by this non-verbal language and it is a lonely world for Emile”.* I also found another way to express my emotional distress - by self-mutilating behaviour. I started scratching myself to such a degree that I was literally covered in wounds. My mother again encouraged me to express my emotions verbally and not to hurt myself. She also made me aware that this sort of behaviour was disturbing and socially unacceptable. My father was aware of my behaviour but did not reprimand or coach me because he did not know how to deal with my mood swings. My father remembers:” *I did not know how to handle it and I knew it was part of the autism diagnoses. It only happened when you were tense. It was not a pretty sight to witness it but throughout the years I got used to this sort of behaviour”.*

Today I know I was a continuous target for bullying, because I could not stand up for myself nor did I report incidents of bulling until I got hurt. I was therefore an easy target and never reacted when I was approached and called names like “Retard”. I noticed that the certain learners talked about my behaviour behind my back. During these incidents I would turn around and walk away.

One day I got injured on the playground. A boy on the playground pretended to hit me, and I got a fright, tried to get away, fell and broke my wrist. In her book, my mother expressed her feelings: “*When I picked Emile up at school I was angry when I saw him in tears, and saw that his wrist was broken. I heard what happened and lashed out at the headmaster,* *and requested an investigation. We went to see a specialist and I knew that they were going to operate. While Emile and I waited for the operation, my heart broke when Emile started to cry and asked me: 'Mom why does this happen to me and not to other children'? It was the first time ever that Emile expressed his emotions of despair and sadness"*. After the incident I was afraid to go back to school.

As my mother recalls*:" You never told me what happened at school. I assumed you were happy. I visited the school daily and the teachers never told me that you were a victim of emotional abuse, and now physical abuse.*

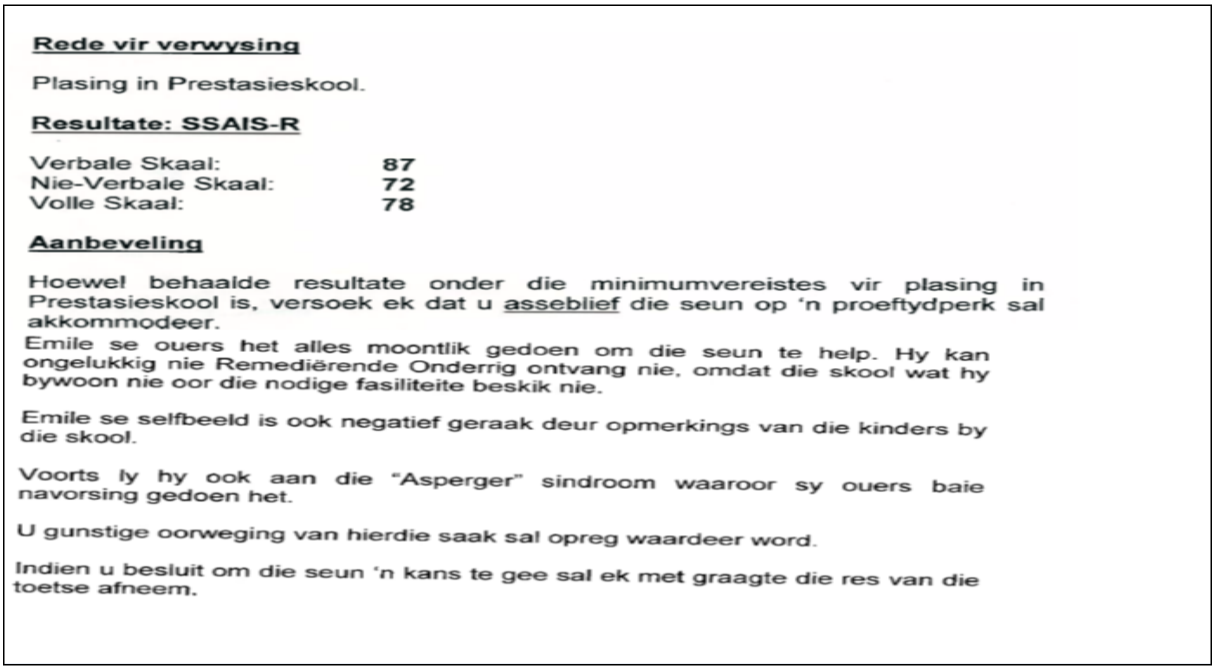
My parents were not aware to what extent I was bullied, because I did not speak about what happened at school. When we did group work in class, the teachers selected the groups and I was always placed with strong learners. But when we as learners could choose the groups, I was always included with the bullies and the academically weak. During these group discussions bullies targeted me and made inappropriate comments when the teacher was out of sight. I endured humiliating remarks and could not defend myself as I did not have the social skills.

My brother was a frequent top achiever in academics and sport and was one of the top athletes in South Africa. My mother assisted him with training for eight years, with the support of a prominent South African coach. For two consecutive years he came second in the South African Championships for sprinting. He was also a brilliant rugby player. The acceptance and acknowledgment that he received and the popularity that he enjoyed in school were overwhelming. The teachers and learners were always shocked to hear that I was a sibling of Ruan Gouws.

As my brother was the proverbial golden boy, he could never understand, nor empathise with my challenges. He could not understand that I was not responsible for my diagnosis and that these limitations affected every domain of my life. We never shared common goals, nor interests, because our learning experiences and personalities were totally different. During our interview, my brother remarked: *"When I was younger I didn't understand why your behaviour was so different from the rest of your peer group. I noticed that his behaviour would change in an instant in an overpopulated environment such as an athletics meeting, shopping centres or even at a big sports event. Then you would change from a cool, calm and collected person to a frustrated, aggressive person who would rant and rave.* My mom added:*"I know it was difficult for Ruan to see this kind of behaviour, and*

I also think he saw the amount of time I had to spend with Emile, and he therefore he tended to blame Emile subconsciously. I tried to make it up to him, by supporting him with his athletics".

Grade 6 was a critical time in my school career and my mother decided to evaluate me again for high school placement. In lieu of the bullying incidents and due to my academic struggles, my mother asked an education psychologist to evaluate me and to make recommendations for placement in a suitable high school. The psychologist recommended that I should be placed in a remedial school for the duration of my high school career (Figure 4.41) as there would be fewer learners and greater emotional security. As the test results she conducted to support me, my applications were not low enough for placement in a remedial school, she applied for placement and mentioned that I was negatively affected by the learners' remarks, I had Asperger's syndrome and the school did not have the necessary facilities to support me. She also mentioned that my parents did everything in their power to support me.



Rede vir verwysing

Plasing in Prestasieskool.

Resultate: SSAIS-R

Verbale Skaal: **87**
Nie-Verbale Skaal: **72**
Volle Skaal: **78**

Aanbeveling

Hoewel behaalde resultate onder die minimumvereistes vir plasing in Prestasieskool is, versoek ek dat u asseblief die seun op 'n proeftydperk sal akkommodeer.

Emile se ouers het alles moontlik gedoen om die seun te help. Hy kan ongelukkig nie Remediërende Onderrig ontvang nie, omdat die skool wat hy bywoon nie oor die nodige fasiliteite beskik nie.

Emile se selfbeeld is ook negatief geraak deur opmerkings van die kinders by die skool.

Voorts ly hy ook aan die "Asperger" sindroom waaroor sy ouers baie navorsing gedoen het.

U gunstige oorweging van hierdie saak sal opreg waardeer word.

Indien u besluit om die seun 'n kans te gee sal ek met graagte die res van die toetse afneem.

Figure 4.41: Psychologist evaluation test results for remedial school placement

Looking back, I realise that the area where my challenges really manifested was socially.

4.3.3 Social domain

Socially I struggled to adapt to what other people would consider natural social situations. Social skills were difficult to internalise as they did not come naturally to me but through constant exposure, my social skills improved. My parents created opportunities to so that I could socialise and form friendships. In her book my mother noted: *"It was revealing to me to see how different from other children Emile acted in a social environment, as he deliberately withdrew from any interaction with other children. Although we constantly exposed Emile to new environments he continued to portray behaviour of resistance in busy places where he refrained from making eye contact with people, or speak to them. When we got home, where I knew Emile would be at ease, I worked on his behaviour. I wanted to change his theory of mind whereby I encouraged him to take risks, and speak to people. I would stop in front of a shop and encourage him to enter the shop to buy milk or bread on his own".*

From the first day in Grade 1, one of my biggest challenges was to learn to adapt in a busy environment that changed constantly. I never told my mother that she placed me in an unfriendly environment because I did not want to disappoint her. It was difficult to form friendships with newcomers because it was not a natural response. According to the following progress report (Figure 4.42), the teacher commented on the fact that I get along with other children and that I am a "pleasant" boy.

My juffrou sê

Emile kom goed met sy maats oor die weg. Hy is 'n aangename seun. Sy stryfbenodigdhede lê nog net oorale rond, maar sy organisasie verbeter. Hy het potensiaal.

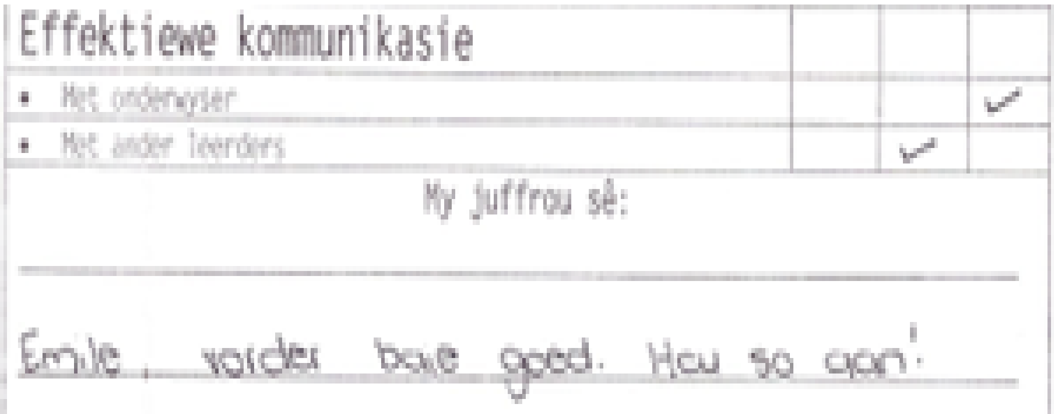
Handtekening Onderwyser :

Handtekening Hoof :

Figure 4.42: Progress report from Grade 1 educator

I didn't have any friends though. The children, who attended the same pre-school as I did, avoided me and did not want to play with me. My mother confirmed: "*When I picked Emile in the afternoons it was sad to see that he did not introduce me to any friends, nor did he tell me about his day".*

I realised that the children’s social skills were more developed than mine. They spoke spontaneously with one another, but I preferred to interact with children individually, as I found it difficult to socialise in a group. I realise that my behaviour also scared them, as I never knew what to say during a conversation and I also felt that when I tried to speak to them, they would respond with a short answer, turn around and walk away. In Grade 2 the teacher noticed an improvement in interaction with the learners as well as my expressive language (Figure 4.43).



Effektiewe kommunikasie			
• Met onderwyser			✓
• Met ander leerders		✓	

My juffrou sê:

Emile, vorder baie goed. Hou so aan!

Figure 4.43: Grade 2 teacher’s remark

As mentioned earlier, I suffered from selective blindness and at school I was the only learner that could not see the eyes of the other children. It was difficult to discern between the learners, but I managed to distinguish them by the name tags on their chests and school bags because my mother taught me to read before I enrolled into primary school. As I felt more at home, the blindness subsided, and I could discern faces. My mother never understood why I didn’t make eye contact with people since I did not tell her that I was incapable of seeing other people’s faces and specifically their eyes when I was in an over-stimulating environment. I learned to cope with all the children when we moved to our next classes. I would walk close to the wall, and merely turn my head to the side when I got anxious.

At school the playground activities were not structured to accommodate my needs. My brother witnessed that I was alone on the playground. During our interview he said: *“I did not understand why you could not make any friends at school. I never saw you speaking to anyone. At home it was the same and you hardly played with me I always invited friends over to play with because the activities that brothers usually do together were absent.”*

From Grade 4 I participated in cultural activities whereby I had to deliver a speech in front of the children. Although I tried my best, the class did not understand how difficult it was for me to speak because speech delay and echolalia (repetition of words) occurred. It did not matter how well-prepared I was, I always made mistakes.

During our interview my mother said*: "I always made sure that you were very well-prepared for your speeches, as I knew you would be less stressed. Speaking in front of other people was something that I encouraged, even if it was difficult for you. That was a sure way that I knew would help you to overcome your social isolation*". Other methods that my mother used to "force" me to speak and to express my needs as the following*: "At a restaurant I would motivate Emile to order his own food. Even though he did not make eye contact with the waiters, I felt that it was important for him to develop his social skills and to discover his own 'voice'".*

My father admitted: *"I was always aware that Emile struggled to pronounce certain words and I believed that it affected his communication with other people. When I tried to talk to Emile, he would ignore me, or just could not respond to my questions. I began to realise that it became a regular pattern for Emile not to communicate to me".*

In order to help me improve my social skills, my parents created opportunities for me to participate in private extra-mural activities where I played chess, took swimming and tennis lessons. During holidays the tennis coach arranged mini -tournaments for all the children she coached, but because it was difficult for me to interact with children of my own age, I was put in a group with children five years younger than me. The parents complained and my mother then stopped the lessons.

At school I participated in the revue in Grade 2 and 5. I desperately wanted to participate and realised that once I was on the stage, I wouldn't be able to leave. I pushed through and enjoyed the six performances per year. In Grade 5, a day before the performance started, I ruptured my Achilles tendon and my leg was in plaster for 12 weeks. My parents carried me onto the stage every night, and my mother also supported me in this regard. She remarked: *"While Emile was in plaster I took him to his classes in the morning and asked the teachers to assist Emile during the day and they ensured me that they will look after him. When I fetched him in the afternoons I carried his suitcase. When his plaster was removed I took him to the physiotherapist whereby he started to walk slowly. Emile* *never complained once to me about the incident".* Participating in the revue promoted my self-confidence and social skills.

My brother participated in athletics, and we visited athletic stadiums before the races to familiarise myself with the surroundings. Before the Gauteng and South African championships my parents separated Ruan and me, because I was too anxious. I would stay with my father, while my mom took my brother to the warm-up area. I remember once, when we arrived at the Ruimsig stadium for Gauteng Championships, I got nervous when I saw the crowd. Before we entered the pavilion, I left my mother's hand, and started running because I wanted to get away from the crowd. That day she learned to pay special attention to my behaviour in unfamiliar surroundings. My mother added:*"National championships were always the most premium school's athletic event of the year. All the best athletes from across the different provinces would compete. It was a highly anticipated event, and we felt that Emile must experience it. We made some modifications to accommodate Emile's needs whereby we would sit in a place that was not so busy, from where Emile could observe the races".*

In Grade 6 I was nominated to attend a leader's camp for two days. I didn't want to go, as I was afraid I would get hurt. The aim of the camp was to identify and select the prefects for the following year. My mother persuaded me to go. The camp was competitive and the Grade 6 learners' leadership abilities were assessed. I knew what the expectations were and made sure to participate in all the different activities. My mother wrote: "*When Emile came home, he did not utter a word. The teachers told me that the children wrestled in the mud, and at night were awake, and according to their observation, Emile was having fun".* The next day a teacher confided in my mother that at the identification camp, the external evaluators were impressed with my performance and gave me the highest marks!

Later that year the names of the new prefects were announced during a prize-giving ceremony. All the potential leaders were told to sit in the front of the hall on the floor because the school prefects would be named for the year 2006. My heart beat faster and faster with every name that was announced. Suddenly I heard my name, and the audience got quiet and you could literally hear a penny drop. As I approached the stage, I did not make eye contact with the audience, because I wanted to prevent potential anxiety. When I got on the stage, I was over the moon and so excited.

In Grade 7 it was a major honour to act as prefect and to assist the learners on the playground. As a prefect I was committed to uphold morals and values in the most challenging phase of my life.

4.3.4 Physical domain

I was enrolled in a primary school where only the best physical performers were chosen to represent the school in various sport activities. The school coaches only chose the fastest athletes in the different sport divisions. Because of ASD, I entered a playing field with disadvantage. I was not chosen because my muscle tone was low; my performance was slow on the tennis court and in the swimming pool. It did not matter how keen I was, my efforts were not good enough.

In Grade one I only played one rugby match and after that game I was never selected to play competitively again. The deputy headmaster decided not to include me in the rugby team based on my low muscle tone and that he was scared that I would get hurt. He agreed that I practise with the team to stay fit. Every afternoon during my years in Grade 1 up to Grade 5 I enjoyed being included during training. My mother remembers:*”I was scared that Emile will get hurt. Physically he was a big child but his muscles were not strong enough to endure injuries on the sport field”.*

I played tennis in the afternoons until I was in Grade 3. Tennis was not a team sport and only two learners were chosen to compete. I was automatically excluded from competitions because the coaches knew that I was on the ASD spectrum and on that basis decided not to include me. I could play tennis and took swimming lessons before I went to school. I had the knowledge, skill and attitude to be a winner but my body and mind could not endure the strain.

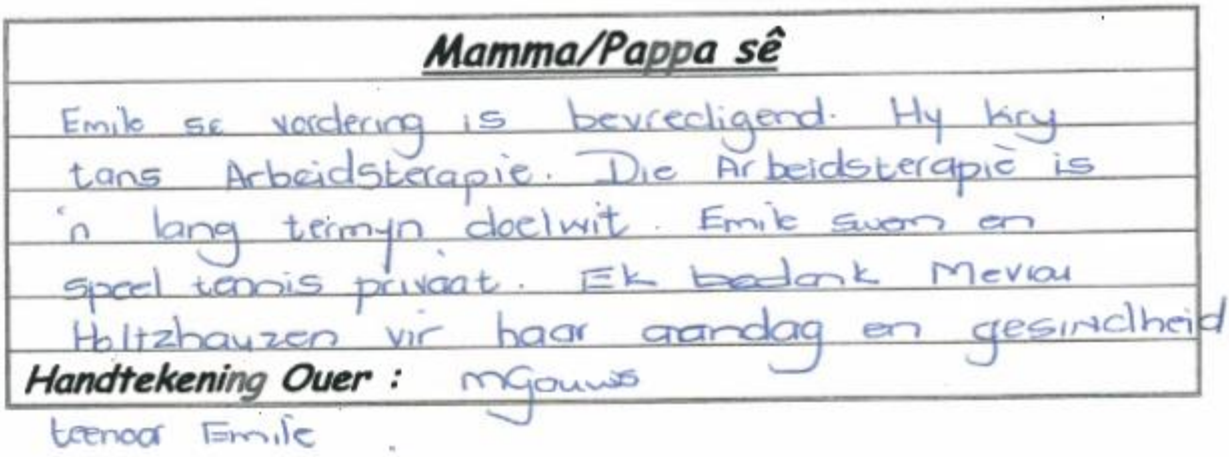
When I was in Grade 4, I have already swum for six years and mastered all the different swimming strokes. Swimming taught me to take risks, and it improved my self-confidence. I swam with other children and learned at the same pace as they did and never felt excluded. At school the opposite occurred when I swam with other learners: my anxiety level increased when sensory overstimulation occurred. During training at school I panicked and could not perform. I was eliminated from the school swimming team because the swimming teacher realised that I would not be able to swim in front of a crowd.

I was disappointed when I could not swim at school level because at the swimming school, my progress was good in freestyle and butterfly, but my backstroke was average. My swimming coach was satisfied with my performance and swimming also improved my gross motor development, as evidenced in my Grade 2 report (Figure 4.44).

