

**FINDING AN EDUCATIONAL NICHE
FOR OUR SON WITH PDD: AN AUTOETHNOGRAPHY**

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for the degree of Master of Educational Support
in the Faculty of Education at Stellenbosch University**



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DECLARATION

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

December 2012

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ABSTRACT

At birth every human being is at the starting point of many different journeys: journeys of discovery and change, and journeys of mental and physical growth. Most children follow a similar path of physical and mental growth to adulthood, achieving predetermined milestones at approximately the same age. But what happens to a child who cannot follow this path, a child born without a map? How do the diagnosis and subsequent educational journey of the child affect the parents of that child, parents who find themselves disabled by their experiences of parenthood and life?

This study is an autoethnography. It was undertaken to reflect on the physical and emotional journey two parents experienced in finding an educational niche for their son who was diagnosed with Pervasive Developmental Delay – Not Otherwise Specified (PDD-NOS), an Autism Spectrum Disorder. In an attempt to engage and involve the non-academic audience, while at the same time addressing the analytical needs of the researcher audience, evocative autoethnographic co-constructed narratives were combined with analytic autoethnography.

Not only did I aim to fill in some of the gaps in researcher knowledge about South African parents' experiences in finding educational support for their children with pervasive developmental delays, but I also wanted to provide knowledge, hope and encouragement to other parents, especially those parents who are at the start of a journey leading to a brighter future for their child with special needs.

OPSOMMING

By geboorte bevind elke mens hom by die beginpunt van verskeie reise: reise van ontdekking en verandering, en reise van geestelike en fisieke groei. Die meeste kinders volg 'n gelyksoortige roete van geestelike en fisieke groei na volwassenheid, deur voorafbepaalde doelwitte op naastebly ooreenstemmende ouderdomme te bereik. Maar wat gebeur met 'n kind wat nie hierdie pad kan volg nie, 'n kind wat sonder 'n roetekaart gebore word? Hoe beïnvloed die diagnose en gevolglike opvoedkundige reis van daardie kind sy of haar ouers, ouers wat hulself gestremd bevind in hul ervaring van ouerskap en die lewe?

Hierdie studie is 'n outo-etnografie. Dit reflekteer op die fisieke en emosionele reis deur twee ouers onderneem, in hul soeke na 'n geskikte onderwysnis vir hul seun wat met PDD-NOS¹, 'n Outisme Spektrumversteuring, gediagnoseer is. In 'n poging om die nie-akademiese gehoor te betrek, maar terselfdertyd die analitiese behoeftes van die navorsergehoor aan te spreek, is die tegnieke van stemmingsvolle outo-etnografiese mede-saamgestelde narratiewe en analitiese outo-etnografie gekombineer.

Ek het nie slegs ten doel gehad om sommige gapings in navorsing rondom die ervarings van Suid-Afrikaanse ouers van kinders met Outisme Spektrumversteurings te vul nie, maar ook om kennis, hoop en aanmoediging te gee aan ander ouers, veral daardie ouers wat aan die begin staan van 'n reis na 'n beter toekoms vir hul kind met spesiale behoeftes.

¹ Pervasive Developmental Delay – Not Otherwise Specified

DEDICATION



A picture paints a thousand words. This painting was done by my youngest son in 2011 and depicts him (right) in his favourite cartoon character outfit, looking up and smiling at his father (left). The blue dots are raindrops, and the white markings on my husband's face are kisses.

This thesis is dedicated to Henré Hanekom,
my husband, my friend, my love and my constant companion
through life and on this journey.

THANK YOU

ACKNOWLEDGEMENTS

I can do everything through Him who gives me strength. (Philippians 4:13)

I would like to express my sincere and heartfelt thanks to the following people:

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Dr Kosie Smit and my colleagues: For understanding my need to do research in a field not related to my position, and for supporting me every step of the way.

Finally, to my youngest son, **Adriaan:** For your perseverance against all odds, and for your unconditional love. Thanks for showing me how to enjoy life, more than any neurotypical life coach could ever have done.

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GUIDELINES FOR THE READER

This thesis is partially written as an autoethnographic narrative. The voices of my husband and I can be heard within the text². In order to facilitate the transition between the multiple voices, different fonts and icons are used to distinguish the different voices and the different artefacts. Icons are also used to enhance readability.

Pauline (as researcher):



Pauline (as mother and wife):



Henré (as father and husband):



Definitions of terminology and textboxes:

Arial Narrow; 11pt

Extracts from e-mails and letters:



ACRONYMS AND ABBREVIATIONS

ASD	Autism Spectrum Disorder
ELSEN	Education for Learners with Special Education Needs
PDD	Pervasive Developmental Delay / Disorder
PDD-NOS	Pervasive Developmental Delay-Not Otherwise Specified
WCED	Western Cape Education Department

In literature the terms “pervasive developmental disorders (PDD)”, “autism spectrum disorder (ASD)” and “autism” are often used interchangeably, although they are not identical in meaning. In general society the term “autism” is often used to describe the condition of a child diagnosed with a pervasive developmental disorder, even if the diagnosis is not autism disorder. Terminology is however explained in the text, or, in order to avoid interrupting the flow of the narrative, as footnotes.

² Both my husband and I have agreed to use our own names, instead of pseudonyms, in this study.

PREFACE

JOURNEYS and DOORS

Journey

- something suggesting travel or passage from one place to another <the journey from youth to maturity> <a journey through time>

Door

- a usually swinging or sliding barrier by which an entry is closed and opened
- a means of access or participation: opportunity <opens new doors> <door to success>

(Merriam-Webster's Online Dictionary, 2011)

Since the beginning of time, mankind has undertaken journeys. The first journeys started in Africa, the birthplace of humankind, from where the earth was populated (Soodyall, 2003). At birth every human being is at the starting point of many different journeys: journeys of discovery and change and also journeys of mental and physical growth. Most children follow a similar path of physical and mental growth to adulthood. They follow a route map with predetermined milestones, such as speaking, walking and developing age appropriate social skills at approximately the same age. But what happens when a child is born who cannot follow this path, a child born without a map? Our youngest son is one of these children. He cannot follow the usual path and faces barriers that influence his ability to negotiate the journey.

When Adriaan was born, I was teaching Life Sciences at a secondary school. My husband, Henré, was a service manager in the motor industry. We already had one son, aged three and a half, and we had our life journey all mapped out. But as John Lennon so eloquently stated in one of his songs: “Life is what happens to you while you’re busy making other plans” (1980). Whereas our eldest son achieved all milestones earlier than most children of his age group, our youngest seemed unaware that his journey had even begun. We always knew that he was different, but it took three and a half years of countless visits to medical professionals before he was finally diagnosed with Pervasive Developmental Delay – Not Otherwise

Specified (PDD-NOS), an Autism Spectrum Disorder (ASD). Our son now had a label, but still no route map.