Liggaamlik (Groot Motories) : Dit het al baie verbeter.

Figure 4.44: Grade 2 report

In Figure 4.45 my mother replies that my progress is satisfactory and that I receive private swimming and tennis lessons.



Mamma/Pappa sê

Emile se vordering is bevredigend. Hy kry
tans Arbeidsterapie. Die Arbeidsterapie is
'n lang termyn doelwit. Emile swem en
speel tennis privaat. Ek bedank Mevrou
Holtzhauzen vir haar aandag en gesindheid

Handtekening Ouer : MGouws

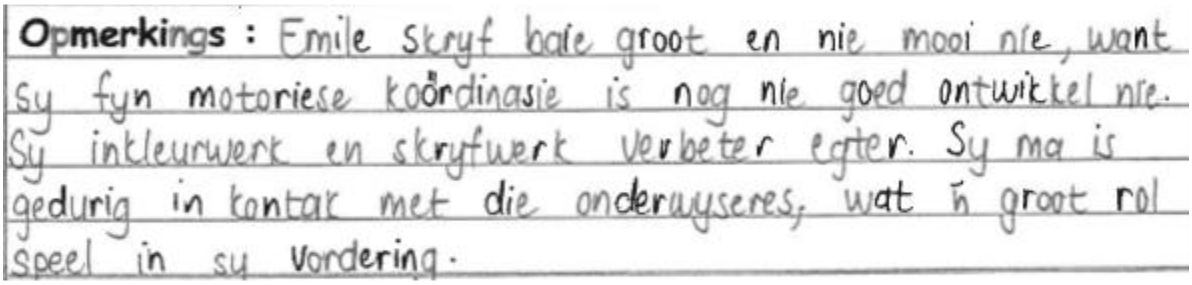
teenoor Emile.

Figure 4.45: My mother's comment on the progress report

I realised that my learning experiences were different from the other school children. My physical performance remained problematic and sensory sensitivity limited me on the sports field. As far as I was aware, I was the only learner in the school that had such extreme sensitivity to sound. I chose to disconnect when a crowd screamed because my brain perceives sound different from other children. To listen to sound would remain one of my biggest challenges that affected my speech as well. What made it worse was the low muscle tone which affected my speech since my mouth takes longer to close when I speak. While learners spoke fluently in class in Grade 1, I struggled to pronounce words and formulate sentences.

My physical challenges were more severe as the muscle tone in my mouth affected my speech. During our interview, the speech therapist explained: *"To prepare you to read was a major challenge because when you spoke your underdeveloped speech influenced your* *word pronunciation. Your tongue and lips were not strong enough and it inhibited the movements of these body parts. Your mouth was able to close but did not have the strength to pronounce the sounds. Your tongue was also not strong enough to lift up to pronounce certain sounds such as R and P, S and it took you longer to pronounce these sounds. You could not control the saliva in your mouth because it was difficult for you to swallow whilst you speak at the same time".*

My low muscle tone also had an impact on my working tempo. In the classroom I struggled to complete basic activities as (Figure 4.46) suggests.



Opmerkings : Emile skryf baie groot en nie mooi nie, want
sy fyn motoriese koördinasie is nog nie goed ontwikkel nie.
Sy inkleurwerk en skryfwerk verbeter egter. Sy ma is
gedurig in kontak met die onderwyseres, wat ŉ groot rol
speel in sy vordering.

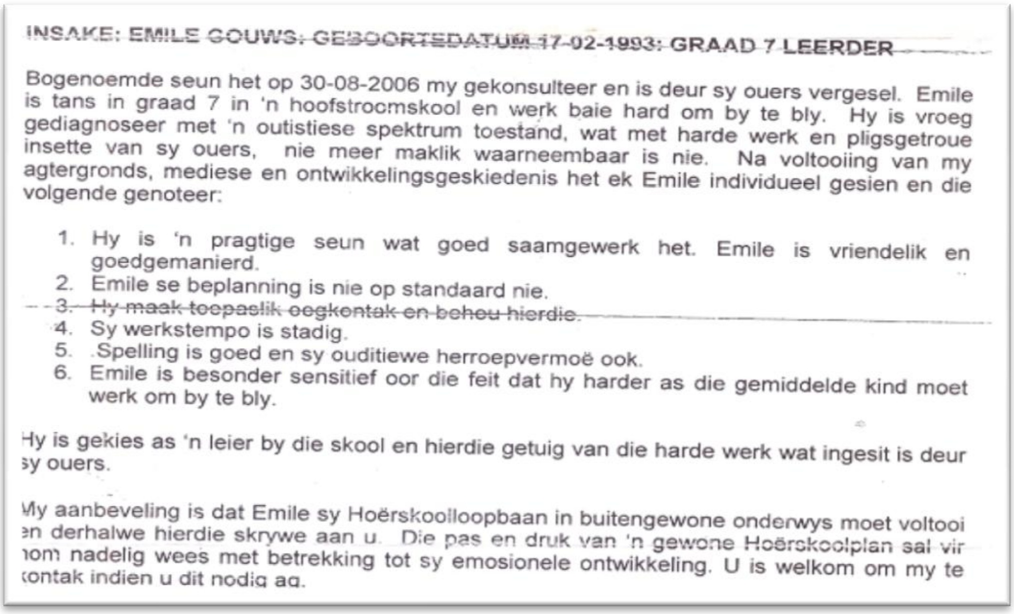
Figure 4.46: Comment from my Grade 2 educator

In this report the teacher noticed that I struggled with fine motor coordination, but that my colouring and writing abilities are improving.

I became a primary school learner who would sit on the bench and watch the other learners compete. In Grade 6 and 7 I became a spectator at school and only enjoyed physical activities with my family. We enjoyed watching different sports such as rugby and athletics when my brother competed. Thinking back I believe it was unfair to enroll me in a school with neuro-typical children with no disabilities, because I had no chance to be included.

My primary school years made my mother bitter in a sense. During our interview she expressed her disillusionment with mankind:"*It is gruesome to expose a child to a learning environment where he tries his utmost to fit in, only to see that the average person is not prepared to allow a child to develop at his own speed. We have invested a lot of money to enable our child to improve his skills and it saddens me that society decided that his best efforts will never be good enough to be included, even though the playing field is not level. I expected more from mankind."*

My mother documented:”*After the application was submitted for remedial placement, we waited, but the school in our district once again denied his application. I was extremely disappointed as I knew the chances were now even slimmer to get Emile into this school. Throughout Emile’s school career I consulted at times with a principal who specialised in autistic behaviour. I was at wit’s end, and consulted her again. She then referred me to a psychiatrist. Specializing in ASD and agreed to evaluate Emile”.* The psychiatrist was impressed with my abilities, but she also recommended that my parents enroll me in a remedial school (Figure 4.47).In her application letter to the Department of Education, she noted all my accomplishments, such as my ability to make eye contact, that I am friendly and good mannered, that my spelling and auditive working ability is good, and that I was a leader in school. Based on her fear for my emotional wellbeing, she recommends placement in a remedial school. This letter, together with the report from the school’s side on my parents’ involvement (Figure 4.48), as well as the motivation for placement (Figure 4.49) provided the breakthrough for my acceptance in the remedial school.



INSAKE: EMILE GOUWS: GEBOORTEDATUM 17-02-1993: GRAAD 7 LEERDER

Bogenoemde seun het op 30-08-2006 my gekonsulteer en is deur sy ouers vergesel. Emile is tans in graad 7 in ‘n hoofstroomskool en werk baie hard om by te bly. Hy is vroeg gediagnoseer met ‘n outistiese spektrum toestand, wat met harde werk en pligsgetroue insette van sy ouers, nie meer maklik waarneembaar is nie. Na voltooiing van my agtergronds, mediese en ontwikkelingsgeskiedenis het ek Emile individueel gesien en die volgende genoteer:

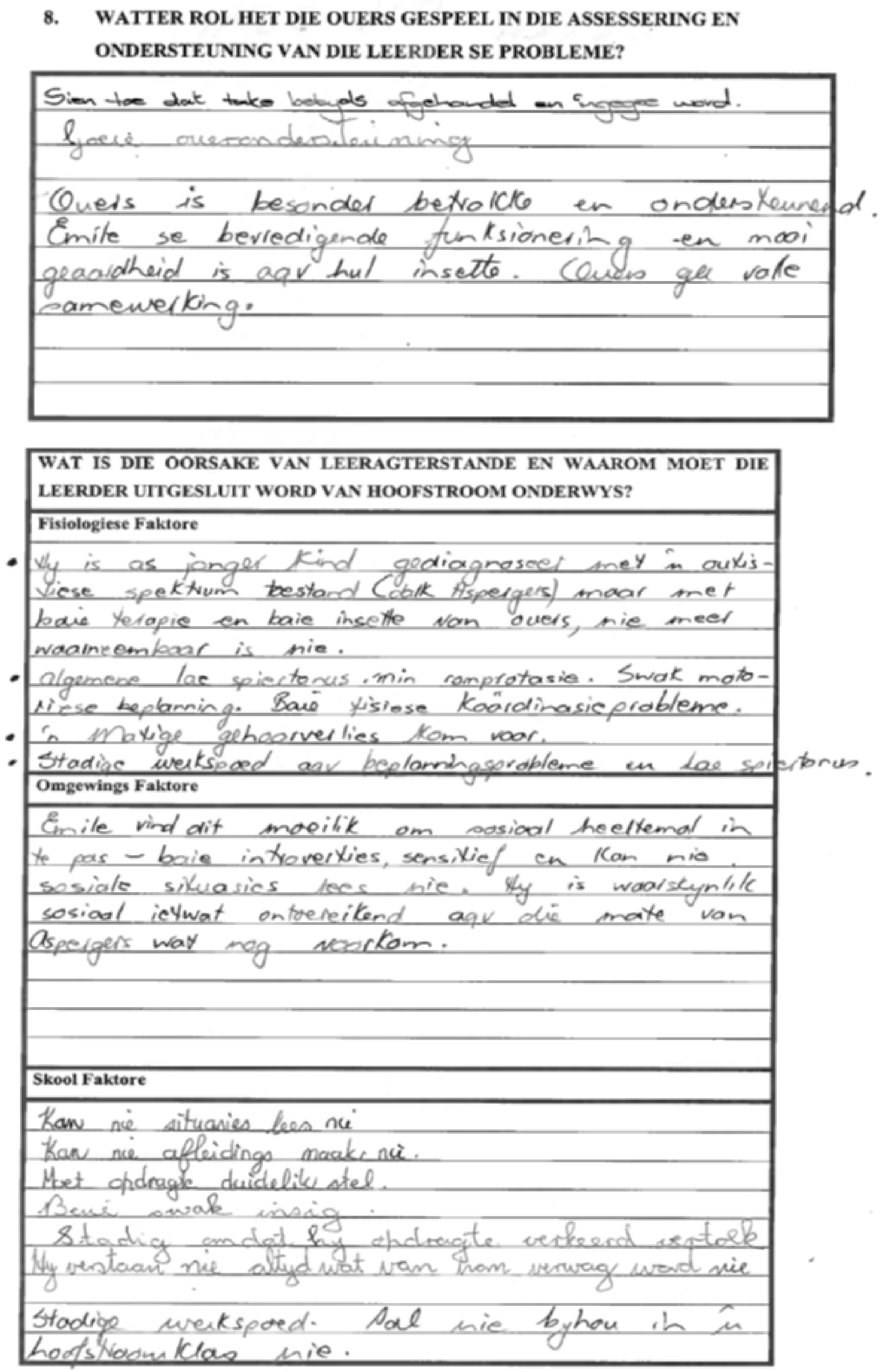
1. Hy is ‘n pragtige seun wat goed saamgewerk het. Emile is vriendelik en goedgemanierd.
2. Emile se beplanning is nie op standaard nie.
3. Hy maak toepaslik oogkontak en behou hierdie.
4. Sy werkstempo is stadig.
5. .Spelling is goed en sy ouditiewe herroepvermoë ook.
6. Emile is besonder sensitief oor die feit dat hy harder as die gemiddelde kind moet werk om by te bly.

Hy is gekies as ‘n leier by die skool en hierdie getuig van die harde werk wat ingesit is deur sy ouers.

My aanbeveling is dat Emile sy Hoërskoolloopbaan in buitengewone onderwys moet voltooi en derhalwe hierdie skrywe aan u. Die pas en druk van ‘n gewone Hoërskoolplan sal vir hom nadelig wees met betrekking tot sy emosionele ontwikkeling. U is welkom om my te kontak indien u dit nodig ag.

Figure 4.47 Referral from Educational psychologist for possible placement

Her motivations to place me in a remedial school were: *“I was diagnosed with autism but it was not noticeable. My work tempo is slow and it is difficult for me to cope with the volumes of the schoolwork. I struggled to plan and organize my work daily. Emotionally it will be a disadvantage to continue high school in a mainstream school.”*



8. WATTER ROL HET DIE OUERS GESPEEL IN DIE ASSESSERING EN ONDERSTEUNING VAN DIE LEERDER SE PROBLEME?

Sien toe dat take betyds afgehandel en ingegee word.
Goeie ouerondersteuning

Ouers is besonder betrokke en ondersteunend. Emile se bevredigende funksionering en mooi geaardheid is agv hul insette. Ouers gee volle samewerking.

WAT IS DIE OORSAKE VAN LEERAGTERSTANDE EN WAAROM MOET DIE LEERDER UITGESLUIT WORD VAN HOOFSTROOM ONDERWYS?

Fisiologiese Faktore

- Hy is as jonger kind gediagnoseer met 'n outistiese spektrum toestand (ook Aspergers) maar met baie terapie en baie insette van ouers, nie meer waarneembaar is nie.
- Algemene lae spiertonus. min romprotasie. Swak motoriese beplanning. Baie fisiese koördinasieprobleme.
- 'n Matige gehoorverlies kom voor.
- Stadige werkspoed agv beplanningsprobleme en lae spiertonus.

Omgewings Faktore

Emile vind dit moeilik om sosiaal heeltemal in te pas – baie introverties, sensitief en kan nie sosiale situasies lees nie. Hy is waarskynlik sosiaal ietwat ontoereikend agv die mate van Aspergers wat nog voorkom.

Skool Faktore

Kan nie situasies lees nie
Kan nie afleidings maak nie.
Moet opdragte duidelik stel.
Baie swak insig.
Stadig omdat hy opdragte verkeerd vertolk
Hy verstaan nie altyd wat van hom verwag word nie

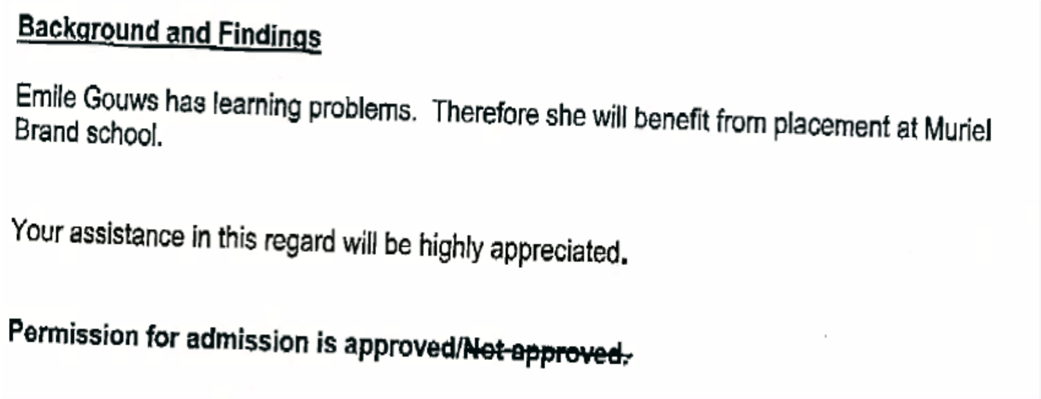
Stadige werkspoed. Sal nie byhou in 'n hoofstroomklas nie.

Figure 4.48: Teacher’s remarks on the role my parents played in my education

After the psychologist received all the letters back from the primary school teacher they gave reasons for remedial placements. In the first section (Figure 4.43) the educators acknowledged the support my parents gave.

The second section provided the reasons for remedial placement. The report noted that I struggled to adapt in social situations. I was an introvert and struggled to read social cues. Socially I experienced difficulties to adapt to the environment.

The third section it was difficult for me to read situations and to make conclusions. I experienced problems to understand and complete tasks and did not understand the questions. My worktempo was slow and I tend to fall behind with schoolwork



Background and Findings

Emile Gouws has learning problems. Therefore she will benefit from placement at Muriel Brand school.

Your assistance in this regard will be highly appreciated.

Permission for admission is approved/~~Not approved.~~

Figure 4.49: Admission letter from Department of Education

4.4 SECONDARY PHASE

The school, Muriel Brand School (MBS) in which I was to complete my high school years, accommodates learners who experience barriers to learning and development. The school was originally designated to cater for learners with severe disabilities such as spina bifida, panplegia, muscular dystrophy and cerebral palsy. There are currently approximately 900 learners in the school that caters for learners from Grade 1-12 with approximately 400 learners who are enrolled in the high school. According to my knowledge I was the only child on the ASD spectrum and they were willing to except me because I did not portray any behaviour problems.

My mother decided to continue with our learning program at home, and to combine this with the formal teaching that I would receive in the remedial school. In her book she explained: *“I didn’t want to replace the teacher, but I felt that Emile could benefit from both* *learning environments".* One aspect that one must keep in mind is that although MBS was a remedial school, the content and the volumes of the workload was exactly the same as that of mainstream schools. Although I was academically supported by the school system, I still needed to put in the effort to receive good marks. My mother's role in the afternoons was again to assist me with my academic work, and to monitor the quality of my class work. She knew the pace in high school would be faster, and that she needed to support me as I was a slow learner. In her book she recalled*: "It was important to strengthen Emile's neurological pathways through learning. Emile could remember the content that was presented, but it was difficult for him to break down and minimise work and therefore it was important to assist him to plan, organise and simplify his work".*

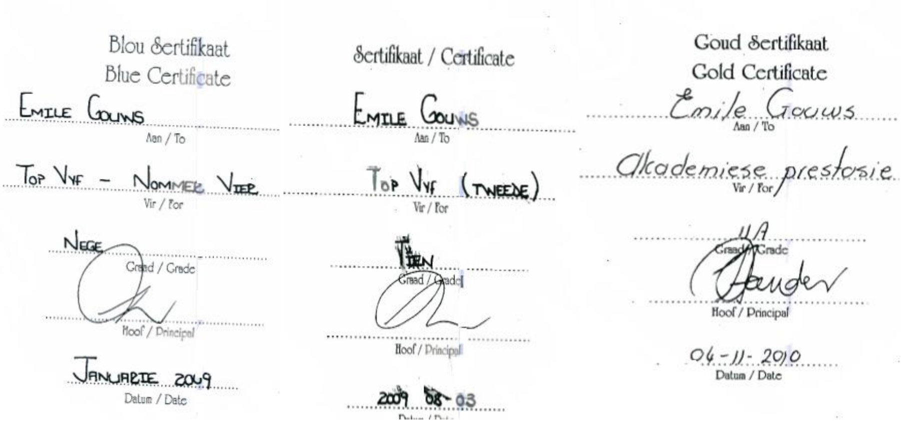
Once again our customary routine commenced – support in all my different domains.