Pervasive Developmental disorders are characterised by “a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills, or with the presence of stereotyped behaviour, interests, and activities”.

Diagnostic and Statistical Manual of Mental Disorders (DSM IV-TR)

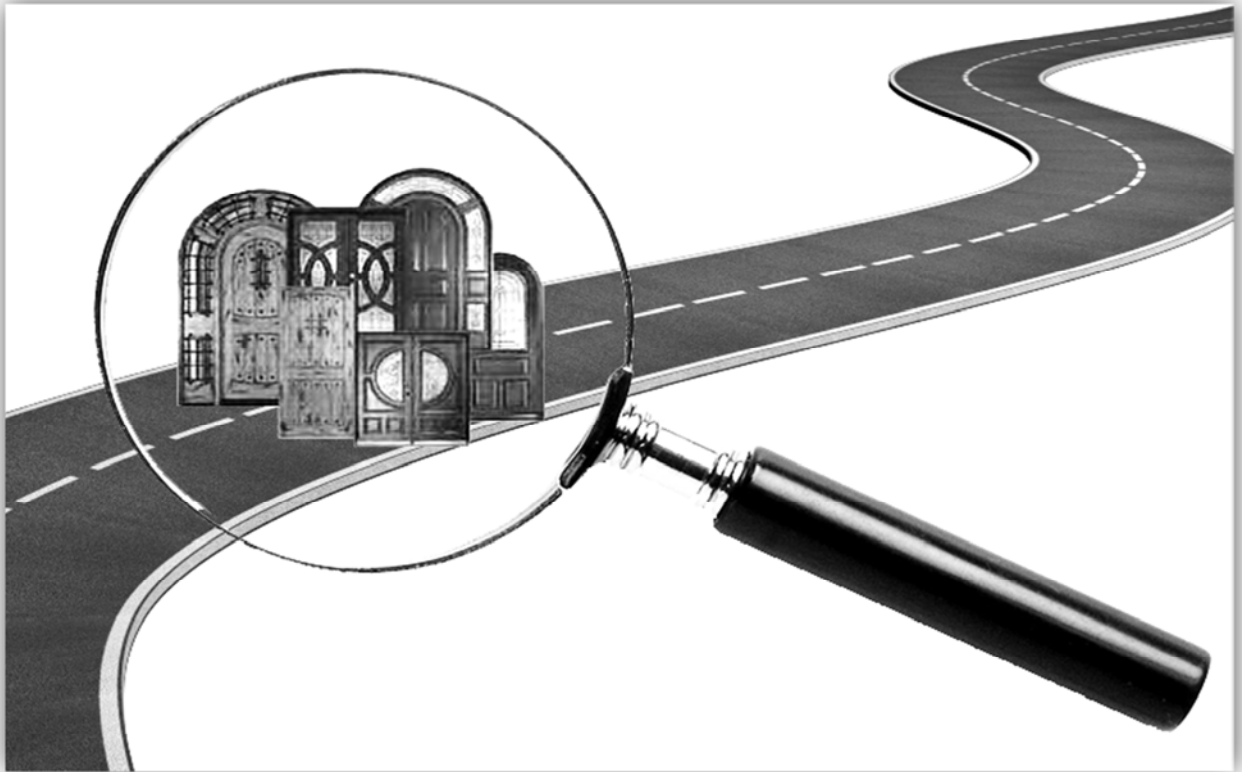
(American Psychiatric Association, 2000, p. 69)

In her study on the use of a journey as metaphor, Turner (1998, p. 25) states:

...every time we move anywhere, there is a place we start from, a place we end up at, places in between, and a direction.

For this study, I chose the metaphor of a journey to research and describe our experiences in planning a route and carving out pathways, to enable our child with PDD-NOS to walk an educational road and to reach his full potential. Our journey includes a place where my husband and I started from, a place we hope to end up at, places in between and the direction in which we are travelling in our quest to find the best possible educational support for our son with PDD-NOS.

This study not only reflects on the barriers to learning our son are facing, but it also critically reflects on the many barriers we, as parents, faced in finding the educational support our son requires. The barriers we faced are represented by locked doors that we, at the start of the journey, did not have keys to. These are doors that, once unlocked, provided possibilities in assisting our son to reach his full potential.



... knowing if one can think differently than one thinks, and perceive differently that one sees, is absolutely necessary if one is to go on looking and reflecting at all.

Foucault (1985, p. 8)

CHAPTER 1 IN THE BEGINNING

*All journeys involve travellers, paths travelled, places
where we start, and places where we have been.*
(Lackoff & Turner, 1989, p. 60)

1.1 THE BEGINNING OF THE JOURNEY

My husband and I met while we were both final year university students. I had completed an honours degree in Medical Sciences, majoring in Human Genetics, and was studying for my Higher Diploma in Education. Henré, was in his final year of a Mechanical Engineering degree. We married that same year and for the next three years we both pursued our careers before deciding to start a family. Our eldest son³, born in 1997, reached all his physical and cognitive milestones long before most of his age group. He astounded friends and family by singing our National Anthem before the age of two; no mean feat, as three of the four verses are in languages other than his mother tongue.

In 2001 our youngest son, Adriaan, was born. Initially, he was an unusually quiet baby, crying only when hungry, sleeping most of the time and showing no interest in his surroundings. He did not even flinch at sudden loud sounds. When Adriaan reached the age of two, his hearing was tested and found to be normal, but still he was not interested in responding to sounds. We knew that something was wrong, even though the doctors we took him to all proclaimed that boys were usually slower in reaching milestones and that, even if something was wrong, they could not perform any meaningful tests until he turned three.

It was Henré who, after receiving the result that Adriaan's hearing was normal, first raised the possibility that our son might be autistic. Our families all told us not to compare Adriaan to our eldest son. We desperately wanted to believe everybody who told us to let Adriaan be, but decided to at least have him assessed by an occupational therapist. The occupational therapist's diagnosis was that he

³ It is by his own choice that my eldest son's name is withheld in this thesis.

experienced problems with sensory integration, and she suggested regular occupational therapy, as well as speech therapy. Over the next year, only a minor improvement was noted, despite the regular therapy sessions. The speech therapist struggled to work with him and we eventually stopped the therapy. The occupational therapist was more successful and, despite not really noticing any major improvement, we continued to take Adriaan. If anything, the decision to continue with the occupational therapy was made because we believed that we could not simply sit back and do nothing, despite what the doctors told us.

By the age of three Adriaan's vocabulary consisted of three words: "*mamma*"⁴ [mommy], "*pappa*" [daddy] and "*nee*" [no]. He had frequent screaming tantrums that could last up to 40 minutes, he did not attempt communication except when he was hungry, and he slept for only three to four hours a night. Going to public places or visiting friends was an ordeal, as Adriaan could change from calm and accommodating to a screaming and kicking ball of fury without any warning. My husband and I desperately needed to find a diagnosis for his condition, in order to find support for our son.