4.4.1 Cognitive domain

When my parents explained to me that I would attend a remedial school for the duration of my high school years, I questioned my learning abilities. My father was honest when he explained to me: *"I was always concerned that you would struggle in high school".* My mother remembered*: "I knew that in a remedial school you would have the opportunity to learn in a small class where your needs could be met".* She also recalled*:"When I visited Muriel Brand School (MBS) I was impressed with the school, therapists, teachers, and medical personnel that assisted the learners.*

Already on the first day in MBS my confidence levels increased; especially when I stepped into Miss Alicia's classroom (English register class). I noticed the class environment was smaller and one-on-one attention was provided. A huge weight seemed to lift from my shoulders when sensory overload did not occur and I was able to see faces of the other learners.

Because of my above-average ability to recall information and the expert knowledge I acquired on certain topics such as tourism, I was capable of recalling renowned attractions, cities, holiday attractions (which we as a family visited or even something that I had read in a newspaper). The following certificates (Figure 4.50) attest to my academic performance.



Blou Sertifikaat
Blue Certificate
EMILE GOUWS
Aan / To
TOP VYF – NOMMER VIER
Vir / For
NEGE
Graad / Grade
Hoof / Principal
JANUARIE 2009
Datum / Date

Sertifikaat / Certificate
EMILE GOUWS
Aan / To
TOP VYF (TWEEDE)
Vir / For
TIEN
Graad / Grade
Hoof / Principal
2009 08-03

Goud Sertifikaat
Gold Certificate
Emile Gouws
Aan / To
Akademiese prestasie
Vir / For
11A
Graad / Grade
Hoof / Principal
04-11-2010
Datum / Date

Figure 4.50: Academic certificates in high school

Some learners in my class noticed that my general knowledge and long term memory were very good, and, for the first time in my life, I was acknowledged for my abilities. Although my long-term memory was good, I could not break down my work into smaller units, and this affected my marks up to Grade 12.

As I progressed to the Further Education and Training (FET) Phase (Grade 10-12) my self-confidence improved. I received immediate feedback concerning my academic performance and thrived in MBS. I learned to do my homework independently, and asked my mother less to assist me with homework. My mother noted: *“I was a bit taken aback one afternoon when Emile decided to complete work on his own. Afterwards when I checked his work, I realised my support is not needed as all his work was correct! I believe that, that day Emile started to believe in himself and made the decision to work on his own. On the one side I was proud, but on the other side quite sad that he did not seem to need me anymore*”. I believe the decision I made to do my homework on my own empowered me and also eliminated stressors at home. I am convinced that the small class environment ensured that I coped and I knew what was expected of me.

The only subject that remained a challenge in high school was Mathematics Literacy. The underdevelopment of my projection skills influenced my math performance. I needed additional assistance with mathematics and my mother appointed a private mathematics teacher to assist me. A former high school headmaster who provided private tutoring in mathematics and science was willing to strengthen my mathematical skills. He was an excellent choice, because he was also a moderator and one of the assessors in mathematics in the National Senior Certificate examinations. His goal was to assure that I would obtain 65% for mathematics. My mathematics improved with his assistance and my morale was high, because he showed me the correct mathematical steps. We also worked through old exam papers and when I wrote the final maths examination papers in Grade twelve, I was well-prepared. My final result in Grade twelve for mathematics was 66% and I am thankful for the support I received.

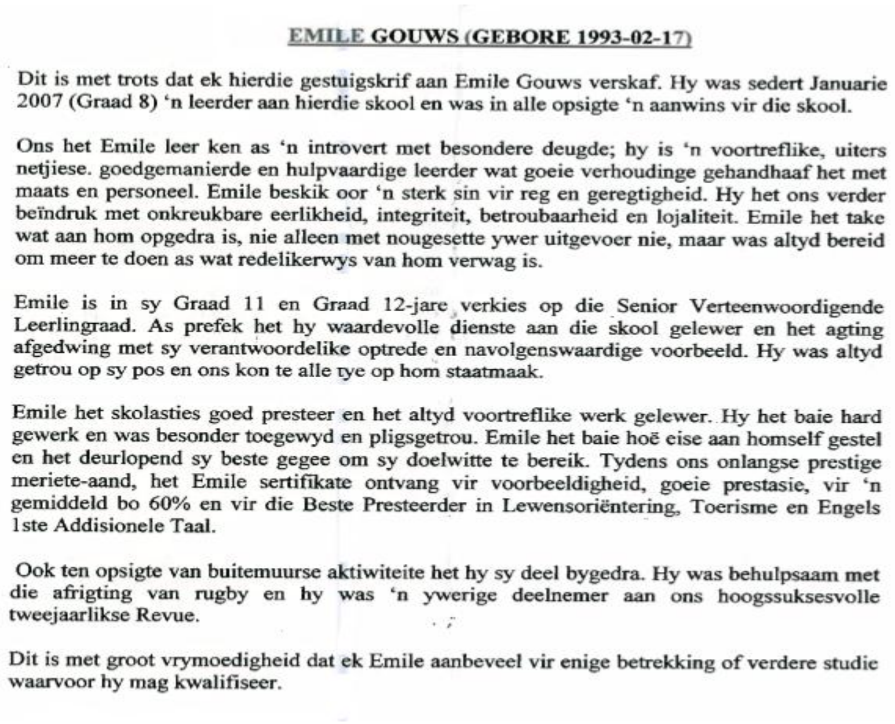
During examinations I needed extra support with all my subjects. As always, my mother was willing to assist me. My mother recalled: "*Preparation for examinations was always a nightmare due to volumes of work, and time constraints. Time management was crucial, and we needed 24 hours a day to study all the work, because Emile's working pace was slow".* Two weeks before examinations I started to study. The difficult subjects were studied first, and then the easier subjects. The work was repeated until it was stored in my long term memory; but as from Grade ten repetition became a problem, because the work was too much and time to little. During examinations I made the mistake in school to study all the work. Sometimes my mother had to repeat work verbally and the process to repeat information was exhausting. My brother remembered:*"During examinations you and Mom would study continuously. I used to invite friends over to play with me, while you were busy".* WhenI wrote two papers on one day, I studied the one subject on my own, while my mother summarised the other subject. While we studied, my mother would softly play meta music in the background that stimulated my memory and during these learning experiences I would be more alert. During the middle of the exams, when energy and motivation levels tended to soar, we would change the teaching strategy: If the content was factual, flashcards were used. Work would be clustered into different topics and I would use different colours of flashcards. I found that it was one of the best study techniques. If I was too tired to study, we would draw spider webs and learn only factual information. This method taught me to summarise only the key concepts and this enabled me to focus on important work.

During Grade 12 year my mother and I decided to work smarter. My prior knowledge about subjects was excellent, and it was time to work through previous matric exam papers. The aim was to get familiar with the types of questions that occurred in previous exam papers. During this learning experience my long-term memory was a major strength, and I was capable of recalling the information. The exam preparation technique was effective. I was well-prepared for my final examinations and felt calm and relaxed.

In Grade twelve I qualified for additional time during my exam papers. The school psychologist allowed me to write my exams in her office during the preliminary and final examination. During our interview my mother recalled: "*I was happy when you told me that you would write your final matric papers separately from the other learners. I knew that it would also help in reducing the stress, even though you were very well prepared".* I was thankful when I wrote my matric examinations in her office and without any disruptions. While writing my exam papers, the psychologist made sure that there were no distracting sounds in the passages, and she also closed the curtains. Fantastic! Someone realised that sensory overload affected my academic performance. During our interview, the school psychologist recalled: "*I also assisted you with general planning and organisational skills. I would help you in numbering your exam paper. My goal was to keep you relaxed, safe and secure so that you could complete your exam paper".*

My dedication and hard work paid off. Each semester from Grade eight to twelve I managed to be among the top five achievers in my specific grade. The academic rewards encouraged me to strive towards excellence. And then the long wait began for the results.

The day of the results, there was an electric sense of excitement in our house. We then got into the car and went to the nearest garage to buy the newspaper. With excitement, I looked for my name; I couldn't wait any longer. I knew there was a possibility of two distinctions. I achieved one distinction in Life Orientation, and for Tourism I achieved 79%. The next morning we went to school. The math teacher gave me a form to complete and asked that my Tourism paper should be remarked. We went to Department of Education, but even after the re-mark, I did not obtain my distinction. I was however very happy and grateful about my overall average of 70.2%, and I obtained university exemption. My school career had peaked and my marks were excellent. The principal acknowledged this achievement in the reference letter he wrote.



EMILE GOUWS (GEBORE 1993-02-17)

Dit is met trots dat ek hierdie gestuigskrif aan Emile Gouws verskaf. Hy was sedert Januarie 2007 (Graad 8) 'n leerder aan hierdie skool en was in alle opsigte 'n aanwins vir die skool.

Ons het Emile leer ken as 'n introvert met besondere deugde; hy is 'n voortreflike, uiters netjiese. goedgemanierde en hulpvaardige leerder wat goeie verhoudinge gehandhaaf het met maats en personeel. Emile beskik oor 'n sterk sin vir reg en geregtigheid. Hy het ons verder beïndruk met onkreukbare eerlikheid, integriteit, betroubaarheid en lojaliteit. Emile het take wat aan hom opgedra is, nie alleen met nougesette ywer uitgevoer nie, maar was altyd bereid om meer te doen as wat redelikerwys van hom verwag is.

Emile is in sy Graad 11 en Graad 12-jare verkies op die Senior Verteenwoordigende Leerlingraad. As prefek het hy waardevolle dienste aan die skool gelewer en het agting afgedwing met sy verantwoordelike optrede en navolgenswaardige voorbeeld. Hy was altyd getrou op sy pos en ons kon te alle tye op hom staatmaak.

Emile het skolasties goed presteer en het altyd voortreflike werk gelewer. Hy het baie hard gewerk en was besonder toegewyd en pligsgetrou. Emile het baie hoë eise aan homself gestel en het deurlopend sy beste gegee om sy doelwitte te bereik. Tydens ons onlangse prestige meriete-aand, het Emile sertifikate ontvang vir voorbeeldigheid, goeie prestasie, vir 'n gemiddeld bo 60% en vir die Beste Presteerder in Lewensoriëntering, Toerisme en Engels 1ste Addisionele Taal.

Ook ten opsigte van buitemuurse aktiwiteite het hy sy deel bygedra. Hy was behulpsaam met die afrigting van rugby en hy was 'n ywerige deelnemer aan ons hoogssuksesvolle tweejaarlikse Revue.

Dit is met groot vrymoedigheid dat ek Emile aanbeveel vir enige betrekking of verdere studie waarvoor hy mag kwalifiseer.

Figure 4.51: Reference letter from the school

In this letter he conveys his pride in being able to write this testimonial. I translate*:*

I am proud to provide this testimony to Emile Gouws. He was a learner at this school since January 2007 (Grade 8) and was an asset to the school in all respects.

We got to know Emile as an introvert with special virtues; He is an excellent and extremely neat, well-mannered and helpful learner who has maintained good relationships with peers and staff. Emile has a strong sense of justice and can distinguish between right and wrong. He further impressed us with his honesty, integrity, reliability and loyalty. Emile did tasks assigned to him not only with zeal, but was always willing to do more that was reasonably expected of him.

Emile was elected as Senior Representative Student Council in his Grade 11 and 12 year. As leader, he rendered valuable services to the school and enforced his responsible actions and leading by example. He was always faithful to his post and was always reliable.

Emile has performed well in school and has always delivered excellent work. He worked very hard and was committed to any cause. Emile has set high expectations for himself and has consistently done his best to achieve his goals. During our recent present merit evening, Emile received certificates for good performances, for an average over 60% and for the best performer in Life Orientation, Tourism and English First Additional Language.

He also contributed his in extra-curricular activities by coaching rugby and by participating in our highly successful two-year Revue.
It is with great confidence that I recommend Emile for any position or further study for which he may qualify.

4.4.2 Emotional domain

Before the Grade 7 learners transitioned to different high schools, one of the most exciting topics was their discussion of the various high schools that they selected. I did not take part in the discussions because I felt ashamed to tell my friends that I would be going to a remedial school. I feared they did not know what remedial learning really implied or if they would just form their own perceptions and assumptions?

Although my mom and I have got a special bond, this time it was difficult to talk about school placement. My mom recalled*: "Emile and I discussed his way forward. We both agreed that he must continue his school career in a smaller environment that accommodates his needs, but I was concerned when we disagreed about school choice.* "I knew my mother has made up her mind when we visited the school, and she introduced me to the school psychologists who would play an important role in the lives of the learners' internal education system. When my mother decided to introduce me to the teachers at MBS,I felt uncomfortable because I was not ready to change my environment.

After I was enrolled at MBS I felt more at ease and comfortable in the classroom environment because there were twelve fellow learners. Most learners had been educated in the remedial environment since Grade 1 and they were more relaxed. I was amazed to see that the environment was therapeutically-friendly and when learners needed therapy they were fetched out of the classes.

My fellow-learners were baffled when I kept quiet in class and did not speak my mind, or give my opinion. As I was the only learner with ASD, they also found my hand gestures and other behaviour quite strange. The school psychologist told me during our interview: "*There were always positive remarks about your behaviour, but the only concern was that you never socialised spontaneously with other learners. It was important to give you guidance to improve your self-esteem, and communication skills with your peers."*

The only person who assisted me emotionally at school was the psychologist. She did not support my withdrawal behaviour and decided to teach me strategies to connect with learners. She arranged therapy sessions to strengthen me and during these sessions, I felt relaxed because of her accommodating and accepting attitude. The school psychologist noted:"*During the therapy sessions I wanted to make you aware of your personality traits*. *You had high expectations of yourself and if these expectations were not* *met it affected you emotionally. You were very sensitive and you took the slightest comment personally. I therefore concentrated on coping skills to handle rejection and to improve your emotional intelligence, by focusing on other learners' feelings and not to experience all criticism negatively."*

In the remedial school my stressors decreased because the therapeutic environment accommodated me and made me feel welcome. The support I received was continuous and in this safe environment, I learned to trust the teachers because I was not blamed for my limitations. In Grade ten the psychologist arranged a meeting with my classmates to discuss the challenges I face daily and gave the learners guidelines to improve the relationship between us. The psychologist noted*: "I decided to talk to the class about your behaviour, while you were not present. I told them not to treat you differently and made them aware that you are a very sensitive learner and that they must take that into account".* I was relieved that the psychologist intervened on my behalf, as my biggest challenge was to translate my non-verbal behaviour into verbal behaviour, in other words, to make the decision to talk about my feelings and voice my opinion, instead of isolating myself and resort to hand-flapping or other comfort behavour.

During our interview the psychologist noted*: "In Grade eleven you compared yourself to the neuro-typical learners and forgot about your unique abilities. I reminded you that you're learning experiences were different from the other learners and that your expectations must be realistic. During this specific period I assisted you in improving your self-confidence. During these discussions I encouraged you to express your emotions verbally*".

In Grade 12 the psychologist further empowered me. She mentioned: "*I was approached by your register teacher just before you wrote your matric examinations. She noticed that your attention was divided. I held a discussion with all your teachers to find ways to accommodate your needs during the preliminary examinations. During this discussion everybody decided that it would be best if write your examinations in a relaxed environment without disruptions and we decided that you will write your examinations in my office".*

When I received my matric results I discussed my career opportunities with the school psychologist. She was concerned when my parents decided to stretch my limits once again by enrolling me at the University of Pretoria's Faculty of Education. During our interview she admitted: *“I was afraid that you would not cope in such a big learning environment and that you would not be able to adapt*. *I wanted to protect you to get hurt emotionally*, *but today I know that you were stronger than I thought because one thing that you have, is endurance and courage.*

4.4.3 Social domain

It was rather comforting for me to realise that there were learners in MBS who also faced challenges daily. In this learning environment I learned to be grateful and saw how my fellow disabled companions fought in the battle of life. This was an eye-opener. It was also the first time in my life that I was exposed to numerous disabilities in a school environment - that taught me to respect the differences in people and to appreciate my circumstances.

Socially it was difficult to adapt to a new environment, and in Grade eight I initially felt that the learners in my class did not want to include me in their social group. The old feelings came back where I felt that once again my fellow classmates preferred to keep their distance. When I discussed my feelings with the psychologist, she encouraged me by saying that some learners might find it offensive when a new learner was placed in the school and performed very well.

Although I experienced rejection in class, it did not limit me to socialise with other learners in the school. MBS was a bilingual school and I had the opportunity to communicate and socialise more with English-speaking learners. I realised that one of my biggest challenges was to start communicating and not to allow fear to hold me back from interaction with other learners. Another barrier was the fact that my social skills were limited and I did not know how to start and end a conversation. I learned to use my general knowledge as an “opening line” when starting a conversation. I also forced myself to participate in class when the teacher would ask questions regarding schoolwork because knowledge became power. When my communication improved with my peers, they also started to respect me. Once again, my mother helped me subconsciously. In her book she wrote: *“I will encourage Emile to speak by asking him questions such as: ‘What do you think, Emile, or what is your opinion?’ If Emile only responded with a ‘yes’, I would ask him to elaborate, and give him time to plan, and organise his language.”*

The only social activity that boosted my self-confidence and that I enjoyed very much was the revue. I participated in the revue in Grade nine (2008) and in Grade twelve (2011).

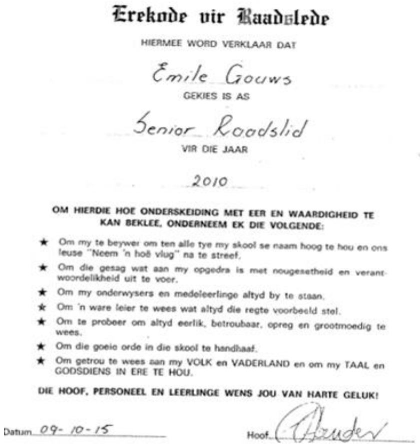
MBS revue was always the highlight on the school calendar. The teachers who were involved did an outstanding job with the choreographic dance movements, and the choices of songs. During the revue performances, all the school’s staff (teachers, psychologists, speech therapists, occupational therapists, hostel caretakers and the school’s personal medical sister) were involved, and the general mood and relationships between the learners were amiable.

An activity during revue that improved my muscle tone and released muscular tension in my body was dancing. It was easy to learn the dance movements by mirroring the teacher’s moves. By listening to the music, and through repetition of movements, I used the left and right side of my brain. I knew I would perform in front of an audience, but fear could not stop or scare me in spite of sensory overload and I tolerated the flashing lights, the over populated audience, and all the movement backstage. Participating in the revue (Figure 4.52), contributed tremendously to my ability to interact with my fellow learners.

Figure 4.52: Photos of me participating in the revue

On Friday Grade 9, the deputy principal approached me and invited me to attend a camp with the boys in my class. I first hesitated but eventually agreed because two of my class mates would attend the camp and I always looked forward to an adventure with them. I knew it was difficult for me to socialise with school friends, due to my anxiety, but my desire to be with my friends was greater than my fears. On 20June 2008, I left with the group of ten boys to Fouriesburg. We attended activities every day, went swimming in a dam and made fire in a conga. We used a ‘donkey’ for water, and stayed in an old stone house. When I returned, my mother was worried because my behaviour had changed – I withdrew to my room and did not want to participate in any household activities such as meals, watching television with the family, and so on. I think the week's activities overwhelmed me, and when I got home, I wandered around aimlessly. By this time my mother realised that the week away from home took its toll. She related how she slowly included me in the household activities again. She did not allow me to isolate myself, and my family made an effort to make me feel included and accepted again. My mother remembered: *“It was necessary to break the cycle of loneliness and separation and you needed our support to communicate with you”.*

It was a proud moment to be elected as a school prefect from Grade ten to twelve. I was the only boy from my class who has been included in the leadership group.