In May 2005 we consulted a team of four medical professionals, consisting of a paediatrician, a speech therapist, a psychologist and an occupational therapist. After assessing him, they concluded that Adriaan had a General Quotient⁵ of 57 and that he had Pervasive Developmental Delay – Not Otherwise Specified (PDD-NOS). During the first feedback session we were told that there was no cure for autism and that our son would probably never speak. They also informed us that Adriaan would never be able to attend a mainstream school.

We accepted the diagnosis, but strongly disagreed with the prognosis. In an attempt to understand Adriaan's diagnosis, I researched every possible source of available information on Pervasive Developmental Delay – Not Otherwise Specified (PDD-NOS). I searched the internet and studied books, journal articles and almost every intervention proposed. Most of the sources concurred that one of the central problems of children affected by PDD-NOS is social–emotional difficulties. The

⁴ Afrikaans

⁵ Determined by means of a Griffith Test

research findings in all the literature that I reviewed at the time, indicated that children on the autism spectrum face many barriers that impact on their ability to interact social-emotionally (Murray-Slutsky & Paris, 2000). These barriers include tendencies to evade eye contact and to either repel or crave stimulation, such as touch and sound. Children on the autism spectrum also lack the use of gestures to show interest, have delayed development of spoken language, lack imitation and imaginative skills, and struggle to interpret body language. These children do however recognize and express basic emotions such as fear, joy, anger, sadness and love (Losh & Capps, 2006). Though people who are diagnosed as suffering from PDD-NOS desire social interaction, they increasingly experience negative feelings when confronted by strangers (Hintzen, Delespaul, Van Os, & Myin-Germeys, 2010).

My husband and I had always taken for granted that both our children would, after attending mainstream schools, go on to study at a university, lead independent lives and hopefully find suitable life partners. Suddenly, with regard to our youngest child at least, all this became a distant dream and, in the eyes of the medical professionals, an impossible dream. The diagnostic team recommended that Adriaan attend a special needs school designated specifically for the education of learners on the autism spectrum. Not only were we not prepared to give up that easily on our long term dreams for Adriaan, but we also did not agree with the medical professionals' choice of school.

When we became parents, we believed that we would be able to choose the schools our children would attend. After Adriaan's diagnosis it seemed that, because our son had barriers to learning, the medical community wanted to make that decision for us. According to Merry and Karsten (2010), the rights of parents to choose suitable educational support for their children is widely recognised and protected by Article 26.3 of The Universal Declaration of Human Rights (United Nations, 1948). The South African School's Act (Department of Education, 1996, p. 4) also states that:

...in determining the placement of a learner with special education needs, the Head of Department and principal must take into account the rights and wishes of the parents of such learners.

In the Education White Paper 6: Building an Inclusive Education and Training System (Department of Education, 2001), a framework for creating an inclusive education system in South Africa is proposed. As set out in the Conceptual and Operational Guidelines for the Implementation of Inclusive Education: Special Schools as Resource Centres document (Department of Education, 2005), “disability” designated special needs schools had to be transformed into general special needs schools that cater for learners with a range of barriers to learning. Within the South African context, the process of converting policy change into physical change had only just started by 2005. It is against this backdrop that my husband and I had to convince a general special needs school and the Western Cape Education Department (who based admission of learners on the reports and recommendations of the medical professionals), to accept our son.

1.2 A POSSIBLE PATHWAY?

The school that the diagnostic team recommended for Adriaan, was specifically established under the previous educational dispensation to cater for the educational needs of children with autism. As it seemed logical to us that Adriaan could not acquire social skills within an environment where all the learners were on the autism spectrum, this school did not meet our educational expectations for our son. Had he attended this school, there would have been little scope for him to observe appropriate social skills, or have others respond with social reciprocity. On the other hand, as Rapin (2007) suggests, an environment where everyone has special needs, provides more opportunities for interacting socially than an inclusive setting where learners with special needs are ignored by their neurotypical peers. We therefore had to find an educational institution where our son would be exposed to social reciprocity and where his special academic needs would be addressed.

Right from the start, we decided to explore all educational possibilities for Adriaan’s schooling, including state and private schools for autistic learners. One of the educational contexts that we explored was a school that catered primarily for individuals with Down syndrome. We perceived children with Down syndrome to be overtly social and with similar cognitive deficits as our son. Our perception of social competence in learners affected by Down syndrome is supported by research,

including Sigman and Ruskin (1999, p. 102) who commented on the innate tendency of Down syndrome learners to “initiate social interactions”; Rosner, Hodapp, Fidler, Sagun and Dykens (2004) who compared the social competence of persons with Prader-Willi, Williams and Down syndromes, and found that learners with Down syndrome were highly sociable, as well as Semrud-Clikeman and Glass (2010, p. 1254) who reported that children with Down syndrome “show particular interest in other people’s emotional responses”. We therefore decided to enrol Adriaan in a general special needs school; a school previously designated to assist learners affected by Down syndrome only.

1.3 A JOURNEY UNTOLD

The slogan of Disabled People South Africa, “Nothing about us, without us!” (2011), calls for the meaningful involvement of disabled people and for the authentic voices of disabled people to be heard. It was also the slogan of the 2004 United Nation’s International Day of Disabled Persons (2004). Parents of children with barriers to learning, although not disabled in the normal sense of the word, are disabled by their experiences of parenthood and life. Jenks (2005, p. 146) writes about parents of children who are visually impaired, and argues that the experiences lived by parents of children with disabilities do not fit into the usual categorization of either a medical or a social model of disability, but “lie somewhere in between”. These parents’ experiences are ultimately very different from the experiences of parents whose children do not have disabilities.

The World Health Organization (2002) refers to “the burden of illness” that is carried by the caregivers, mostly parents. Autism South Africa (2010) estimated that at least 136 000 children in South Africa have an autism spectrum disorder (ASD). This figure implies that there are at least 136 000 caregivers of children with an ASD in South Africa, and therefore 136 000 caregiver voices which remain silenced. Richards (2008) states that people with disabilities are frequently advised by outsiders, but very seldom by insiders. I am arguing that this is also true for parents of children with Pervasive Developmental Delays (PDD). As such, this thesis, in the form of an autoethnography, provides me with an opportunity to give voice to our

family's experiences, as well as to provide insight into the roads travelled by many caregivers of people with disabilities.

1.4 REFLECTING ON IMAGES IN THE REAR VIEW MIRROR

Most research into the education of learners with pervasive developmental disorders, nationally as well as internationally, focus on whether learners should be placed in special needs schools or included in mainstream schools. Very little research have been done on the education of learners diagnosed with PDD-NOS within general special needs schools in South Africa. This is mainly because special needs schools in South Africa used to be designated to specific barriers to learning, namely aural, visual, cerebral palsy, epilepsy, autism, mental retardation and physical disabilities (Naicker, 1999). Research on parents of children with barriers to learning are mostly quantitative, or focus on the parents' reactions to the diagnosis of barriers to learning (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011), support programmes for parents (Luther, Canham, & Young Cureton, 2005; Steiner, 2011) or family resilience (Altiere & Von Kluge, 2009; Lee, et al., 2009).

There is a definite knowledge gap due to the absence of research into the physical and emotional experiences of South African parents who seek optimal educational opportunities for their children with barriers to learning, especially those parents with children who have pervasive developmental delays. The aim of this study is to document our experiences as two parents in pursuit of the best educational opportunities for our son. The study's contribution lies in the insights that could be gained into the experiences of parents of a special needs child. It also contributes to increasing the body of knowledge, and raises awareness about the South African special needs landscape.

The research question that guided this study was: How did my husband and I experience the journey of searching for an educational niche for our son with PDD-NOS within the South African special needs landscape? The study delimits itself to the physical and emotional aspects of the journey. As such, the two sub-questions that guided the study were:

1. What did the physical journey entail?
2. How did we experience the journey from an emotional point of view?

1.5 MAPS AND ROUTES

Understanding the map

Ronai (1992) argues that describing one's own experiences narratively, could become a transformative process for the narrator. Linear story lines cannot portray lived experiences as, according to Denzin (1984), the narrative or the story is a circular process of interpretation. Clandinin and Connelly (2000, p. 18) suggest that, since "narrative thinking is a key form of experience", experiences need to be studied narratively. Mezirow (2000) states that humans are defined by their need to understand their own experiences. His transformative learning theory focuses on how, as adults, we learn to deal with, and act upon our feelings, purposes, values and meanings following, for example, a disorienting dilemma. Our lives as parents of a child with PDD-NOS are woven by many disorienting dilemmas that are not only once-off "acute internal and personal crises"; rather they are extended periods of reframing and restructuring of assumptions and expectations (Taylor, 2000). Taylor (2000) proposes that the journey of transformation be explored in everyday situations and that one studies the process of change over a number of years.

Mezirow (1997) poses that our frames of reference consist of two dimensions: habits of mind and points of view. According to Costa and Kallick (2000) habits of mind are those character traits, dispositions, attitudes and inclinations that influence our ability to engage in intelligent behaviours in different situations. Our point of view regarding a topic is influenced by our habitual thinking (Mezirow, 1997). For example, whether we see individuals with disabilities as equals or as inferior, will influence our point of view regarding educational support for those individuals. New habits of mind can be learnt and old habits changed. Habits of mind are also linked to culture, and influence how children are raised to think about people of a different class, race, religion or (dis)ability. Thus, in transformative learning, when habits of mind are challenged, the adult learner or individual could experience distress or anxiety. In this study, the aim is to critically reflect on how the journey to find appropriate educational support for our son transformed, and is still transforming, our frames of

reference, by focussing on both the physical and emotional components of the journey.

Deciding on the routes

This study is a narrative, partly written as an autoethnography. Over the last 20 years autoethnography has become a popular, yet contested form of qualitative research (Anderson, 2006). According to Ellis (1999, p. 669) autoethnography is an attempt at fusion between social science and literature and “connects the practices of social science with the living of life”. Reed-Danahay (1997) describes autoethnography as an intricate interplay between the research process, the graphy, culture, the ethnos and self, the auto. In this study I combine evocative autoethnographic co-constructed narratives (Ellis & Bochner, 2006) with analytic autoethnography (Anderson, 2006), in an attempt to engage and involve the non-academic audience, while at the same time addressing the analytical needs of the research process.

The data for this study consists of co-constructed narratives. As a first step in the creation of the co-constructed narratives, I provided a framework wherein the parental narratives had to be compiled. Both my husband and I then created individual parental narratives within this framework. These narratives were combined with a personal radio interview transcription and other artefacts, including poems, letters and medical professionals’ reports. Sessions of reflexive sharing of each other’s stories followed, and through dialogue and co-construction the parental narrative, as presented in this text, was created. At times a reflexive layer is provided in this thesis to explain the researcher’s stance on the narratives, artefacts, field notes of the dialogue and co-construction sessions. In this autoethnography, the preference for co-narratives rejects the single voice in favour of multiple voices. The amount of perspectives on the problem studied is thereby increased and, in doing so, also the validity of the accounts (Gergen & Gergen, 2000).

At times during Adriaan’s educational journey, my husband was considerably more involved in the physical process of finding suitable support for Adriaan than I was. As a result, some of his narratives are considerably longer than my own. I did not

attempt to shorten his narratives, as I felt this could be equated to an attempt to silence his voice. It could also have led to important information being left out.

1.6 FIRST DO NO HARM

Ellis (2007, p. 13) argues that “autoethnography starts with personal experiences and studies ‘us’ in relationships and situations”. It is therefore difficult to anonymise participants within this study. The names of participants in other types of studies are usually anonymised as an ethical consideration, in order to protect them from possible harm. In an autoethnography anonymity is not possible, as the researcher is a participant in the study. Our son is autistic and attends a specialised school. The main ethical consideration in this study revolves around not causing harm to our son who, because of the disability and his age, is part of a vulnerable population. As parents, we have never attempted to hide his condition, as that would be as impossible as concealing the fact that someone has lost a limb. Our struggle to find educational support for our son is already in the public domain, since it was broadcasted on a regional radio station prior to the start of this study. We try to see our son and ourselves as survivors and advocates of hope, not victims. I therefore believe that the potential for harm is minimal and that there is no need or motivation for anonymising our names or location. I agreed to anonymise institutions and medical professionals that I refer to in the text, as requested by the Research Ethics Committee. My husband has given written consent for his name to appear in this study.

Ethics is also about research making a contribution to the existing knowledge base. This study’s contribution is to tell the story of parents’ efforts to carve out an educational pathway for their child. At times this process caused confrontation with generally accepted norms and with the status quo. Any attempt to silence the voices of parents who, at times, not only had to fight the system, but also individuals who were not willing to consider alternatives, can be regarded as unethical behaviour in itself. People who find themselves in a similar situation to ours, need to be informed that they ultimately have a choice with regard to the educational decisions made for their children. By undertaking this research and selecting autoethnography as the design, I am able to make such a contribution.

1.7 JOURNEY ITINERARY

Chapter 1 describes the starting point of the journey, followed by my motivation for researching the journey. It explains the knowledge gap in research into the physical and emotional experiences of South African parents who seek optimal educational opportunities for their children with barriers to learning. This is followed by a summary of the research design and methodology of the study, as well as a brief mention of ethical considerations.

In Chapter 2 a literature review is undertaken. It presents the theoretical framework for the study, focussing on psychological models that have impacted on education, the history of special needs education, the history of PDD-NOS as a diagnosis and the theory of transformative learning.