Erekode vir Raadslede

HIERMEE WORD VERKLAAR DAT

Emile Gouws

GEKIES IS AS

Senior Raadslid

VIR DIE JAAR

2010

OM HIERDIE HOE ONDERSKEIDING MET EER EN WAARDIGHEID TE KAN BEKLEE, ONDERNEEM EK DIE VOLGENDE:

- ★ Om my te beywer om ten alle tye my skool se naam hoog te hou en ons leuse "Neem 'n hoë vlug" na te streef.
- ★ Om die gesag wat aan my opgedra is met nougesetheid en verantwoordelikheid uit te voer.
- ★ Om my onderwysers en medeleerlinge altyd by te staan.
- ★ Om 'n ware leier te wees wat altyd die regte voorbeeld stel.
- ★ Om te probeer om altyd eerlik, betroubaar, opreg en grootmoedig te wees.
- ★ Om die goeie orde in die skool te handhaaf.
- ★ Om getrou te wees aan my VOLK en VADERLAND en om my TAAL en GODSDIENS IN ERE TE HOU.

DIE HOOF, PERSONEEL EN LEERLINGE WENS JOU VAN HARTE GELUK!

Datum 09-10-15

Hoof

Figure 4.53: Code of Conduct for prefect

It was an exciting feeling to be a prefect, but the other prefects did not involve me in discussions. Once again I asked mom: “Why me? Why was I selected as prefect but once again excluded from the group”? I told her that I was tired and that I didn’t want to go to school anymore. I hardly ever cried, but during this conversation I started to cry, and my mother realised I had reached breaking point. She then said to me: *“You have two options. You can either make an appointment with the principal or discuss the situation with him, or the other option is to go and see the psychologist”.* I decided to visit the psychologist, and in the following sessions we concentrated on coping skills to deal with rejection. Another disappointment occurred in Grade twelve when I was not selected as the head boy, as that was one of my dreams. I was very disappointed in myself, blamed autism and questioned my leadership abilities.

Looking back at my social development in high school I realise that during that time, I made the decision to take responsibility for my own social development. I could not always rely on my parents to create the opportunities for social exposure. Following my instincts by avoiding social contact would leave a void in my life, but I have learned that I have the key to open the door, or to close the door to social exploration. It took courage not to isolate myself, and to force myself to be involved in experiences that I knew would be vital for my social growth.

4.4.4 Physical domain

I could not believe that my parents decided to place me in a remedial high school with physically disabled learners. My first thought was that most learners were diagnosed with disabilities and would not be able to participate in activities. I was disappointed when I realised that MBS does not provide for any sport activities that could accommodate me. My very first day at MBS was an anti-climax. The school had a swimming pool, but it was empty. I realised I would not have the opportunity to swim, play rugby or tennis.

After two weeks I realised the main sport activity on the school calendar was the annual inter-house athletics meeting. The learners who participated were all diagnosed with cerebral palsy and underwent an assessment by medical doctors for placement in a specific category in order to compete. After being assessed by the school's medical doctor, the results showed that I was not diagnosed with spinal dystrophy and would not be able to participate in the chosen categories. The teachers decided to accommodate me whereby I would be able to compete in discus but would not be able to receive certificate. My mother took me to the athletics meeting and recalled*:"I did not have any expectations when Emile told me he would be participating, but I wanted to support him because I knew Emile was proud to represent the school at the inter house athletics meeting. When I entered the stadium and I saw all the children with different disabilities my stomach made a turn, as I realised that physically, there is no school that accommodates Emile's needs. "*

Because of the limited sort activities, I started my own rugby team and selected a team out of the primary school learners between the ages of eleven and thirteen who wanted to play rugby who were not physically disabled but were diagnosed with learning difficulties. The school provided therapy for disabled learners and did not accommodate physical sport activities at school. The learners were physically able to play rugby and it was an enjoyable moment to coach a team sport that I was passionate about. They practised during every break and I was so happy to note that they wanted to play games competitively .When I was in matric I selected a team to play against Danville Primary on the 15 July 2011. Although the learners lost the match, they still enjoyed the experience.

From Grade ten to eleven I spent more time on my academics, and I slowly but surely I became inactive at school and decided to participate privately in activities that I enjoyed such as to gym and to run on the treadmill at home. Where we live, it is not safe to walk alone in the streets. My mother made sure that we went for a daily walk when it was quiet in the streets. She was also afraid that someone would notice that I am sensory sensitive and that I look over my shoulder all the time. We as a family found alternative ways to be active during weekends and holidays.

To be active became a life style and especially during holidays we made a point to be active, although it was not always fun. One of our most challenging excursions occurred when I was 18 years old, when we decided to go backpacking through the Tsitsikamma forest. We bought sleeping bags, food and all the equipment we needed for the hike. My challenge was not to walk the pathways, but to carry my backpack. The tour involved a 30 kilometer hike through the forest, and every night we slept at a different place. I enjoyed that a lot, and another favourite was to go to the seaside and swim in the sea – I loved jumping the waves.

I finally entered a phase in my life whereby I decided to participate in activities that I enjoyed and I decided that nobody or nothing would be able to limit me.

4.5 CONCLUSION

Through this novella, I have shared my personal experiences as a child with autism and how the educational support I received enabled me to overcome various challenges situated in the four developmental domains and ultimately, to succeed in a formal school system. In this chapter my main research question was partially answered as I explained how I was educationally supported in dealing with autism during my school years.

In the next chapter my novella will be interpreted by referring to the literature review, my empirical study, theoretical framework, as well as my research questions.

CHAPTER 5

DATA INTERPRETATION

5.1 INTRODUCTION

Data interpretation involves the ability to review the data which was gathered and to make formal conclusions (Miles, Huberman & Saldaña, 2014:594). McMillan and Schumacher (2006:327) add that data interpretation is the process where the research findings are linked and related to the literature (see section 2.3). Creswell (2015:15) notes that personal views, perceptions and reflection remain an integral part of interpretation and therefore the researcher can relate and make sense of the research findings.

Esteve and Lee (2017:599) furthermore believe that the data interpretation process involves the researcher's ability to interpret the data through the selection of holistic themes that correspond with the theory and analysis. The selected themes represent a minority of the broader sample and can therefore represent the true reflection of reality. As this study set out to investigate the support that enabled me, as a learner with ASD, to complete my school career, 'support' was the major theme that guided the data interpretation. It was discussed by means of the four categories, also presented as the conceptual framework of my study, namely the cognitive, emotional, social and physical domains (see section 2.2.1).

The Gordian knot is a metaphor presenting the support I have received, and for the purpose of my study, it is depicted as follows:

Figure 5.1: The Gordian knot as adapted for the purpose of my study

The figure illustrates the educational support that I received during my school career in various developmental domains, each presented by a ‘loop’ with a specific color. These loops are intertwined to form an intricate whole (the knot) which, if detangled, will disintegrate. Put differently, the Gordian knot depicts the interrelatedness between the four domains and it furthermore represents the improbability of dividing the different domains in separate self-containing elements.

5.2 THEME AND CATEGORIES PERTAINING TO EDUCATIONAL SUPPORT

The following figure explains the theme and four categories that emerged from the data analysis and will form the framework for the interpretation of the data.

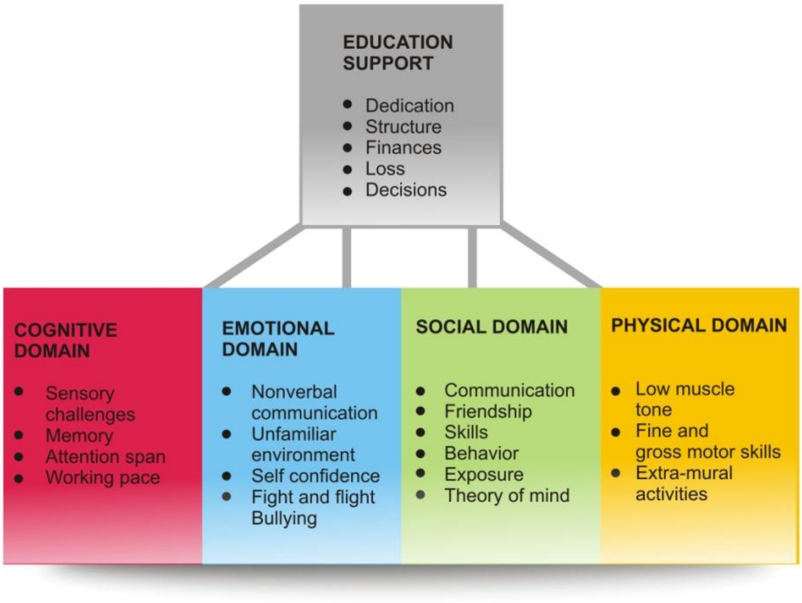


Figure 5.2: Four categories that emerged from the data analysis

As mentioned before, only one theme has been identified, namely educational support, which also represents the essence of my study. Under each category, various sub-categories were identified. This figure constituted the framework for the data interpretation.

5.3 THEME: EDUCATIONAL SUPPORT

Vygotsky (1978) is one of the most well-known theorists on support. His theory is based on the premise that when children are supported by an adult or a stronger peer, they are capable to “transfer from their actual developmental level to their potential capability” (Westhoff, 2014:5). His FGT holds that there are three elements in the support process, namely the subject, tools and objects: the subject represents the child, the tools represent the instruments or methods employed to make the support possible and the object represents the ultimate goal for which support is needed (see section 2.2.1).

As a child with HFA, I needed support with basic skills, which were natural for neuro-typical children. The ability to communicate, socialise and function on an accepted emotional and behaviour level, were challenges and I needed assistance to acquire these skills to fit into society.

My main research question asked what constitutes support for a child on the autism spectrum disorder. Clansy (2017:2) mentions that leadership has transformed to adapt a more supportive role and consists of “challenging the process, modeling the way, sharing a bond with and inspiring followers, and begin able to empower others through a shared vision and trust". This quote truly encapsulates educational support; in the FGT vernacular it means taking the lead in the journey where a subject (child) with a disorder has to reach a specific outcome. Support therefore implies establishing an intimate relationship of trust with the subject by empowering him/her to achieve educational milestones and ultimately to become independent.

My mother was the personification of support and was the main figure in my educational support network throughout the various stages of my development. My mother was therefore at the center stage of a community of practice that shared a common purpose concerning me and the support I needed. Each member of my external support system made a unique contribution to my development and also equipped my mother by giving advice and supplying her with knowledge to support me. The literature that I reviewed for the purpose of this study, concentrated on support per se, but not on characteristics of the supporter. My experience with the support of especially my mother, led me to identify aspects, which form the categories of education support, namely dedication, structure, finances, loss and decisions.

5.3.1 Dedication

The first element of support that I identified was dedication, which is indispensable to reach an outcome or a goal. Throughout the years of support I received, all members of my support network were very dedicated in their efforts to help me overcome the barriers that I faced. My external support structure's involvement was seasonal, whereas my mother's support was continuous. Her dedication implied that she had to put her own life on hold, resign from her job and spend all her time to help me through my school career. My mother believed in me as a person, and she had faith in my abilities. Her trust motivated me to persevere and to continue on this difficult journey with all its numerous obstacles. There were many setbacks and disappointments, but my mother overcame them all and continued to encourage me – she helped me up when I was down; she was the one that dragged me along the way, when I felt that I could not go on. My mother could truly be regarded as an "activist for autism" (see section 2.4) and adopted all three roles identified by Sheperd, Landon, Taylor and Goedeke (2018:3)(see section 2.4). As 'consumer', she had to make certain decisions for the benefit of the whole family, In our case, it was that I could be acceptable in all the different developmental domains to society. As ‘caregiver’, she carried the bulk of the ‘burden’ and was my constant companion and supporter on this difficult journey. As ‘clinical supporter’, she involved other support systems by getting various professionals on board.

This dedication however, also had repercussions, as explained in the following sub-category.

5.3.2 Loss

Although this aspect of support was not identified in the literature consulted, it was a strong sub-theme that emerged during the data analysis of my auto-ethnography. The fact that I was diagnosed with ASD and my mother’s whole-hearted support alienated both my father and my brother to some extent. In line with reports from the literature (see section 2.3.4), my father distanced himself emotionally from my development and left the entire responsibility of my support to my mother. I am however very grateful for his financial assistance, which enabled the engagement of my external support system to provide specialised support.

With regard to my brother, he was compelled to find his own friends who could meet his need for brotherly companionship, as I could not fulfil this need. I did not have this natural inclination to spend time with my younger brother or to play with him. Sadly I was never able to invest in our relationship and I realize that we will never have a close relationship, as the emotional distance between us cannot be bridged, even though it may be desired.

Loss may also be seen as symbol of positivity, growth and success in the light of the milestones I achieved and barriers I overcame throughout my development. My ability to overcome common barriers, to cope in multiple social environments and to refrain from taking flight can be regarded as a loss of the characteristics of autism, which are no longer visible in my behaviour. This type of loss symbolizes my personal growth and milestones I achieved to cope in society.

5.3.3 Structure

A person with ASD should be continuously stimulated to acquire new skills in a structured environment such as a home or a school. A structured environment teaches the child on the ASD spectrum to obey rules and regulations in the home and school environment. This concurs with literature findings that indicate that children on the ASD spectrum perform at their best in a structured environment where rules and structured routines are present (Whipple & Van Weelden, 2012:33) (see section 2.4.2).

In a therapeutic environment my limitations were in a sense overcome. In both the mainstream and remedial environment I received education in a structured and disciplined manner. Since primary school my mother has introduced a structured environment apart from the school that involved discipline and routine where I completed my homework in the afternoons. Structure enabled me to persevere, provided security to complete my homework and therefore allowed me to succeed academically.

Service providers such as psychologists, speech and occupational therapists collaborated with my mother in order to support me (see section 2.4.3). These support sessions also took place in a structured environment: I attended these sessions at a specific time and had to adhere to certain social rules. This structured routine produced stability in my life.

5.3.4 Finances

When taking the FGT into account, ‘tools’ represent the means/methods/instruments by which support is rendered, and is one of the three legs of the FGT framework (see section 2.2.1). Both subject and object are dependent on the tools that enable support in order to achieve the required outcome. The support that I received was made possible by the fact that my mother could stay at home and devote all her attention to me, by financing the various therapists who assisted me, and by allowing me to participate in the various extramural activities which assisted me on a social, emotional and physical level. My father had to work overtime to meet our family’s financial needs and to finance private therapy and extra mural activities.

5.3.5 Decisions

Considering my mother’s role as consumer (see 5.3.1), decisions had to be made that had an impact on the functioning of my family and also to what I was exposed. Karpov and Haywood (1998:27), in their explanation of Vygotsky’s theory, assert that the adult is responsible for the well-being of the child and therefore decisions are made that may be unpopular, but which are ultimately for the benefit of the child. In my case, I blamed my mother for enrolling me in a mainstream school where I could not fit in. I could not understand how she could be so ‘cruel’ as to expose me to situations where I felt inadequate and inferior. Sometimes I would rebel against these decisions as it was cognitively, emotionally, socially and physically difficult for me; I would have preferred to take the flight response and avoid the situation (see section 2.3.3.1). Looking back, I realise that my mother’s decisions were always in my interest and exposure to these difficult situations moulded me into a person who can persevere and who is very resilient.

Educational support took place on various levels, and these are now discussed.

5.3.6 Cognitive domain

Cognition refers to the child’s ability to learn and is a determinant factor for functioning in a mainstream environment (see section 2.3.3.1). The most far-reaching challenges that the child with ASD experiences are situated within this domain (see section 2.3.1) as these represent the make-and-break dynamics that define a person’s future.

The cognitive difficulties that I experienced affected my ability to concentrate, to pay attention, to complete my homework, to prepare for examinations, plan and organise my work. It influenced my academic performance and without the support of my mother, therapists and teachers, I never would have been able to complete my school career with university exemption. Support took place in the form of my mother who assisted me in the afternoons with homework as well as different support given by various service providers such as the educational psychologist, the speech and occupational therapist. The following sub-categories emerged (sensory challenges, memory, attention span and working pace) which denote the various challenges that I experienced within this domain as well as the support that I received in this regard.

5.3.6.1 Sensory challenges

Schoen *et al* (2009:1) postulate that sensory processing involves the ability to make sense of information received from the different senses. Challenges in this regard involve low endurance abilities, as well as visual and auditive sensitivity which also inhibit the child’s ability to function with other children in a learning environment (see section 2.3.3.1).

As a learner I experienced daily sensory challenges that affected my academic performance and which required specific support. Visually, I experienced selective blindness when confronted with large groups of people, so that I could not discern faces. I order to overcome this challenge, my mother deliberately exposed me to such situations, but made sure that she accompanied me, holding my hand and assuring me of her presence and also talking me through the experience by giving me perspective. Placement in a remedial school with much smaller classes also helped me to overcome this blindness.

My auditory sensitivity, which impacted on my ability to function in a group, was addressed by my various class teachers. Since they showed real understanding of ASD, I was allowed to sit apart from the rest of the class and work on my own. I was never forced to participate in any activities and for that I am very grateful. Although the fact that I isolated myself from other people upset my mother, she also respected this need and allowed me time on my own.

My kinaesthetic sensitivity manifested in various ways. I could not stand combing my hair, but in this case my mother stood her ground as being presentable was more important to her than having an unkempt child. Regarding my sensitivity to different textures, my mother did not force me to wear clothes that irritated me, but rather bought different textures to minimise the sensitivity. The occupational therapist provided therapy by exposing me to different textures, such as the playing with dough and sand. These exercises also helped me to try different textures in food. My parents allowed me to make my own choices with regard to my clothes. As a teenager I could choose my own style and made sure that my clothes was agreeable to my sensitivity. I also did not like any form of physical contact and therefore avoided touching, hugging and kissing family members. My parents always motivated me to make eye contact with people but never forced me to demonstrate physical signs of affection.

In retrospect, I realise that the most valuable support I received with regard to my sensory challenges was that my parents never forced me to do anything against my will (expect the combing of my hair!). On the other hand I also realise that certain social rules need to be obeyed and apart from empathy, a strong hand is also necessary.

5.3.6.2 Memory

Memory involves the ability to remember and retrieve information (Van Denbroucke, Spilt, Verschueren, Piccinin & Baeyens, 2018:128). Children on the ASD spectrum's long term and auditive memory are above standard due to a larger brain volume (see section 2.3.3.1). My mother capitalised on my long-term memory by focusing only on the work that I could not remember. By making use of flash cards and spider webs she helped me to internalise content. Literature reports that children with ASD experience problems with complex memory tasks as they do not have the ability to plan and organise (see section 2.3.3.1). In order to help me, my mother packed my suitcase every day after school and organised my handbooks according to my class register. As the academic demands increased, my grandmother made bags for my different school subjects to enable me to find my work quickly and to know exactly where what was. Every afternoon my mother and I went through the day's school work and completed any incomplete work. To plan and organise my school work gave me security and assisted me in functioning in the school environment.

My good long-term memory was a major strength but the challenge was the bulk of information that I received at once. My mother assisted me and taught me to break down all the work during examinations. While I attended school during examinations, my mother would summarise my work at home, so when I arrived at home in the afternoons, my learning environment was organised. That made the work load digestible and I managed to cover all the necessary content necessary to pass my tests and examinations.

5.3.6.3 Attention span

Attention span is one of the general challenges a child on the ASD spectrum is associated with (see section 2.4.1). Especially when my senses were overloaded, my concentration levels diminished and I could not concentrate on my class work and had to take it home. Both the occupational and speech therapists concentrated on broadening my attention span during our sessions, they helped me to remember work in sequences and assisted me with innovative methods to recall information. I am grateful for the individual attention I received in this regard, because I struggled to function in a crowded environment. A major step was placement in a remedial environment with smaller classes and fewer children.