In Chapter 3 the research methodology and design summarised in Chapter 1, are expanded on.

Chapters 4 to 8 present the data. These chapters illuminate the themes that emerged during the research, in the form of co-constructed narratives, interwoven with reflexive researcher commentary.

Chapter 9 discusses the findings and contains recommendations for further study.

CHAPTER 2

THOSE THAT WENT BEFORE US

My husband and I are not the first parents of a child with barriers to learning. Nor are we the first parents to seek appropriate support for our child, or the first to be transformed by the experience. However, our desire to record our story, and to share it within an academic framework, is probably not that common. In this chapter I will give an overview of how the landscape of educational support has changed over the centuries, parents' struggle for educational support in other countries, the many recorded attempts to classify the symptoms our son displays and the framework wherein this research is located.

2.1 THE LANDSCAPE OF EDUCATIONAL SUPPORT

Before colonisation of the Cape of Good Hope in 1652, most African tribes passed on skills and knowledge through non-formal educational practices. No form of special education existed. The need for special education was probably negated as, according to literature, all babies who were diseased or who deviated from what was seen as "normal", including babies with disabilities or babies from multiple births, were killed (Du Toit, 1996; Naicker, 1999). The first formal schools established in South Africa during the colonial era⁶ were missionary schools. These schools were segregated according to race and class, and therefore catered separately for white and slave children. According to Du Toit, the first effort to cater for diverse needs was facilitated through Act 29 of 1928, the *Vocational Education and Special Education Act*, that paved the way for the establishment of so called Vocational and Special Schools for white "cripples, epileptics and the chronically sick" learners (Du Toit, 1996, p. 9). This act made no provision for learners with any form of mental disability, nor for access by races other than those classified white. It was only in 1948, with the proclamation of the *Special Schools Act*, that medical diagnosis, mental diagnosis and treatment were included in special education (Du Toit, 1996). The act, however, still only made provision for white learners.

⁶ 1652 - 1910

As societies continuously changed, so did psychological models that attempted to explain the diverse needs of learners, as well the interventions needed to support these learners. Since the early 1900's the medical model, or with-in-child model, was used to diagnose, classify, treat and exclude from schools, and in the process from their communities, learners who did not fit into the education system of the time (Swart & Pettipher, 2005). The focus of educational support systems was on diagnosis and treatment, the goal being to change the learner and enable him or her to fit into the static education system. No consideration was given to the context within which the learner functioned. Diagnosis and treatment were seen as the exclusive fields of specialised teachers and health professionals. According to Swart and Pettipher (2005) a paradigm shift took place during the 1970's and the 1980's. There was a shift from the medical model to human rights based social and bio-ecological models, resulting in awareness amongst people of their human, social and political rights.

Various researchers proposed models to explain the challenges faced by education and support systems dealing with diverse learners. Bronfenbrenner's bio-ecological model (Bronfenbrenner in Swart & Pettipher, 2005) has however, since its inception in the 1970's, been used as the main theoretical framework for transformation. Bronfenbrenner's bio-ecological model focuses on the different relationships that exist between an individual, the microsystems (face-to-face interactions), the mesosystems (interactions between microsystems), the exosystems (interactions that influence mesosystems without any direct interaction with the individual) and the macrosystems (values, beliefs, culture and politics) (Swart & Pettipher, 2005, p. 9). When looking at a barrier to learning through the lense of Bronfenbrenner's bio-ecological model, the focus is therefore not only on the person or the disability, but on all the influences and interrelationships that exist in the context of a person with a disability.

During the Apartheid era⁷ exclusion in South African education was taken to new levels through formalisation by law. Every South African was classified according to race by the Population Registration Act of 1950. Each race was allocated its own

⁷ This refers to the period 1948 to 1994.

residential areas, as well as separate resources. In line with this policy, segregated education departments were established and by 1990 there were seventeen different education departments that existed parallel to each other (Du Toit, 1996; Naicker, 1999). Guidance and counselling services and special education fell under the psychological services of various departments. School health resorted with the health departments, while school social work was divided between the education departments and the Department of Social Welfare (Donald, 1996). With the end of the Apartheid era in 1994, a new education system was prioritized by the newly instated government (Padayachee & Harding, 2011). The first step was to create a single national department of education, which was then subdivided into nine provincial departments of education (Jansen & Taylor, 2003).

The White Paper on Education and Training (Department of Education, 1995) promulgated key initiatives for South Africa's new education system. According to Lomofsky and Lazarus (2001), the initiatives that focused on special needs education were the Outcomes Based Education (OBE) curriculum strategy to respond to diverse learner needs, and a new language policy that recognised Sign Language and the 11 official languages as mediums of educational instruction. The new OBE curriculum strategy was the beginning of the creation of a flexible curriculum, one of the principles named in the Salamanca Statement (UNESCO, 1994) as crucial for inclusive education to succeed.

In 1996 two important policy documents were promulgated. The first, The Bill of Rights in South Africa's Constitution (1996, p. 1257), states that:

...all learners have a right to basic education, including adult basic education and further education.

and that

...in determining the placement of a learner with special education needs, the Head of Department and principal must take into account the rights and wishes of the parents of such learners.

The second, the South African Schools Act (Department of Education, 1996), made education compulsory for all learners between the ages of seven and fifteen. This act effectively did away with exclusion in legislation, a first in South African education

history. The Education White Paper 6: Building an Inclusive Education and Training System (Department of Education, 2001), presented a framework for creating an inclusive education system in South Africa through a system of full service schools and resource schools. Full service schools can be described as schools that aim to provide for the needs of all learners (Department of Education, 2005). Resource schools are transformed special schools that serve as resource and professional support centres to the full service schools (Department of Education, 2005), while at the same time catering for learners who, because of severe or multiple barriers to learning, need high levels of support. Some learners are therefore still excluded from mainstream education. Hegarty (2001) proposes that some learners' behaviour, need of personal care, or cognitive gaps would require the creation of such special environments within the mainstream class, that eventually these environments in itself could become barriers to learning to the rest of the class.

2.2 OUR LANDSCAPE IS NOT UNIQUE

When my husband and I started looking for educational support for our son in 2005, there were two small government run schools for autistic learners in the Western Cape province of South Africa. These two schools only catered for 160 learners on the autism spectrum. South Africa is not the only country where parents of children with special needs struggle to find educational support for their children. Altieri and Von Kluge (2009), in their study on how family functioning is influenced by the presence of a child with autism, reported on the many hours spent by American parents searching for support services for their children. These parents' criticisms included complaints about unhelpful schools, doctors and clinicians, and how "helping professionals" often made them feel redundant. In Sweden, Isaksson, Lindqvist and Bergström (2010) found that parents of children with special educational needs struggle to find educational support, due to a lack of collaboration between medical professionals and educators. On 10 March 2011, BBC News reported that England's Special Educational Needs system is "one of the most controversial areas of England's education system" and that a Commons Education Committee had in 2006 labelled it as "not fit for purpose" (British Broadcasting Corporation, 2011). In the same report parents are also quoted by the Children's Minister as being frustrated by endless delays in the local services that supply their

children with educational support. Kenny, Shevlin, Noonan-Walsh and McNeela (2005) reported that, despite substantial changes in educational policy, parents in Ireland still experienced obstacles in securing appropriate educational support for children with special needs. Zhang and Araki (2006) stated that, in China, children with autism were unlikely to receive public system educational support and that they were dependent on support from private facilities. From the literature, it is apparent that parents' struggle to find appropriate educational support for their children with barriers to learning, is a world-wide phenomenon.

2.3 PERCEPTIONS OF THE LANDSCAPE

Priestley (1998) distinguished between four theoretical models for engaging with disability. He divided these four models into individual and social approaches. Within these divisions he proposed materialist and idealist traditions. Priestly based his divisions on what he called "units of analyses" (1998, p. 78). For the individual-materialist tradition, which he equates to the medical model, Priestley's unit of analysis is the impaired body. For the individual-idealist tradition, the units are beliefs and identities. The units of analysis for his socio-idealist tradition are cultural values and cultural representations. Lastly, for the socio-materialist tradition, according to Priestley (1998) often inaccurately called the social model, the units are disabling barriers and material relations of power.

Reindal (2008) also divided disability models into individual and social models. He based his models on the assumption that an initial biomedical condition leads to reduced functioning of an individual, but his models differ as to the perception of disability. According to Reindal (2008), the social constructionists see disabilities as natural variations of the human species, whereas the social creationists argue that reduced functioning only causes a perception of disability because of social barriers and power play within a society. He further proposed two individual models, namely the biomedical and the interactionist model. According to the biomedical model, a disability is caused by a biological defect that influences the functioning of an individual, whereas the interactionist model proposes that disability is a cognitive created identity. A diagrammatic representation of Reindal's models is shown in figure 1.

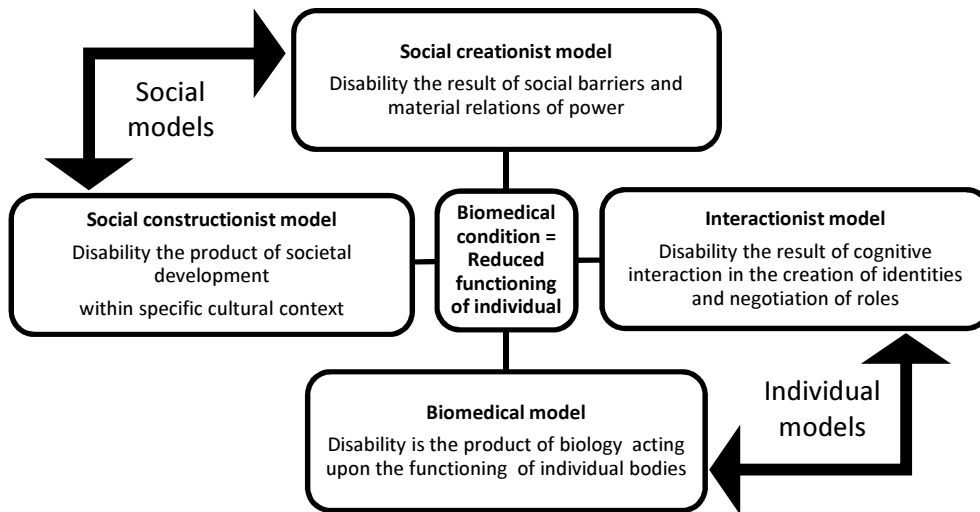


FIGURE 1: Special needs and models of disability (redrawn from Reindal, 2008, p.140)

My personal viewpoint on disability is more aligned with the views of Shakespeare and Watson (2002) and Fineman (1995), who argue that both the social and individual models are just different sides of the same coin. I agree with Fineman's view that, by focusing on the origin of differences, both biological and social, the effects of differences, such as exclusion and discrimination, are overlooked. She further argues that, when society focuses on differences instead of valuing all people as equally deserving of support, that support is often viewed by society as a burden. This view is shared by Siebers (2008, p. 30), as depicted in the following example:

It is taken for granted that non-disabled people may choose when to be able-bodied. In fact, the built environment is full of technologies that make life easier for those people who possess the physical power to perform tasks without these technologies. Stairs, elevators, escalators, washing machines, leaf and snow blowers, eggbeaters, chainsaws, and other tools help to relax physical standards for performing certain tasks. These tools are nevertheless viewed as natural extensions of the body, and no one thinks twice about using them. The moment that individuals are marked as disabled or diseased, however, the expectation is that they will maintain the maximum standard of physical performance at every moment, and the technologies designed to make their life easier are viewed as expensive additions, unnecessary accommodations, and a burden on society.

In society, according to Shakespeare and Watson (2002), people are being disabled by their bodies, as well as by social barriers. In Adriaan's case, PDD-NOS is a neurological dysfunction affecting his cognitive and social functioning. This condition influences the way society classifies and values him as a human being, thereby doubling his disability.

2.4 NAMING AND RENAMING A DOOR

The term "autistic" was first coined in 1910 in an article on schizophrenia. The author, Swiss physician Bleuler, referred to a state of mind where a patient with schizophrenia withdraws into his fantasies "against which any influence from outside becomes an intolerable disturbance" (Bleuler, 1910-1911). Bleuler used the term to describe a symptom and not a syndrome (Grinker, 2007). In 1943 Leo Kanner⁸ published his article "Autistic disturbances of affective contact" where he described a syndrome which he called infantile autism after studying eleven American children, previously diagnosed with schizophrenia, who all showed a similar impairment in social functioning (Kanner, 1943). Kanner further argued that, since the children he described did not seem to hallucinate or have delusions, they were in essence different from patients with schizophrenia.

Until the 1970's clinicians would use the term "infantile autism" or "Kanner's syndrome" when referring to people with autism, even though the official category of the American Psychiatric Association was still schizophrenia (Grinker, 2007). Because of World War II and the resulting lack of communication between America and Europe, Kanner did not know at the time that, in 1943, another Austrian, Hans Asperger⁹, used the term "autistic psychopaths" to describe a group of Austrian children he had been studying for his second doctoral thesis (Asperger, 1944; Frith, 1991). Although both Kanner and Asperger described children with impaired social functioning, there were also many differences between the two groups, specifically regarding language and cognitive abilities. Today most researchers describe autism as a spectrum of problems, with Kanner's and Asperger's diagnoses at opposing ends of the spectrum (Grinker, 2007).

⁸ Kanner was born in Austria and immigrated to America in 1924.

⁹ Asperger was born in Austria and worked and published in Austria.