5.3.6.4 Working pace

A person’s working pace is affected when struggling to process information (see section 2.4.1). Due to sensory overload, I struggled to maintain a productive working pace and was therefore unable to complete my work in time. In the classrooms my tempo was too slow, and I needed extra time to complete classwork and homework in the afternoons. Moreover, the mainstream school that I attended did not accommodate my need for extra time. Only when I went to a remedial school, did the school psychologist arrange for extra time and also arranged with my teachers to accommodate my sensory needs, as she realised that my academic performance was compromised. Due to the smaller classrooms, teachers had time to help me manage the learning content so that I could process it. Only in Grade 12 due to the overcrowding of the lecture halls, the educators noticed that I tended to rush my examination paper and that my attention was distracted. Thus, the educators and the school psychologist agreed that it would be best if I wrote my examinations separately in the psychologist’s office. I received additional time and therefore could succeed academically.

5.3.7 Social domain

The social domain refers to the ability to communicate effectively with others and to form relationships (see section 2.3.3.2). Bellini (2004:79) suggests that these skills are fundamental to survive in society. I experienced challenges in communication, as I could not speak properly and I therefore also struggled with common social skills such as forming social relationships. I also was incapable of reading social cues and identifying the intentions of other people (see section 2.3.3.2). Due to my lack of these skills, my peers did not want to associate with me and I found it difficult to adapt to and function in a social environment. My mother believed through exposure to numerous social environments I would develop the necessary social skills to form interpersonal relationships and to function in the community and society in general. My parents involved speech and occupational therapists in helping me with word production and pronunciation, whereas the educational psychologist assisted me in understanding which behaviour was appropriate in social situations. The following sub-categories were identified as important under the social domain.

5.3.7.1 Communication

Communication is a vital part of socialising and its purpose is to share information (Maguire & Pitcheathly, 2002:698). Children on the spectrum find it difficult to communicate due to lack of emotional expression and social skills (Hale & Flusberg, 2005:158). When I communicated with my family, I tended to repeat sentences and certain key words (see section 2.4.3) or would respond by repeating what my parents would say to me. What furthermore hampered my communication was poor speech due to the weak muscles in my mouth. I received speech therapy up to the age of seven years and my speech development played a major role in my ability to read. Learning to read at a young age, contributed towards the development of word pronunciation and word production. When I moved to the remedial school, my social skills improved and I was able to communicate more effectively with my family members and my own peer group.

5.3.7.2 Friendships

Children on the spectrum find it difficult to form friendships and to establish long-lasting relationships (see section 2.4.3). I was the only learner in primary and secondary school who was diagnosed with ASD and my peers were well aware of my ‘strange’ behaviour. As I was different, they did not want to play with me or include me in their social groups. My mother kept exposing me to familiar settings such as family gatherings with the aim of making me feel comfortable and creating a platform to socialise. In this safe space, my self-confidence improved and the more we visited family members, the more I communicated with them. Throughout my primary and high school career, I had many acquaintances, but they were not interested in becoming friends. To establish friendships remained a challenge throughout my school career and the school psychologist made me aware of what behaviour was appropriate and what social skills were vital for friendships.

5.3.7.3 Social Skills

Social skills refer to the ability to communicate effectively, to follow through with conversations and express the relevant emotional responses in different social situations (see section. 2.4.3). To me as a person with ASD, these skills did not occur naturally and I had to learn through therapy the ability to communicate effectively, to understand non-verbal behaviour and the use of sarcasm and humour during conversations. My mother exposed me to different social situations in which I acquired new skills. It remained difficult for me to follow a conversation. The assistance of the school psychologist was vital in this regard as she assisted by explaining the process of a conversation and the appropriate behaviour that is required to have a good conversation, such as making eye-contact, listening to the other person and so forth.

5.3.7.4 Behaviour

Children with ASD portray behaviour that can make them socially vulnerable. In this regard Fisher, Moskowitz and Hodapp (2013:2) explain that these children portray certain behaviour traits which are not regarded as socially acceptable (see section 2.3.3.2). In my case I did not make any eye contact, my behaviour was reserved and I did not share my emotions and feelings with anybody. My mother was aware of my behaviour and at home she constantly made me aware of unacceptable behaviour and suggested alternative ways of acting when talking to other people. I was however unconditionally accepted at home and never felt that my behaviour alienated my family members. The school psychologist was a great help in this regard as she made me aware of which behaviour would make me more presentable in any given social situation.

5.3.7.5 Exposure

Exposure is vital for the child on the spectrum to develop important social skills. Fisher, Moskowitz and Hodapp (2013:2) however advise that parents and caregivers should create a protective environment for the child where they can be shielded against any form of discrimination and victimisation. My parents’ philosophy was that exposure to social situations would promote social skills, and that protecting me against the eyes of the outside world, would limit my abilities. The occupational therapist and educational psychologist also recommended that my communication skills would develop when being exposed to different environments (see section 4.2.3). The occupational therapist also assisted in this regard by including another client as part of my therapy to compel me to interact with someone else.

5.3.7.6 Theory of mind

Theory of mind is the ability to understand other people’s emotions, situations, desires and intentions (see section 2.4.3). The ability to empathize is a common problem for individuals on the spectrum and has a detrimental effect on social functioning (Goldman, 2012:4). It remained one of my most severe challenges to interact with other people, especially my peers and to understand their intentions. My mother constantly talked me through different situations to help me in understanding social rules and behaving appropriately when interacting with other people. The assistance of the educational psychologist was critical as he concentrated on how I processed information, as well as my response to the emotions and desires of other people and the non-verbal cues that they portrayed.

5.3.8 Emotional domain

Emotionally, a person with ASD cannot respond appropriately, which affects interpersonal relationships and involves inappropriate responses in challenging situations (see section 2.3.3.3). Although I also experienced the same emotions as any other person, I was unable to express emotions in a way that neuro-typical people do, such as facial and verbal expressions. I did not often cry as young children usually do, and from my physical appearance, it was difficult to detect what I was feeling (see 4.2.2). To express my emotional distress, I resorted to hand flapping as a form of comforting behaviour. The following sub-categories emerged during data analysis and represent the challenges as well as support I received in this domain, namely non-verbal, unfamiliar environments, self-confidence and bullying.

5.3.8.1 Non- verbal communication

Non-verbal communication is defined as a way to communicate without using verbal language (Hinde, 1999:12). As I struggled with limited language capabilities (see section 2.3.1), I resorted to hand gestures every time I felt psychologically threatened or unhappy, which usually occurred in unfamiliar and overpopulated environments. This non-verbal behaviour upset my mother as she knew it was socially unacceptable, and she therefore motivated me constantly to tell her about my emotional experiences.

Considering the circumplex model, parents must be considerate towards the needs of their child and therefore it is critical to not evoke any situation that can possibly trigger an emotional outburst (see section 2.3.4). My mother was always focused on my emotional well-being and tried to avoid any form of conflict that could possibly upset my emotional balance. She also involved a speech therapist to help me with my pronunciation of words as well as the production of sounds and speech to enable me to express my emotions verbally. However, it took years of therapy and effort from my mother to enable me to express my feelings and to voice my own opinions.

5.3.8.2 Unfamiliar environments

Inappropriate behaviour can usually take place in an environment that is unknown to the child with ASD. My behaviour changed in an unfamiliar environment as I felt anxious and then looked for an escape route. Although my parents were aware of my behaviour in a strange environment, on the recommendations of the educational psychologist and occupational therapist, they continued to expose me to these types of situations. Although at times it broke my mother's heart, she did not back down from 'forcing' me into situations that I tried to avoid. I always had the security that she was there – either physically, to hold my hand and assuring me of her presence, but also psychologically, as I always knew she would be there for me. Her determination helped me to become resilient and to persevere.

5.3.8.3 Self-confidence

Self-confidence is a person's belief in his/her own capabilities (Chalfant, Rapee & Carroll, 2006:3). Baumer and Spence (2018:250) postulate that the self-confidence of children on the ASD spectrum can be affected due to the inability to 'read' social cues and to respond to the emotional expressions that other children or people in general express. My self-confidence plunged at a young age when I realised that my behaviour was different from those of neuro-typical children. I always compared myself to my peers, and soon realised that I was different and therefore many a time unacceptable.

To boost my self-confidence, my parents exposed me to situations where I could mix with neuro-typical children, such as the mainstream, primary and remedial school which I attended, as well as extra-mural activities. Even though I had the opportunity to learn and socialise with these children, I was never accepted in their social circles, and always felt excluded. That was also one of the main reasons why my mother persisted in her efforts to get me enrolled in a remedial school, as she believed that a smaller learning environment with other disabled children would benefit my self-confidence. I participated in social activities such as the school play and was selected as a prefect.

At home I always had the support from my mother who motivated and encouraged me and at school; the educational psychologist reminded me that I was unique and that I should stop comparing myself to other children. The school psychologist gave me exercises in order to identify my personal strengths and limitations. On some occasions we would role play different situations to prepare me for potential challenging situations.

5.3.8.4 Fight and flight response

In any situation an individual has a choice to resort either to a fight -or flight response. Cannon (2013:95) explains that the fight response refers to the ability to remain in a situation and to handle whatever the situation involves whereas the flight response supposes the avoidance of a specific situation, which may be either physical or emotional (also see section 4.2.2.). I usually chose to remove myself from an unbearable situation – either by sitting on my own in the classroom, or withdrawing into my own world (see section 4.2.3).

My way of challenging a situation through the fight-response was to involve my mother, as was the case when I was being bullied (see section 4.3.2). My mother then reacted on my behalf by approaching the principal. The school psychologist was instrumental in enabling me to confront fellow learners who bullied me.

5.3.8.5 Bullying

Children with some form of disability are targets for bullying as they usually are vulnerable to any form of abuse (Cappadocia, Weiss & Pepler, 2012:4). In the primary school I attended, I became a victim of emotional abuse where the bullying varied from name calling to swearing (see section 4.3.2). I was also a victim of physical abuse where I broke my wrist (see section 4.3.2). The teachers were not aware that I was being bullied, and they seemed oblivious by the fact that I was emotionally vulnerable. I did not have confidence or boldness to approach my teachers with my problems due to the fear of their responses and therefore I only relied on my mother to handle the situation. My mother confronted bullies and she talked to the teacher and principal about possible solutions.

One of my biggest challenges was to confront bullies whose approach was aggressive and confronting. In the remedial school, I increased my emotional intelligence skills by learning to express my opinion which helped in safeguarding me bullying. The school psychologist was instrumental in equipping me with the necessary skills to become more assertive.

Together we role played different scenarios which taught me how to confront and deal with emotionally demanding situations.

5.3.9 Physical domain

The physical domain refers to the physical, motor and neurological challenges with which the child with ASD is confronted (Barretoa, Andrieua, Rolland & Vellas, 2018:52). Hetzroni and Shalahevich (2017:825) explain that the underdevelopment of the child's muscle tone, as well as lack of fine and gross motor skills are common in these children and also have an impact on their academic functioning, as in my case. In order to improve these muscles and skills, my mother and the therapists worked hand in hand (see section 4.2.4).The following sub-categories represent the challenges that were experienced in this domain, namely low muscle tone, fine gross motor skills and extra mural activities.

5.3.9.1 Low muscle tone

Goo, Tucker and Johnston (2018:660) explain that low muscle tone occurs more frequently in children with neuro-developmental disorders such as ASD. The low muscle tone was also evident in my speech and the way I ate (see section 4. 2.4). The speech therapist assisted with exercises to strengthen the muscles in my mouth. Eventually I was able to close my mouth while chewing and I could pronounce all sounds necessary for speaking fluently. Speech therapy was also a determining factor in my literacy abilities as it laid the foundation for learning to read at the age of five years.

The low muscle tone also hampered my ability to participate in any physical sports (see section 2.4.4.3) as my muscles responded slowly to instructions and it took me longer to respond to actions. My coordination and balance was affected. The occupational therapist provided activities to improve my low muscle tone such as climbing, jumping and running activities. My parents allowed me to participate in private extra mural activities such as swimming, tennis, playball, pottery and karate to improve my low muscle tone. At first it was a challenge to participate, as my reaction time was too slow on the tennis court and in the swimming pool in comparison with the children my age. Through continuous participation, my low muscle tone improved and I was able to compete with neuro-typical children. Although my muscle tone improved over years, it still remained challenging to perform a task as swiftly as other people do.

5.3.9.2 Fine and gross motor skills

Fine and gross motor skills are seen as fundamental as these provide the basis for reading and writing (see section.2.4.4.3). These skills involve the development of the muscles in the hands, toes and wrists (Buja, Volfovskyb, Kriegera, Lordc, Lashb, Wiglerd & Lossifov, 2018:1859) (also see section 2.4.4.3). In pre- and primary school, I struggled with activities, such as cutting out pictures, colouring and drawing, tying of shoe laces and the building of puzzles. The assistance of the occupational therapist helped me to improve the finer motor muscles in my hands and toes. The occupational therapist provided homework activities that I needed to complete with the assistance of my mother.

5.3.9.3 Extra-mural activities

Extra-mural activities refer to those activities that are presented additionally by the school or can be offered privately (Jakobsson, 2018:3). Participation holds numerous benefits for the child's health as well as creating a platform for social interaction (see section 2.4.4). My parents combined the therapy with extra mural activities. Each activity, such as swimming, karate and tennis lessons, improved my gross motor skills, my hand-eye coordination and balance. The pottery and playball lessons also helped me to improve my fine motor skills as well as hand-eye coordination.

5.4 SYNTHESIS

Supporting a child with ASD educationally is a difficult task due to the number of the challenges in the cognitive, emotional, social and physical domains. Having the dream that I should function optimally in society, acted as impetus for my mother to resign her job and devote all her attention to me. In order to afford specialised support, my father had to work overtime, and with his help, the services of an occupational and speech therapist, as well as an educational psychologist could be engaged and various extra-mural activities could be financed to provide additional support.

From the data that was collected, I realise that without full-time support in the form of a dedicated parent or caregiver, as well as specialised support, I would not have been able to complete my school career and obtain university exemption.

What saddens me is that the education system makes it so difficult for parents to access special schools. For seven years my mother tried her best to enrol me in a remedial school – without success. The fact that I appeared physically ‘normal’ and that my marks were reasonable were stumbling blocks that prevented me from receiving my education in a smaller environment that would meet my needs in all domains. South Africa supports the inclusive education policy, which holds that all children, irrespective of their abilities, are entitled to mainstream education. I personally believe that it is an injustice to children with disabilities, such as myself, to be forced to attend a school where you cannot function to your potential, as the classes are too big, and where you cannot experience unconditional acceptance, as you are different.

Mainstream schools also do not employ teachers with the necessary knowledge and skills to handle a diverse classroom. There is very little understanding and empathy for the child who is differently abled. Teachers therefore are not aware of the vulnerability of these children, and they also do not notice when and if these children fall through the cracks. The sub-categories that emerged from the data analysis clearly indicates that a child on the spectrum, travels a long and uphill journey, and in Vygotskian terms, he/she needs a capable adult to scaffold him/her to reach his/her full potential.

5.5 CONCLUSION

This chapter presented the interpretation of my auto-ethnography based on data collected through interviews with my support system, as well as my own experience during my school career. One theme was prevalent, namely educational support and the four domains (cognitive, social, emotional and physical) were used as categories to guide the interpretation. Various sub-categories emerged from the data and served as markers to explain my challenges but also the support I received in this regard. The literature that I have consulted, as well as the theoretical framework and my research questions were all combined to make sense and attach meaning to my data (see section 2.2.1).

In the next chapter an overview of my key literature and empirical findings will be presented, my research questions will be answered, and the chapter will conclude by the submission of several recommendations.

CHAPTER 6

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

In chapter five I interpreted the data according to the different categories and subcategories that emerged from the data analysis. To conclude this study, this chapter commences by summarising the key findings that emerged from the literature review on the autism spectrum, the challenges the child on the spectrum are confronted with and the support needed to overcome these barriers. This section will be followed by the most important empirical findings that emerged from my auto-ethnographic account where I shared my personal experiences as an individual on the spectrum with special emphasis on the educational support I received throughout my school years. I conclude this chapter by presenting recommendations to the Department of Education (DoE), universities, teachers and parents.

6.2 SUMMARY OF KEY LITERATURE AND EMPIRICAL RESEARCH FINDINGS

The following section sheds light on the findings that originated from the literature review that was conducted for this study as well as empirical research findings which emerged from the interviews with participants, as well as my own contribution. The conceptual framework which guided my literature review, also acted as lens for my data analysis and interpretation.

6.2.1 Summary of key literature findings

Autism Spectrum Disorder (ASD) is a neurological disorder that affects the individual's functioning abilities in society. Literature identifies four domains where the challenges of the child with ASD manifest, namely the cognitive, emotional, social and physical developmental areas (see section 2.3.3). Without support, the child will not be able to reach his/her full potential. Vygotsky's First Generation Theory (FGT) identifies three elements in the support process, namely the subject, tools and object. For the purpose of this study, the subject was represented by the child with ASD (me), who needed different types of support (tools) to reach an outcome (to complete my grade 12 year)(see section

2.2.1). Children with autism are diagnosed according to two categories of functioning, namely high functioning autism (HFA), where the child is still able to function in society with additional support, and low functioning autism (LFA), where these children are not able to function in society (see section 2.3.2).

Challenges emanating from this disorder manifest in four domains; the most important is the cognitive domain which involves the child’s ability to function academically in school. Academic success is therefore dependent on cognitive skills and this is where support is most needed as these children tend to present with numerous sensory and intellectual challenges which require specialised support. The teacher plays a major role in this domain as this is where the curriculum should be adapted and content broken up in smaller sections. Teacher understanding and knowledge of ASD is crucial to ensure a safe space for these children to explore and thrive.

The social and emotional domains are interrelated, as the child’s social incompetence has a negative impact on the emotional domain. Because of the child’s inability to form relationships and manifestation of unusual physical manifestations such as repetitive movements, hand flapping and so on, (see section 2.3.3.2), other children tend to avoid social activities where the child on the spectrum is included, which causes a low self-concept and feelings of rejection. The child with ASD then resorts to a fight or flight response, where a situation is confronted or most often, where the child would rather remove him/herself from a situation. Physically the child also struggles to perform on the sports field because of low muscle tone and lack of perceptual skills.

Regarding support, the internal support system remains the primary and the most constant support system of the child. According to the circumplex model, families have a choice to either embrace or reject the diagnosis with ASD (see section 2.3.4). Parents can embrace the diagnosis by involving the assistance of specialist external service providers such as occupational and speech therapists as well as the help of an educational psychologist to strengthen their knowledge base and to assist their child in the best possible manner (see section 2.4). Each service provider has their own responsibility as they address the common challenges with which the child on the spectrum is confronted. The speech therapist’s involvement is vital as her assistance contributes towards the improvement of the basic word pronunciation and speech production. The occupational therapist provides numerous activities to improve the child’s basic gross and fine motor skills and assist with sensory sensitivity. The educational psychologist's assistance is vital as the activities that are provided help the child to improve his/her self-confidence and basic planning and organisational skills (see section 2.3.4).

Therapy is beneficial as its focuses on school readiness but cannot guarantee that the child will function in a formal schooling system. Therefore, early intervention and one-to-one tuition are vital to improve the capabilities of the child.

6.2.2 Summary of key empirical research findings

The diagnosis of a child with ASD has a drastic effect on a family, which became evident from the empirical findings. Data was gained by means of self-interview, semi-structured interviews, conversations, my mother's book and analysing historic artifacts such as psychologist and therapist reports, school progress reports and certificates.