Our son was diagnosed with Pervasive Developmental Delay - Not Otherwise Specified (PDD-NOS). The DSM-IV TR (American Psychiatric Association, 2000) uses the term Pervasive Developmental Delay (PDD) to define the autism spectrum. It divides PDD into five subtypes, namely Autistic Disorder (AD), Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder and PDD-NOS. Fombonne, Quirke and Hagen (2009) reviewed surveys on the prevalence of PDD and concluded that one child in every 150 fell within the diagnosis. According to Snow and Lecavalier (2011) PDD-NOS is the most frequently diagnosed subtype, but its definition is the vaguest. It is usually used when an individual does not meet all the diagnostic criteria of AD. Towbin (2010)¹⁰ describes PDD-NOS as a heterogeneous group of conditions that share three common features: profound impairment in social reciprocity, early onset of symptoms and exclusion of the other pervasive developmental disorder subtypes. Consequently, very few studies on the treatment or educational support of children with PDD-NOS exist, which meant that my husband and I had to rely on studies done on other PDD subtypes. We also drew heavily on my experience as a teacher and sometimes even on our gut feeling, in our search to find appropriate educational support for our son.

2.5 JOURNEYS CAN CHANGE LIVES

At the time that Adriaan was diagnosed with PDD-NOS, my frames of reference were defined by my different roles, namely that of an adult, an employee, a daughter, a wife and the mother of a neurotypical child. Mezirow (2000) describes frames of reference as structures of assumptions we employ to understand our experiences of life, and states that these frames can be challenged by what he referred to as disorienting dilemmas. My son's diagnosis and the challenges we faced to find him appropriate educational support, presented my husband and I with many disorienting dilemmas that forced us to reframe and restructure our assumptions and expectations. Mezirow forged the term "transformative learning" to describe the restructuring of frames of reference.

¹⁰ Also available online at <http://hstalks.com/bio>

According to Mezirow (2000), there are two types of transformative learning processes, namely objective reframing, that refers to critical reflection on the assumptions of others, and subjective reframing, that comprises critical self-reflection of one's own assumptions involving difficult and intensive emotional struggles. For objective and subjective reframing to be transformative, Novak in Paprock (1992) claims that life must not only be seen from a new perspective, but also lived from that perspective. One aim of this study is to critically self-reflect in order to determine whether, and how, our journey had been transformative. Brookfield (2000, p. 126) proposes that reflection is not always critical and that critical reflection does not necessarily mean "a deeper, more intense and probing form of reflection". He believes that critical reflection of a process includes analysis of the context in which the process has taken place, as well as the pre-assumptions the researcher might hold.

Our intellect and feelings do not function autonomously. Our thoughts are frequently charged with emotion, and our feelings arise in response to what we think to be true. To reify and alienate these facets of our inner life is to fragment each of us from within.

(Wallace, 2000, p. 8)

Internationally, the change in psychological models from a medical to a human rights based social or bio-ecological model, fueled a shift in focus from barriers to learning to needs appropriate, inclusive educational support. Changes in the South African educational support system was not driven by a change in psychological models, but rather by a change in government and the accompanying change in human rights policies.

As our journey progressed, it became clear that the PDD-NOS diagnosis left us, as parents, with more questions than answers, specifically with regard to educational support for our son. Our disorienting dilemmas became what Mezirow (2000) described as the driving force for transformative learning. The situation we found ourselves in, forced us to plot a route through uncharted territory, since we were not convinced that any existing route would allow our son to reach his full potential.

CHAPTER 3 DRAWING MAPS AND PLANNING ROUTES

3.1 AT THE CROSSROADS OF PARADIGMS

Terre Blanche and Durrheim (2006) propose three major social sciences paradigms: positivist, interpretive and constructionist. According to Terre Blanche and Durrheim, paradigms are defined by three dimensions: ontology, that refers to the nature of the reality that will be studied; epistemology, that refers to the relationship between the researcher and that which will be studied, and methodology, that refers to the research processes used in studies.

Research within the positivist paradigm views reality as a stable, external truth, which is not influenced by context. My research experience lies mainly within this positivist paradigm. During my Honours degree in Human Genetics, the research I conducted was experimental, testing hypotheses, and producing quantitative data. Where I am currently employed, research also focuses on quantitative methodologies.

The positivist paradigm is not the paradigm I chose for this study. This is due to the limitations it poses, specifically its limitations within the special education realm where quantitative research methodologies have been used to classify learners, mainly in an attempt to exclude them from mainstream schooling, and in doing so, also from society in general. According to Brantlinger, Klingner and Richardson (2005, p. 96), the purpose of quantitative research in special needs education “is to produce and validate classification systems and effective interventions”. However, as this type of research is mainly quantitative in nature, it does not take into account the voices and preferences of either the individuals that it seeks to classify or their caregivers.

Terre Blanche and Durrheim (2006) state that, in the interpretive paradigm’s engagement with ontology, the researcher views the nature of reality not as stable and independent of context, as in the positivist paradigm, but rather as made up of people’s subjective experiences of their world. The interpretive researcher’s

epistemological stance towards this reality is to become part of the research, in contrast with the positivist stance that the researcher has to be objective by detaching from the reality. This leads to an interpretive methodology that is interactional, inductive and qualitative. Merriam (1998) describes the qualitative researcher as someone interested in gaining insight into people's realities from the participant's perspective. She refers to this perspective as the emic or insider perspective. It is this emic perspective of the interpretive paradigm that is crucial in research on special needs education, as it informs researchers how to design or improve their interventions aimed at learners with barriers to learning. It also breaks down barriers to inclusion created by a focus on research within the positivist paradigm.

Researchers within the constructionist paradigm views reality as socially constructed and use methodologies that allow them to deconstruct and analyse different versions of reality (Terre Blanche & Durrheim, 2006). This study therefore falls within the boundaries of both the constructionist and interpretive paradigm. I utilised a research methodology that allowed me to deconstruct and analyse different versions of reality, while still addressing the emic perspective of the interpretive paradigm.

3.2 TELLING OUR OWN STORY

In order to document our experiences as parents of a child with special needs, I needed to find a research method that would allow me to not only clinically analyse our journey, but also to tell the story and to share the emotions and transformations we experienced. Tappan and Brown (1989) state that narratives are the preferred way of communicating when we must explain things the way it really occurred. Cajete (1994) proposes that storytelling could be the most elementary method the brain uses to structure and relate experiences. Lawrence, Buckley, Cueva, Giordani, Ramdeholl and Simpson (2006) suggest that participants and also researchers use stories to increase understanding, heal wounds, find hope, share our feelings, and reinforce community. According to Ellis and Bochner (2000), autoethnography is a first-person account that is written as a story, expressing vivid details of the author's own experiences. Although the story is also the research text, it steers clear of academic terminology and abstracted theory because of its narrative format. Jensi-

Hart and Williams (2010) and Sparkes (2000) describe autoethnography as a research approach written as personal narratives that allows the author or researcher to draw on her own experiences, and that actual artefacts and data and/or memories of intense life experiences are used to construct these personal narratives. Charmaz and Mitchell (1996) propose that one of the advantages of autoethnography is that it creates a voice that allows the reader to develop a better understanding of the situation that is being researched. This stance is echoed by Quicke (2010) and Sikes (2005) who state that autoethnography allows the reader to achieve a sense of feel and place of the life-world of the researcher. Storytellers use the concept of life-world to write hope-without-illusion stories (Quicke, 2010).