My main support figure was my mother, who made the decision to embrace this diagnosis, and therefore resigned from her job to devote her full attention to me. In the process a special bond developed between the two of us as she was my confidante and the champion of my battles. My father undertook the role of financial provider and the assistance of external specialists could be afforded in supporting me with my various challenges (see 4.2.1).Financial means was indispensable in the support process as it paid for the much needed therapy and the private extra-mural activities (see section 4.3.3 & 4.3.4). The therapy that I received was beneficial as it helped in improving my low muscle tone which was also noticeable in my speech production, word pronunciation and physical movement. Both the speech and occupational therapist admitted that therapy was not the only solution to overcome these challenges and mentioned that the combination of therapy and individual sessions improved my muscle tone and my school readiness (see section 4.3.1). Despite the numerous challenges I struggled with, the therapists believed that I could reach my developmental milestones in a mainstream setting with hard work and dedication.

Because of my inability to form social relationships, the bond between me and my brother was damaged, and he had to devise his own plans to accommodate his need for brotherly love and companionship (see section 4.3.2). As I never had friends, I grew up as a lonely boy whose overall ambition to prove himself was the main driver of my daily life. I fought a battle in all four developmental domains and was encouraged by my mother and the educational psychologist to persevere.

To cope in a mainstream primary school remained a challenge as the classrooms were overpopulated and I experienced sensory overload on a daily basis. The teachers were not equipped to deal with a learner with ASD and no support was received from their side. Basic planning and organisation also remained a major challenge for me and the assistance of my mother was indispensable for academic progress. She combined formal schooling with individual attention in the afternoons to ensure that I did not fall behind and that I was fully prepared for assessments and examinations.

My parents were aware of the different challenges I experienced and needed to make an informed decision for my cognitive, emotional and social wellbeing. A remedial school was the best option as the teachers were trained in special education, classrooms were smaller, work content was organised and a safe psychological space was created where my skills could improve (see section 4.4). I progressed well in the high school, cherished high expectations and continued to compare myself with members from my peers. My high expectations motivated me to work hard and resulted in achieving good marks in Grade 12 and in obtaining university exemption.

6.3 RESEARCH CONCLUSIONS

In the following section, the conclusions will be drawn from the research questions which were selected as framework to guide this study. The secondary questions will be answered first as it leads to the final research conclusions and the answering of the main research question.

6.3.1 Secondary research question 1: What were the experiences of my educational support system?

Educational support took place internally (from my family’s side) and externally (from a professional side). The internal support system is emotionally involved; the diagnosis of a child with ASD usually is a devastating experience, as family members’ hopes and dreams for the child may initially be shattered. My parents were confronted with the choice to either place me in a governmental owned autism facility or to take the responsibility for my education on their shoulders by providing me with the same educational opportunities as neuro-typical children. This compelled my mother to resign from her job to dedicate her full attention to my support while my father had to work overtime to meet the financial demands of professional support. To succeed in a mainstream primary school required hard work and dedication, with the fear of failure always lurking. Failing was not an option and by setting her personal goals and dreams aside, my mother assisted me every afternoon with homework. Long hours, late nights and challenging situations along the way made the support journey arduous, but she kept believing in me and therefore persevered during difficult times. Although confronted with criticism, my mother remained steadfast and continued to expose me to different situations even when being queried about my strange and “inappropriate behaviour” by family members and people from the community.

The positive experiences overshadowed all the challenges as the dedication and hard work was rewarded when I achieved certain academic and social milestones, which would not be possible if it was not for the support of my mother. My mother does not regret the time she spent to assist me, but would have made some decisions differently in terms of school choice and to spend more time with my brother.

My diagnosis with ASD also had a significant effect on my father. Because he did not know how to deal with my diagnosis and everything it involved, he distanced himself emotionally and was an uninvolved figure throughout my developmental journey and left all the decisions regarding my development to my mother. My father found meaning in his work and avoided all the challenges with which my mother and I were confronted. My father saw his role as the financial provider and I am so grateful for this as it financed the therapy and the participation in extra-mural activities crucial to address my cognitive, emotional, social and physical challenges. However, I realise that my diagnosis with ASD and the associated challenges had a tremendous impact on our family dynamics.

My external support system involved a speech and occupational therapist as well as an educational psychologist. As these professionals were trained in working with children with disabilities, their experiences were based on professional observances. My mother’s intense involvement in my therapy made her a partner in the professional support process; she continued the support at home and stayed in contact with the external support system to notify them about challenges and progress. They all mentioned the value of an involved parent and admitted that success would not have been possible, had it not been for the dedication of my mother.

6.3.2 Secondary research question 2: What are the key elements of an educational support structure for a child with ASD?

The key elements of an educational support structure are presented in bullet format:

- The most important element of a support structure is involved parents or caretakers. A parent/caretaker who is dedicated to the child's holistic well-being will sacrifice personal time and resources to ensure that the child develops according to his/her potential. Parents/caretakers also lead by example and instil values, such as hard work, patience, determination and faith during difficult times.
- Qualified teachers are another key element in the support process as these are the people with whom the child spends the largest part of his/her day. Apart from the necessary knowledge about the child's syndrome, the teacher should also establish an emotional safe climate in the classroom from where the child will be able to explore and interact with peers.
- Parents should involve the assistance of professional service providers such as an educational psychologist, speech therapist and occupational therapist to start with early intervention in order to address challenges associated with ASD. These professionals also act in an advisory capacity to parents and teachers as how to improve different skills that contributes towards cognitive, social, emotional and physical progress.
- A partnership among the caretakers, school and professional services is indispensable in the support process as continuous communication and collaboration between these three parties are fundamental for support to be successful.
- Educational support should be launched from a supportive environment, which is not a mainstream school, but an educational institution which has the necessary human and other resources with the main aim of supporting the child educationally.
- The last element of the support structure, that is often overlooked, is an additional support network for parents/caretakers. Having a child with ASD is emotionally draining and often leads to an isolated life where there is seldom an understanding for the challenges which confront the affected family. The extended family or friends should be involved to alleviate the pressure which accompanies raising a child on the spectrum.

6.3.3 Main research question: How was I educationally supported in dealing with autism during my school years?

Since my diagnosis with ASD, my educational support commenced when my parents decided to raise me in a mainstream environment with the support of therapeutical intervention. The educational support I received from my internal and external support systems had a determining influence on my emotional, social, cognitive and physical development. Therapy was combined with extramural activities to improve my low muscle tone and motor skills. Swimming lessons helped in improving my gross motor skills; tennis lessons, karate and pottery classes helped in improving my hand-eye coordination and finer motor skills.

My mother was the single support figure who, in Vygotskian terms, scaffolded me throughout my school career and ensured that I achieved my academic goals. By assuming the roles of consumer and caregiver (see section 2.4), my mother made sure that my homework was correctly done and that I was adequately prepared for examinations. We were a team who met every academic challenge head-on with an unspoken drive to disprove the verdict from years ago: that I would not be able to cope in a mainstream education environment and, by implication, that I would never be able to function independently in society.

My placement in a remedial school at the end of my primary school years lent momentum to my educational support as the classes were smaller, individual attention was possible and the teachers were equipped to deal with learners with disabilities. The school psychologist was available on a permanent basis to assist me every time I experienced emotional challenges, which could have potentially impacted my school career.

6.4 MY STUDY'S CONTRIBUTION

The writing of this auto-ethnography created a platform from where I could share my personal experiences as an individual with autism. Through this novella, my story may serve as an inspiration for families in a similar situation, provide guidelines for support and provide a strategy for addressing challenges associated with ASD.

The following points were made in this study, which I regard as my contribution to the educational field:

- Without a clear and strong educational support network, a child with autism cannot overcome any challenge, which implies that without a dedicated community of practice, academic and social success is impossible. My study therefore acknowledges the contribution of a support network to my development and overall school performance. Hafeez, Alghatas, Foroudi, Nguyen and Gupta (2018:4) quote Wenger *et al*. (2002) who define communities of practice as "groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis". In other words, a community of practice produces a collective effort by influential and knowledgeable people who share a common interest and by collaborative effort strive towards a greater cause.
- Mandell and Salzer, (2007:1) suggest that the earlier the child receives support, the greater the probability to overcome challenges (see section 2.3). These authors furthermore warn that parents cannot solely rely on the assistance of service providers but should undertake their responsibility as they are seen as the 'cornerstone' of their child's support base (Mandell & Salzer, 2007:2).Parents remain a continuous source of support, whereas service providers are periodic assistants throughout the different stages of the child's development.
- In my study I also elaborated on the risks involved of placing a child with autism in a mainstream school as large classrooms and inexperienced teachers contribute towards the sensory challenges and overall (lack of) academic performance (section 4.4). I also briefly compared the two different schooling systems (mainstream versus remedial) and in my narrative the benefits of remedial schooling are evident as it is a smaller but more secure environment. Mandell and Salzar (2007:30) also point to the benefits of a remedial environment for parents who are unable to afford specialised service providers, as remedial schools provide therapy and education support. My study however indicates that children diagnosed with autism can cope in a mainstream school system, with additional support, but their sensory needs must first be accommodated (see section 2.3.3.1).
- Attwood (2013:13) postulate that children on the autism spectrum find it difficult to attune their behaviour, which include basic communication and social skills, to

unfamiliar environments. These social skills do not occur naturally as is the case with neuro-typical children and must be deliberately acquired through constant exposure and stimulation. This study may motivate parents to expose their child to unfamiliar environments and to stretch their comfort zones, as the child is then compelled to acquire new skills through the stimulation of brain paths which may ultimately lead to new behaviour patterns.

Through the report of my experiences, I believe that I provided a modus operandi to overcome challenges associated with autism through educational support.

6.5 RECOMMENDATIONS

With reference to the findings of my research, the following recommendations are made to the Department of Education, universities, teachers and parents:

6.5.1 Recommendations for the Department of Education (DoE)

The following recommendations are directed at the DoE as custodian of education in South Africa:

Recommendation 1

As South Africa underwrites the inclusive education policy which holds that all children, irrespective of ability, should attend mainstream schools, all teachers should be trained and equipped to deal with learners with special needs in mainstream schools. In-service training for all practicing teachers should focus on equipping teachers with the necessary skills in accommodating learners with special needs in these schools.

Recommendation 2

There should be collaboration between the DoE and universities, who are responsible for teacher training. Universities should be mandated by the DoE to train student teachers with relevant skills in enabling learners with disabilities to function according to their potential with the necessary accommodations.

Recommendation 3

Access to remedial schools should be simplified. Parents who know their children cannot function in a mainstream setup should be able to voice their concerns to the relevant educational authorities and their personal experience with their child should be acknowledged.

6.5.2 Recommendations for universities

Universities as teaching training institutions should be sanctioned to do the following:

Recommendation 4

Faculties of Education at universities should devote special modules on disabilities and disorders that are prevalent in the education system, such as ASD. Currently ASD is only briefly dealt with in core modules such as Learning Support and Life Orientation methodologies. These modules provide students with basic knowledge about the disorder but do not focus on the broad spectrum and the types of support that is available to improve and overcome common barriers associated with this disorder.

Recommendation 5

Faculties of Education should make use of specialists when presenting modules on disabilities and disorders such as ASD. Specialists include therapists, parents (particularly mothers) of children with ASD and even a person with ASD, who can share their experiences and advise student teachers. Lack of experience with these disorders, results in a superficial and limited exposure to this knowledge field, whereby the student teacher is inadequately prepared for school practice.

6.5.3 Recommendations for teachers

The following recommendations are directed at teachers, who are in the front-line of the larger education support network:

Recommendation 6

Teachers should take responsibility for their knowledge base. When confronted with a learner who displays some or other form of unacceptable or strange behaviour, teachers should follow different routes to determine possible causes for specific behaviour patterns:

- Observation of the child is very helpful, not only in the classroom, but also on the playground or sports field;
- The child’s home background should be investigated with reference to the home environment and the internal relationship among family members;
- Articles can be consulted and the insights of knowledgeable professionals should be sought before any conclusions are drawn. By eliminating all the ‘grey areas’ with regard to questions teachers have, the parents can be approached and possible methods of assistance can be discussed considering the child’s well-being and progress.

6.5.4 Recommendations for parents

The following recommendations are directed at parents of children with ASD:

Recommendation 7

Once a child has been diagnosed with ASD, parents should immediately get a support structure in place. Ideally, support should include professional assistance such as relevant therapists and psychologists, but this is not always financially viable. The diagnosis should be discussed with the extended family as well as with the principal and teachers to ensure an understanding of the challenges associated with ASD and that the necessary support measures are put in place – not only for the child, but also for the parents.

Recommendation 8

Children on the spectrum have unique challenges that can affect the child’s abilities to function in a mainstream schooling system, therefore the selection of an appropriate school is of utmost importance. Before parents consider school placement, parents should do research by interviewing the principal and gathering information about the different services and activities the school has to offer.

6.6 CONCLUSION

This study gave an account of my experiences with ASD during my school career and the impact of educational support on my development and academic success. Throughout my school journey, every milestone I achieved refuted critics and stressed the importance of continuous educational support. This auto-ethnography queries common misconceptions regarding the learning and functioning abilities of children with ASD spectrum in a mainstream schooling system by referring to my experiences in pre- primary, primary and high school. Each phase had its own unique challenges in the different developmental domains.

Personally my master's dissertation was particularly meaningful and therapeutic. On the one hand, I had to consult the literature regarding autism and the devastating effect of the syndrome on the person with this syndrome and on his/her family. That provided an objective look at what my family had to endure and it also made me extremely sad to realise the extent of the impact on familial relationships. The information I gained through conversations with my internal support system as well as reading my mother's book gave me an intimate glance into each one of my family member's experiences; only then did I realise the impact that my challenges and behaviour had on my family. Their contributions were honest and although it was difficult and painful to hear, I believe it was necessary as it helped me to look beyond my own needs and experiences and to experience empathy for their experiences. However, time heals – I have learned through this process to accept and respect my internal family's (participants) feelings regarding autism and their attitudes towards me.

This auto-ethnographic experience changed the way in which I now value my achievements during my school career. Throughout the years I always compared myself with my peers. I always was second best in basic social and academic activities. Through the writing of my novella, I was enabled to view my school career through different eyes. For the first time I accept myself and I am so grateful for how my life turned out. Apart from the help of Almighty God, I am convinced that I would not have been able to write this report, were it not for the sacrifices of my beloved mother.

Another intention that I had with this study was to create a direction for parents to follow to ensure that their child achieves common education goals and milestones. This study can be used to create ASD awareness and can motivate and inspire parents to support their child continuously and start with intervention as soon as possible. It was also important to give hope to parents and urge them not to isolate their child from the outside world, but to expose their child to numerous environments as frequently as possible although this may prove very difficult. It was important to share the message that parents or children with ASD must not hide behind the diagnosis, but rather embrace it.

Raising a child with ASD is no picnic, but from personal experience I can say with conviction that through hard work and with a committed educational support structure, children diagnosed with ASD can reach educational milestones and function optimally in society.

Autism is a lifelong disorder; I know that I cannot be healed but through exposure, I have earned new skills to improve my life. The future remains unknown, but I believe through the retelling of my personal story, parents can be reached, inspired and motivated to broaden their child's horizons and to believe in their capabilities despite the diagnosis with ASD.

The strongest message that this study can provide is that children with ASD can learn and reach their full potential if they have a continuous support structure available. Another important message is that children on the spectrum can achieve common milestones just as their neuro-typical counterparts - there must just be opportunities for them to explore their gifts and talents.

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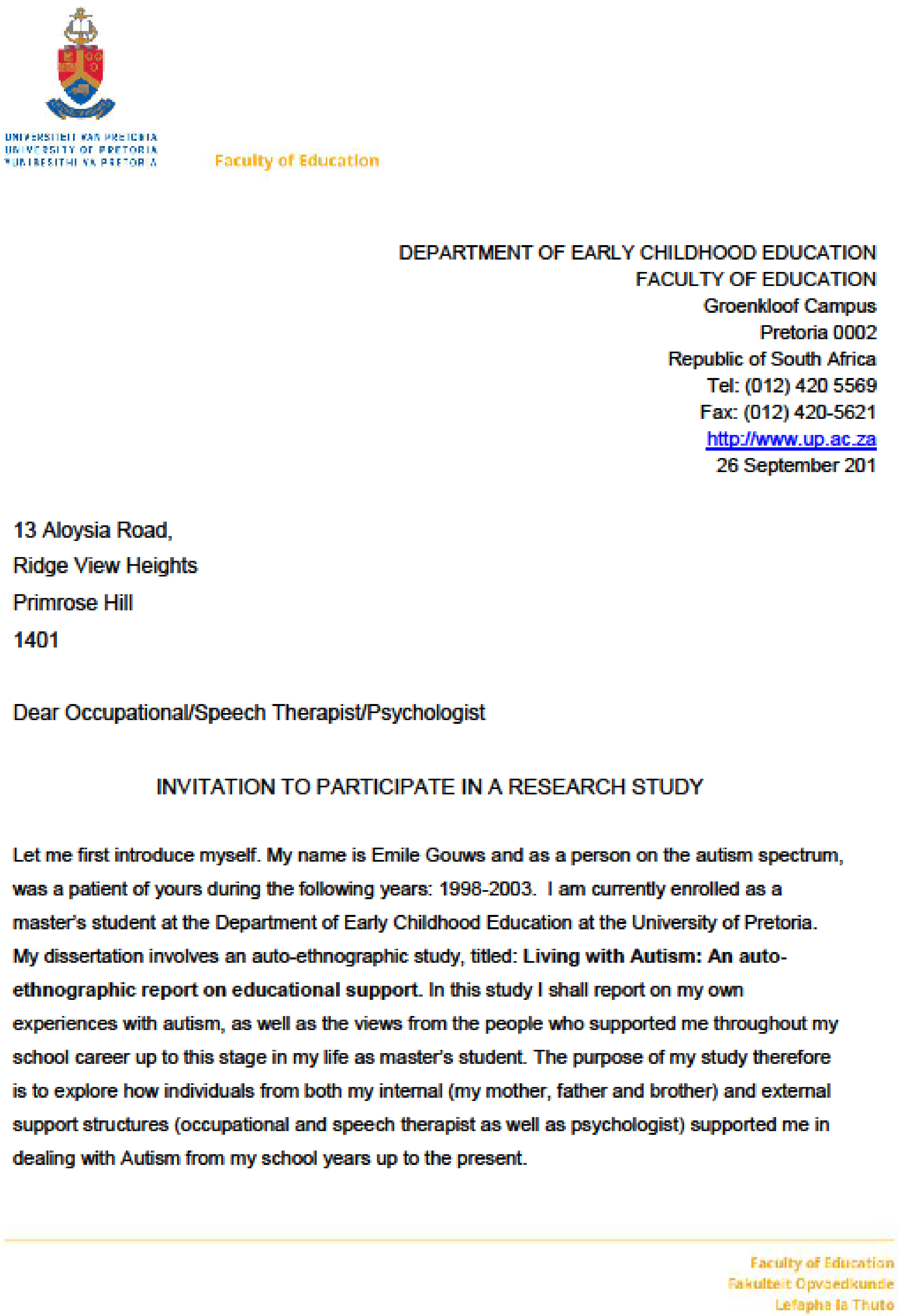
ANNEXURE A: Invitation to participate in a research study – School Psychologist



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http://www.up.ac.za

26 September 201

13 Aloysia Road,
Ridge View Heights
Primrose Hill
1401

Dear Occupational/Speech Therapist/Psychologist

INVITATION TO PARTICIPATE IN A RESEARCH STUDY

Let me first introduce myself. My name is Emile Gouws and as a person on the autism spectrum, was a patient of yours during the following years: 1998-2003. I am currently enrolled as a master's student at the Department of Early Childhood Education at the University of Pretoria. My dissertation involves an auto-ethnographic study, titled: **Living with Autism: An auto-ethnographic report on educational support**. In this study I shall report on my own experiences with autism, as well as the views from the people who supported me throughout my school career up to this stage in my life as master's student. The purpose of my study therefore is to explore how individuals from both my internal (my mother, father and brother) and external support structures (occupational and speech therapist as well as psychologist) supported me in dealing with Autism from my school years up to the present.

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Faculty of Education

As you were one of the members of my external support system, I would be grateful if you will agree to participate in my study. Your participation will involve taking part in a semi-structured interview(s) to explore your experiences with me as a patient, and also sharing your general experiences with people on the autism spectrum. I shall also make use of your therapeutic reports that you made available to my parents during the consultation period. These will be available during the interview session for your reference.

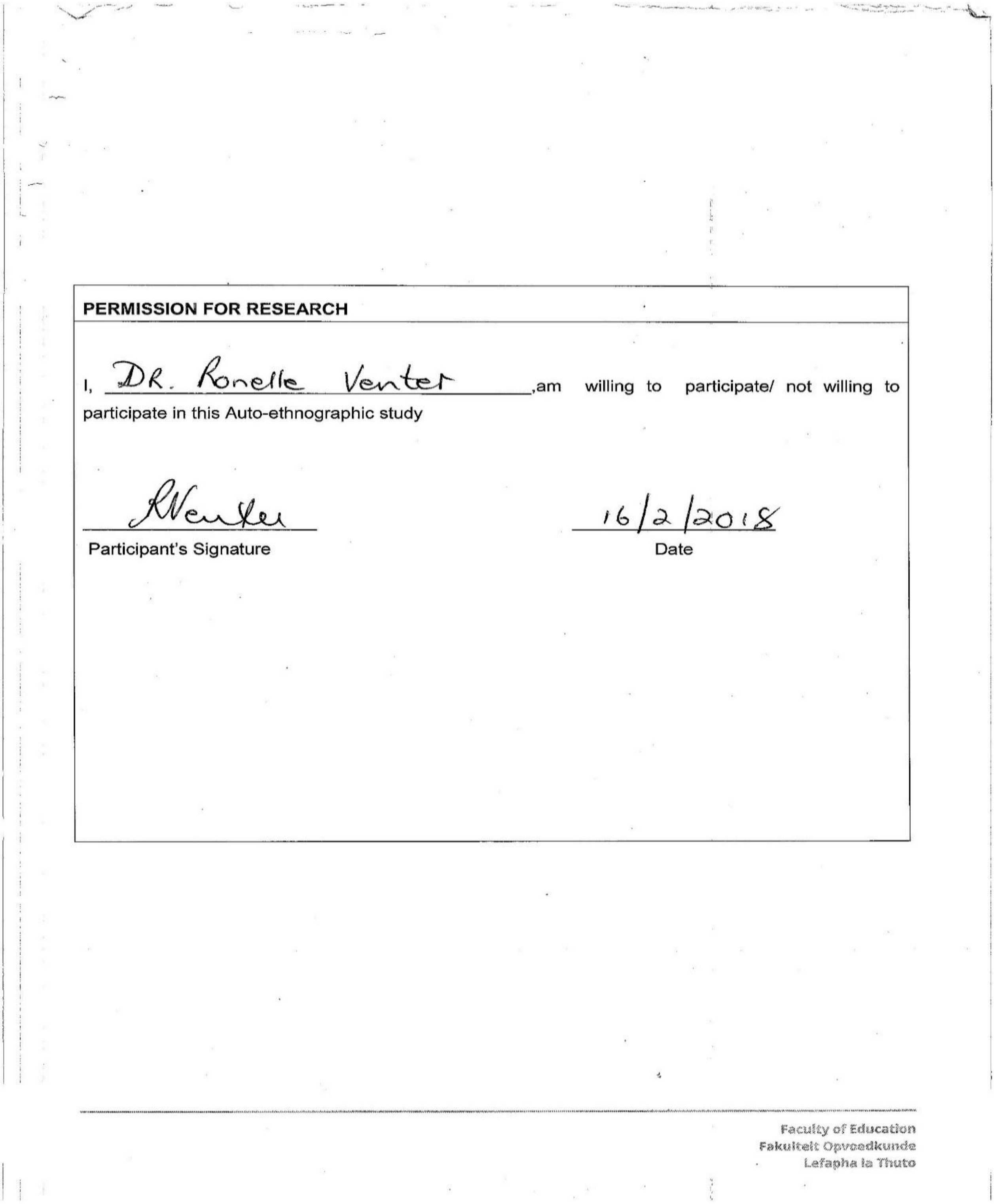
One of the fundamental criteria of ethical conduct is confidentiality and anonymity. I will make use of a pseudonym when I will be referring to you in my study so that your identity will be protected.

Should you be willing to participate in the study, I can assure you that no information that you may regard as personal or confidential, will be mentioned in my study. You will have the opportunity to read my dissertation throughout its progress, and will be able to share your comments and insights with me. Participation is voluntary which means that should you feel at any stage during the course of the study, that you want to withdraw as participant, you may do so.

Should you agree with the above mentioned information and are comfortable to be a participant in my study, please complete the attached letter of consent.

Kind regards
Emile

Emile Gouws	Prof MG Steyn (supervisor)
Mieliemeel93@gmail.com	mg.steyn@up.ac.za
0837048326	(012) 420 5289
	0822022133



PERMISSION FOR RESEARCH

I, DR. Ronelle Venter ,am willing to participate/ not willing to participate in this Auto-ethnographic study

RVenter
Participant's Signature

16/2/2018
Date

Faculty of Education
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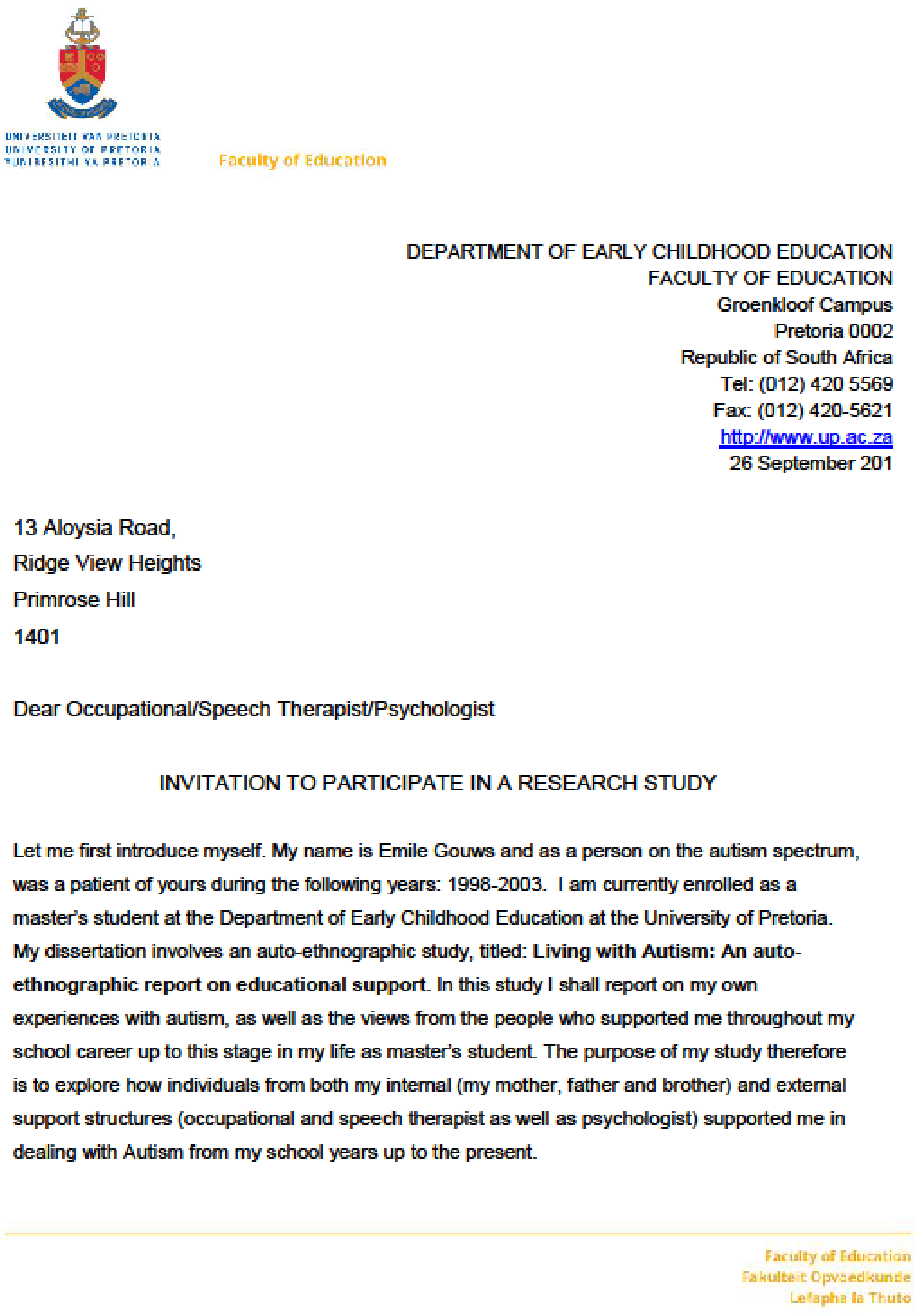
Lefapha la Thuto

ANNEXURE B: Invitation to participate in a research study – Speech Therapist



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26 September 201

13 Aloysia Road,
Ridge View Heights
Primrose Hill
1401

Dear Occupational/Speech Therapist/Psychologist

INVITATION TO PARTICIPATE IN A RESEARCH STUDY

Let me first introduce myself. My name is Emile Gouws and as a person on the autism spectrum, was a patient of yours during the following years: 1998-2003. I am currently enrolled as a master's student at the Department of Early Childhood Education at the University of Pretoria. My dissertation involves an auto-ethnographic study, titled: **Living with Autism: An auto-ethnographic report on educational support**. In this study I shall report on my own experiences with autism, as well as the views from the people who supported me throughout my school career up to this stage in my life as master's student. The purpose of my study therefore is to explore how individuals from both my internal (my mother, father and brother) and external support structures (occupational and speech therapist as well as psychologist) supported me in dealing with Autism from my school years up to the present.

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Lefapha la Thuto

As you were one of the members of my external support system, I would be grateful if you will agree to participate in my study. Your participation will involve taking part in a semi-structured interview(s) to explore your experiences with me as a patient, and also sharing your general experiences with people on the autism spectrum. I shall also make use of your therapeutic reports that you made available to my parents during the consultation period. These will be available during the interview session for your reference.

One of the fundamental criteria of ethical conduct is confidentiality and anonymity. I will make use of a pseudonym when I will be referring to you in my study so that your identity will be protected.

Should you be willing to participate in the study, I can assure you that no information that you may regard as personal or confidential, will be mentioned in my study. You will have the opportunity to read my dissertation throughout its progress, and will be able to share your comments and insights with me. Participation is voluntary which means that should you feel at any stage during the course of the study, that you want to withdraw as participant, you may do so.

Should you agree with the above mentioned information and are comfortable to be a participant in my study, please complete the attached letter of consent.

Kind regards
Emile

Emile Gouws	Prof MG Steyn (supervisor)
Mieliemeel93@gmail.com	mg.steyn@up.ac.za
0837048326	(012) 420 5289
	0822022133

PERMISSION FOR RESEARCH

I, Sontie van Aartsen ,am willing to participate/ not willing to participate in this Auto-ethnographic study

Participant's Signature

01|03|2018 .
Date

Faculty of Education
Fakulteit Opvoedkunde
Lefapha la Thuto

ANNEXURE C: Invitation to participate in a research study – Mother

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http://www.up.ac.za

26 September 201

13 Aloysia Road,
Ridge View Heights
Primrose Hill
1401

Dear Mother

INVITATION TO PARTICIPATE IN A RESEARCH STUDY

As you know, I am currently enrolled as a master's student in the Department of Early Childhood Education at the University of Pretoria. My dissertation involves an auto-ethnographic study, titled: **Living with Autism: An auto-ethnographic report on educational support**. In this study I shall report on my own experiences with autism, as well as the views from the people who supported me throughout my school career up to this stage in my life as master's student. The purpose of my study therefore is to explore how individuals from both my internal (my mother, father and brother) and external support structures (occupational and speech therapist as well as psychologist) supported me educationally in dealing with autism from my school years up to the present.

As you were and still are the main support figure in my life, I shall be grateful if you would agree

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Lefapha la Thuto

to participate in my study. Your participation will involve the following:

- Taking part in semi –structured interviews in order to garner general information pertaining to your life, as well as several conversations to get an insider's perspective of your personal experiences with the raising of a child on the autism spectrum and the personal challenges and sacrifices you were confronted with in order to support me. These interviews will be recorded to allow me to revisit our communication and to enable me to transcribe the interviews.
- Granting me permission to constantly refer to and quote from the book that you wrote entitled "Mother, why me?" which narrates the journey that both of us undertook.
- Making use of old progress reports as well as photographs in order to refresh my memory and to relive some experiences.

One of the fundamental criteria of ethical conduct is confidentiality and anonymity. As my identity will be known, I cannot guarantee anonymity to you. Should you be willing to participate in the study, you must be aware that your identity will be known to whoever reads the study. I can however assure you that no information that you may regard as personal or confidential, will be mentioned in my study. You will have the opportunity to read my dissertation throughout its progress, and will be able to share your comments and insights with me. Participation is voluntary which means that should you feel at any stage during the course of the study, that you want to withdraw as participant, you may do so.

Should you agree with the above mentioned information and are comfortable to be a participant in my study, please complete the attached letter of consent.

Kind regards
Emile

Emile Gouws

Prof MG Steyn (supervisor)
Mg.steyn@up.ac.za
0822022133
(012) 420 5289

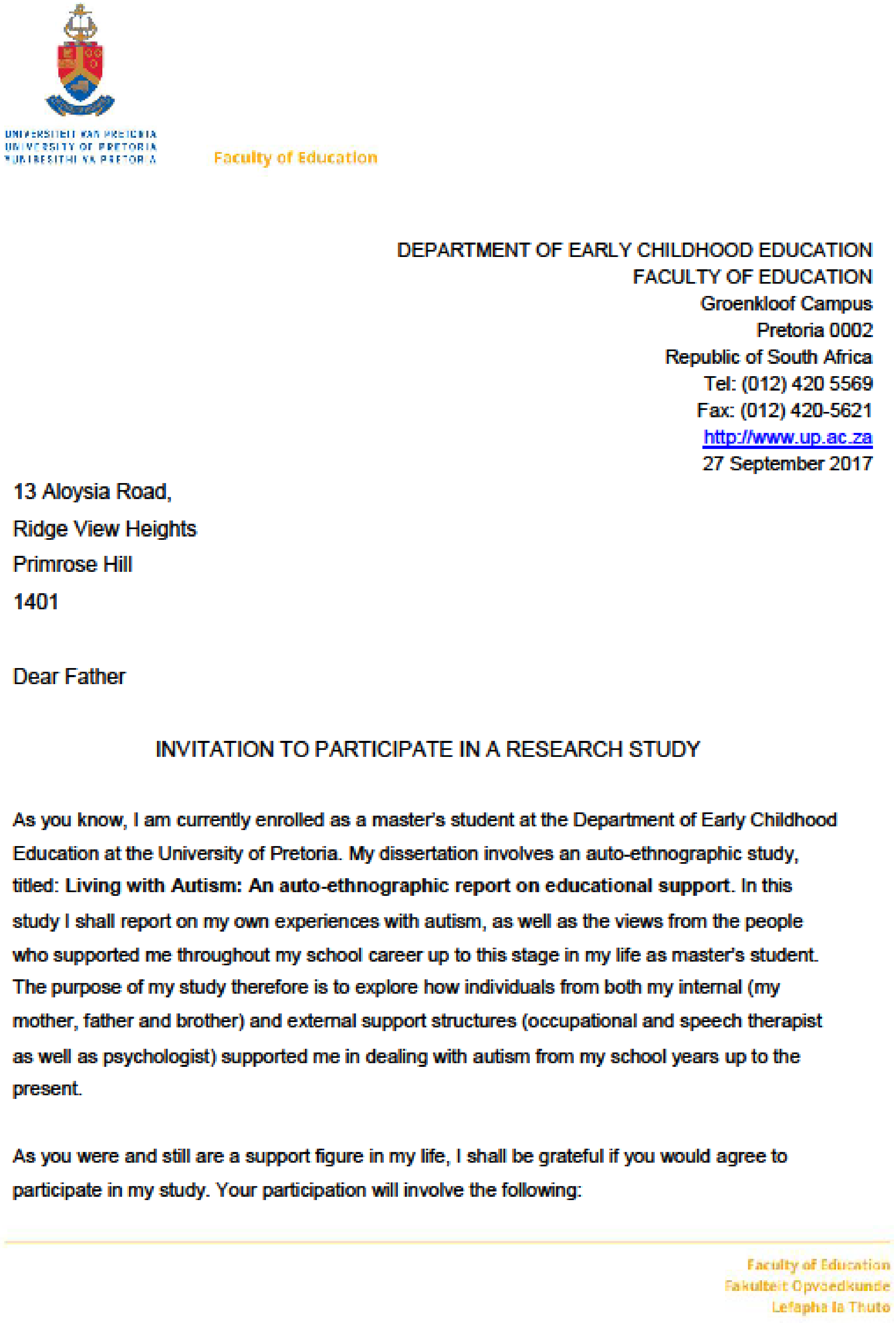
PERMISSION FOR RESEARCH

I, Mariè Gaus ,am willing to participate/ not willing to participate in this auto-ethnographic study

Participant's Signature

14-02-2018
Date

ANNEXURE D: Invitation to participate in a research study – Father



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http://www.up.ac.za

27 September 2017

13 Aloysia Road,
Ridge View Heights
Primrose Hill
1401

Dear Father

INVITATION TO PARTICIPATE IN A RESEARCH STUDY

As you know, I am currently enrolled as a master's student at the Department of Early Childhood Education at the University of Pretoria. My dissertation involves an auto-ethnographic study, titled: **Living with Autism: An auto-ethnographic report on educational support**. In this study I shall report on my own experiences with autism, as well as the views from the people who supported me throughout my school career up to this stage in my life as master's student. The purpose of my study therefore is to explore how individuals from both my internal (my mother, father and brother) and external support structures (occupational and speech therapist as well as psychologist) supported me in dealing with autism from my school years up to the present.

As you were and still are a support figure in my life, I shall be grateful if you would agree to participate in my study. Your participation will involve the following:

- Taking part in a semi –structured interview in order to garner general information pertaining to your life, as well as several conversations to get an insider's perspective of your personal experiences as father with a son on the autism spectrum.

One of the fundamental criteria of ethical conduct is confidentiality and anonymity. As my identity will be known, I cannot guarantee anonymity to you. Should you be willing to participate in the study, you must be aware that your identity will be known to whoever reads the study. I can however assure you that no information that you may regard as personal or confidential, will be mentioned in my study. You will have the opportunity to read my dissertation throughout its progress, and will be able to share your comments and insights with me. Participation is voluntary which means that should you feel at any stage during the course of the study, that you want to withdraw as participant, you may do so.

Should you agree with the above mentioned information and are comfortable to be a participant in my study, please complete the attached letter of consent.

Kind regards
Emile

Emile Gouws	Prof MG Steyn (supervisor) Mg.steyn@up.ac.za 0822022133 (012) 420 5289

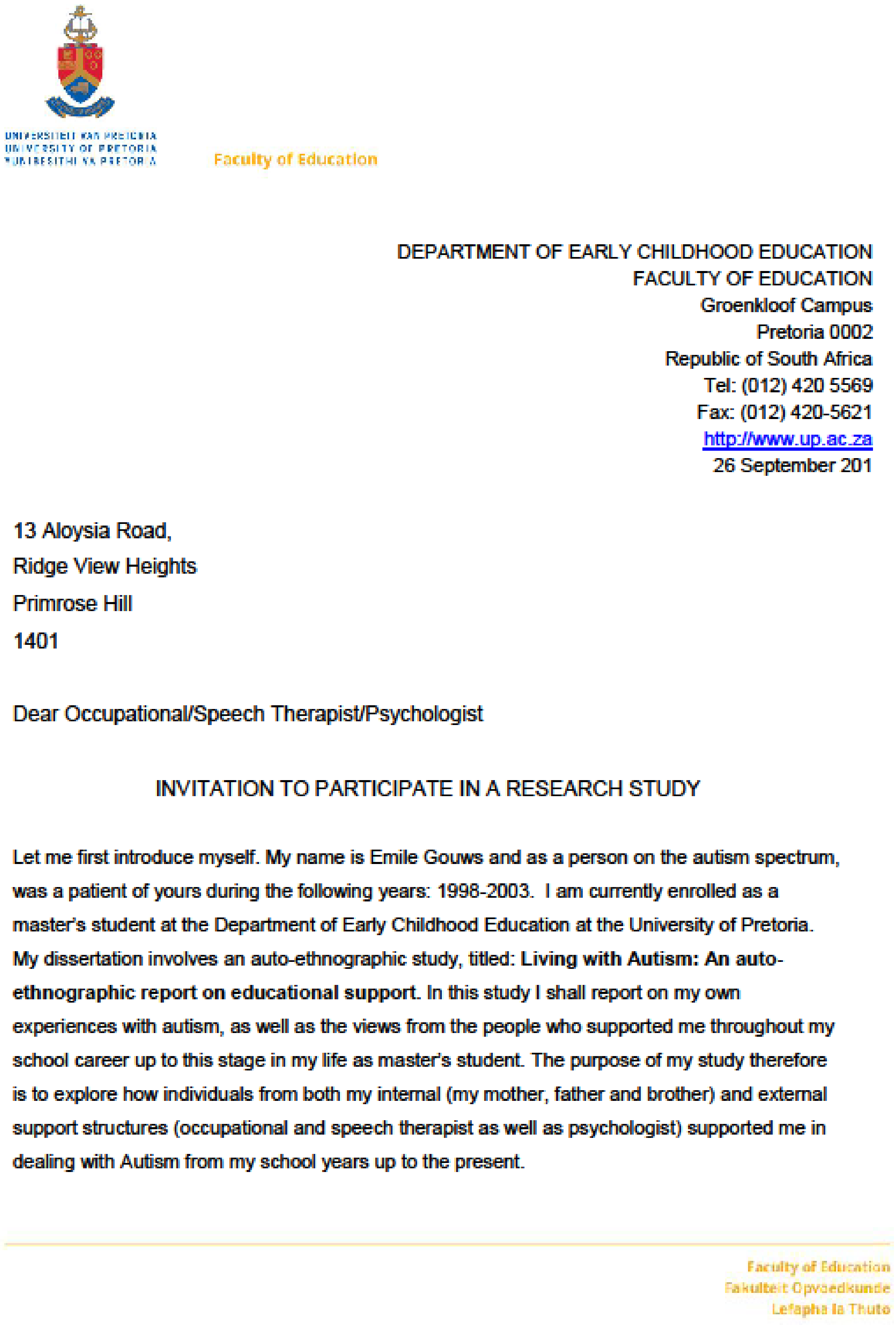
PERMISSION FOR RESEARCH

I, ETTIENNE GOUWS ,am willing to participate/ not willing to participate in this auto-ethnographic study.

Participant's Signature

09-02-2018
Date

ANNEXURE E: Invitation to participate in a research study – Occupational Therapist



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26 September 201

13 Aloysia Road,
Ridge View Heights
Primrose Hill
1401

Dear Occupational/Speech Therapist/Psychologist

INVITATION TO PARTICIPATE IN A RESEARCH STUDY

Let me first introduce myself. My name is Emile Gouws and as a person on the autism spectrum, was a patient of yours during the following years: 1998-2003. I am currently enrolled as a master's student at the Department of Early Childhood Education at the University of Pretoria. My dissertation involves an auto-ethnographic study, titled: **Living with Autism: An auto-ethnographic report on educational support**. In this study I shall report on my own experiences with autism, as well as the views from the people who supported me throughout my school career up to this stage in my life as master's student. The purpose of my study therefore is to explore how individuals from both my internal (my mother, father and brother) and external support structures (occupational and speech therapist as well as psychologist) supported me in dealing with Autism from my school years up to the present.

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Lefapha la Thuto

As you were one of the members of my external support system, I would be grateful if you will agree to participate in my study. Your participation will involve taking part in a semi-structured interview(s) to explore your experiences with me as a patient, and also sharing your general experiences with people on the autism spectrum. I shall also make use of your therapeutic reports that you made available to my parents during the consultation period. These will be available during the interview session for your reference.

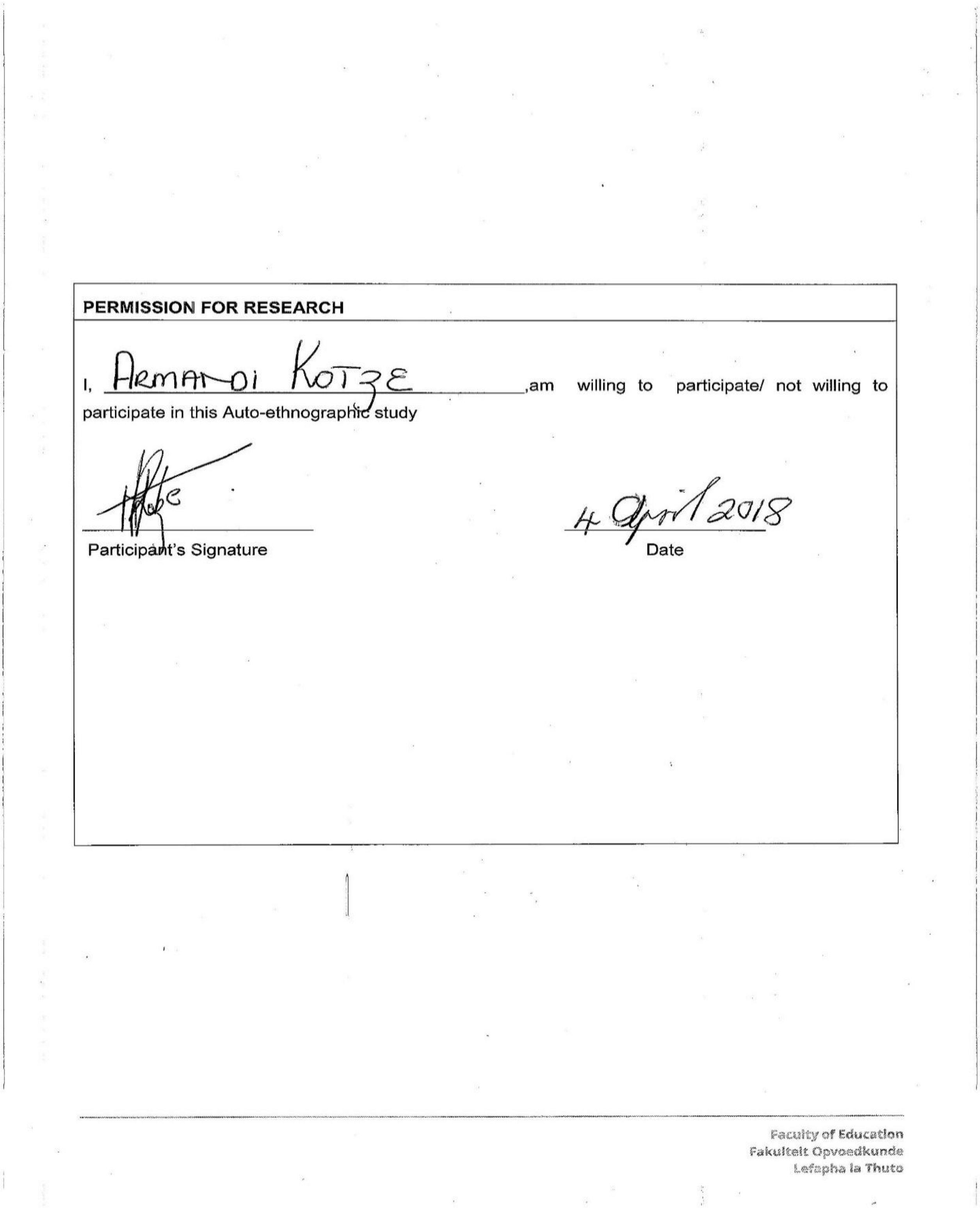
One of the fundamental criteria of ethical conduct is confidentiality and anonymity. I will make use of a pseudonym when I will be referring to you in my study so that your identity will be protected.

Should you be willing to participate in the study, I can assure you that no information that you may regard as personal or confidential, will be mentioned in my study. You will have the opportunity to read my dissertation throughout its progress, and will be able to share your comments and insights with me. Participation is voluntary which means that should you feel at any stage during the course of the study, that you want to withdraw as participant, you may do so.

Should you agree with the above mentioned information and are comfortable to be a participant in my study, please complete the attached letter of consent.

Kind regards
Emile

____________________	____________________
Emile Gouws	Prof MG Steyn (supervisor)
Mieliemeel93@gmail.com	mg.steyn@up.ac.za
0837048326	(012) 420 5289
	0822022133



PERMISSION FOR RESEARCH

I, ARMAND KOTZE ,am willing to participate/ not willing to participate in this Auto-ethnographic study

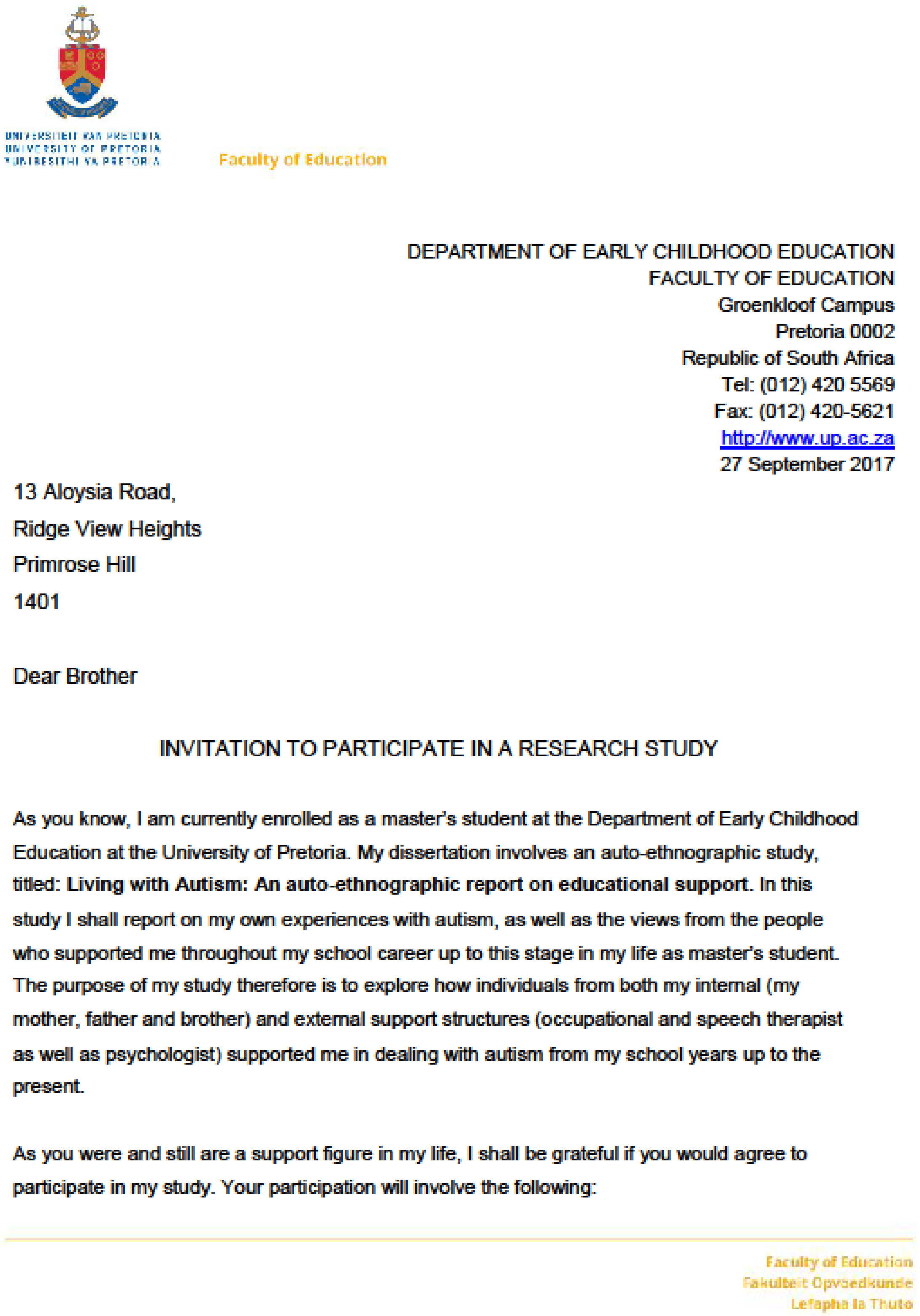
Participant's Signature

4 April 2018

Date

Faculty of Education
Fakulteit Opvoedkunde
Lefapha la Thuto

ANNEXURE F: Invitation to participate in a research study – Brother



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http://www.up.ac.za

27 September 2017

13 Aloysia Road,
Ridge View Heights
Primrose Hill
1401

Dear Brother

INVITATION TO PARTICIPATE IN A RESEARCH STUDY

As you know, I am currently enrolled as a master's student at the Department of Early Childhood Education at the University of Pretoria. My dissertation involves an auto-ethnographic study, titled: **Living with Autism: An auto-ethnographic report on educational support**. In this study I shall report on my own experiences with autism, as well as the views from the people who supported me throughout my school career up to this stage in my life as master's student. The purpose of my study therefore is to explore how individuals from both my internal (my mother, father and brother) and external support structures (occupational and speech therapist as well as psychologist) supported me in dealing with autism from my school years up to the present.

As you were and still are a support figure in my life, I shall be grateful if you would agree to participate in my study. Your participation will involve the following:

- Taking part in a semi –structured interview in order to garner general information pertaining to your life, as well as several conversations to get an insider's perspective of your personal experiences as sibling to a brother on the autism spectrum.

One of the fundamental criteria of ethical conduct is confidentiality and anonymity. As my identity will be known, I cannot guarantee anonymity to you. Should you be willing to participate in the study, you must be aware that your identity will be known to whoever reads the study. I can however assure you that no information that you may regard as personal or confidential, will be mentioned in my study. You will have the opportunity to read my dissertation throughout its progress, and will be able to share your comments and insights with me. Participation is voluntary which means that should you feel at any stage during the course of the study, that you want to withdraw as participant, you may do so.

Should you agree with the above mentioned information and are comfortable to be a participant in my study, please complete the attached letter of consent.

Kind regards
Emile

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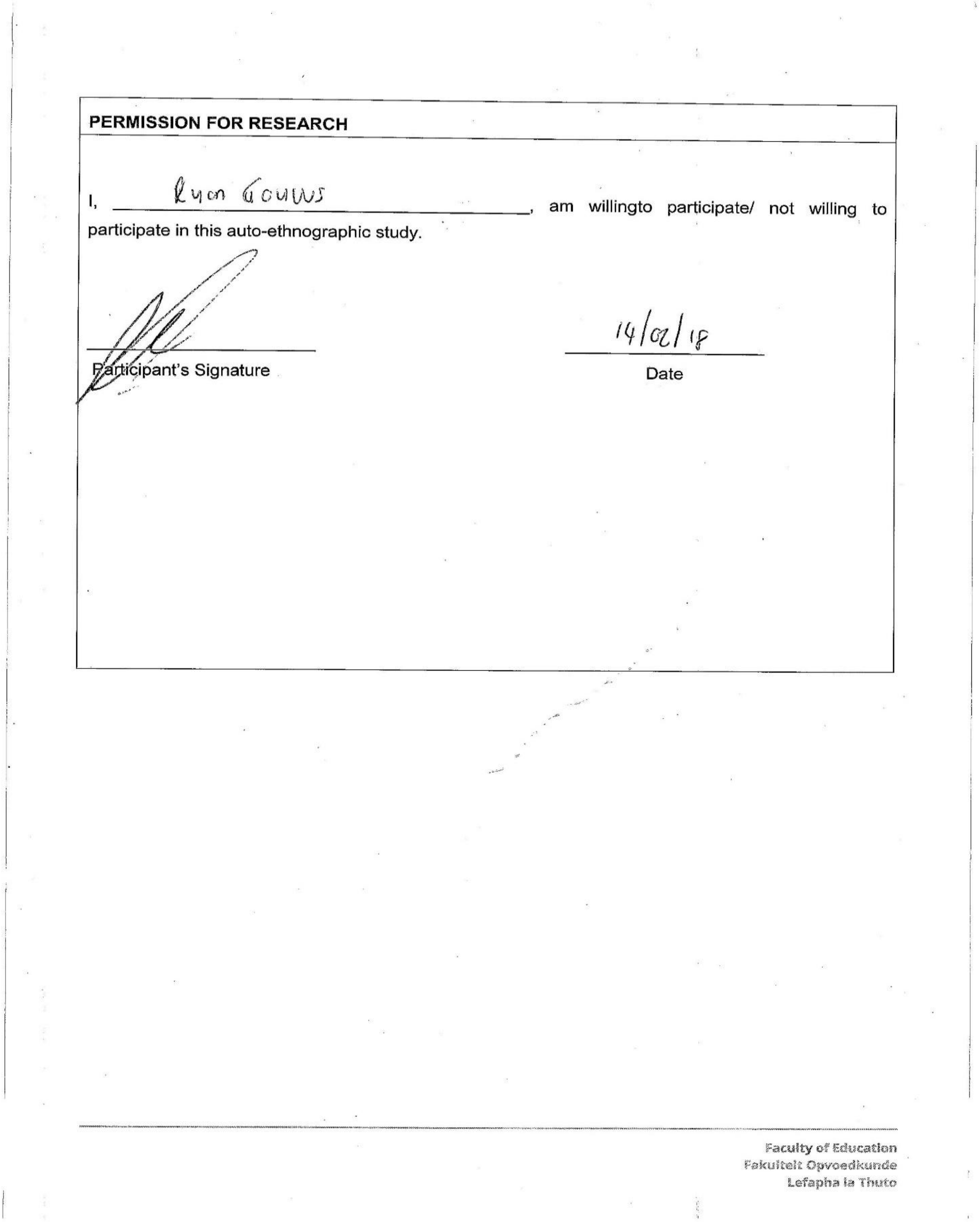

PERMISSION FOR RESEARCH

I, Ryan Gouws, am willingto participate/ not willing to participate in this auto-ethnographic study.

Participant's Signature

14/02/18
Date

Faculty of Education
Fakulteit Opvoedkunde
Lefapha la Thuto