Although autoethnography is still considered to be an emerging methodology, the term has been in use since 1975 when Karl Heider used it in an article published in the *Journal of Anthropological Research* (Heider, 1975). He used the term to describe accounts by Indonesian Dani schoolchildren of their own lives. In 1979 Hayano used the term *autoethnography* to describe anthropologists' studies of their own culture (Hayano, 1979). As is the case with other methodologies or processes used by social scientists, the meanings and applications of autoethnography have undergone many changes and development since its inception (Ellis & Bochner, 2000). Many studies done since, can now, although originally classified by different terms, be included within the genre of autoethnography, for instance narratives of the self (Richardson, 1994), personal experience narratives and self-stories (Denzin, 1989), complete-member research (Adler & Adler, 1987), lived experience (Van Manen, 1990), evocative narratives (Bochner, Ellis, & Tillmann-Healy, 1997) and Reed-Danahay's autobiographical ethnographies and ethnic autobiographies (1997), to name but a few.

To shed more light on autoethnography as a blurred genre, Jensen-Hart and Williams (2010) distinguish two main types of autoethnographic researchers, namely analytic autoethnographers and evocative autoethnographers. Analytic autoethnographers subject their written personal stories to traditional content analysis, while evocative autoethnographers build their analysis into their stories. Ellis and Bochner (2006) state that evocative autoethnography allows the reader to feel and empathise with the researcher, and to subsequently act in response to the research.

Within this study there are two voices that need to be heard. Where autoethnography is usually a self-reflective, single-voiced method, this study utilises autoethnographic co-constructed narratives. It is a form of autoethnography usually told around a life changing experience, to explain how “people collaboratively cope” with the uncertainties, obscurities and paradoxes of the situation (Ellis, Adams, & Bochner, 2010).

The methodology of evocative autoethnography has drawn criticism for being literarily and intellectually lazy, lacking in analytical outcome and focussing on the wrong side of the power divide, i.e. on the researcher (Delamont, 2007). Atkinson (1997) criticised the methodology for being self-centred, narcissistic, introspective and individualised, since it focuses on the self as source. He further proclaimed the researcher’s process of engagement with the data to be unsystematic. I however, consider autoethnography to be the best suited methodology for this research enquiry. I find support for my stance in Frank (2000, p. 355) who, in response to Atkinson, states that the “point is not to engage systematically, but to engage personally”. Frank also states that storytelling is just as much for other people as for oneself, implying that, although the focus of a narrative might be on the self, its purpose is to inform the other. To address the problem of intellectual laziness, Anderson (2006) proposes analytic autoethnography, where the insider researcher still follows a systematic gathering, analysis and interpretation of data. I further challenge Delamont’s (2007) statement of being on the wrong side of the power divide, as my voice as parent of a son with PDD-NOS, also puts me on the side of the powerless whose voices need to be heard.

3.3 TRAVELLER AND RESEARCHER

As I am both parent and researcher, the issue of insider/outsider perspective in qualitative research needs to be teased out. In this study I will take on an outsider role as the researcher and an insider role as a participant in the research process (Adler & Adler, 1987). For my insider stance I draw support from Foucault (1985, p. 9) who opposed a discourse which “tries, from the outside, to dictate to others, to tell them where their truth is and how to find it” and from Greenfield (2000) who states that whereas the outsider might misunderstand or devalue the motives behind in-

group behaviours when looking through their own cultural values lenses, the insider already understands these meanings and motives. Asselin (2003) suggests that, as an insider, I will be faced with unique challenges and that I have to be aware of the fact that my beliefs, past experiences, expectations and emotions can influence my objectivity when gathering and analysing data. Asselin (2003) also warns against role confusion where the researcher analyses data from a perspective other than that of researcher. However, similar to Rose (1985, p. 77), I believe that research is never neutral and that “there is only greater or less awareness of one’s biases”. As pointed out by Dwyer and Buckle (2009), the outsider researcher is also not immune to the influence of personal perspective. My stance is that, through detailed reflection, an awareness of my own personal perspectives and biases, and a commitment to honest, open, authentic and accurate representation of my experiences, the objectivity of my research will be enhanced. Merriam, Johnson-Bailey, Lee, Kee, Ntseane and Muhamad (2001) suggest that, although the researcher as insider might understand and see the research differently to the outsider researcher, it does not change the validity of what she understands and sees. This view of Merriam et al. (2001) resonates with that of Lewis (1973) who, nearly 40 years ago, argued that both insider and outsider views had to be acknowledged as valid attempts to understand the nature of culture. To ensure the validity of my research, I followed the suggestions of Feldman (2003) by supplying detailed and clear accounts of how I collected, constructed and analysed the data in this study.

3.4 THE MAP

Data was collected through artefact gathering and a process of co-constructing narratives. This entailed the narration of both parents’ stories of how we experienced the journey, followed by sessions of sharing of, and reacting to, each other’s stories. Through dialogue and co-construction a parental-narrative was created. McIlveen (2008) compares narrative analysis and analysis of narratives and concludes that autoethnography should be seen as a form of narrative analysis. He suggests that, in analysis of narratives, the story is seen as a form of qualitative data, whereas in narrative analysis the construction of the story is ultimately a form of analysis. The first step of my narrative analysis took place during the writing of

the parental narratives through a process of continuous reflection and re-questioning. Common elements emerged during the process of co-construction, and the metaphor of keys was used to represent some of these themes. In an effort to avoid being biased by other researchers' findings, a group of narratives would first be constructed, after which I would critically reflect on the narratives in order to find key points. Only then would I search for literature to help with the analysis of the narratives. The analysis was then added as part of the researcher reflexive layer.

McNaught and Lam (2010) and Wu, Provani, Wei, Liu and Ma (2011) state that word clouds can be used effectively to find key points within a piece of text. I made use of two open-source word cloud generators, Wordle (<http://www.wordle.net>) and Tagxedo (<http://www.tagxedo.com>), to create word clouds for each parental narrative and to find possible themes within these narratives. Figure 2 shows two word clouds from the first set of parental narratives in Chapter 4. Word clouds, also called tag clouds, are computer generated images based on the frequency of words found in a particular text. The word cloud generators hide grammatical and non-frequent words. The size of a word in the word cloud is directly related to the frequency of the particular word in the text.

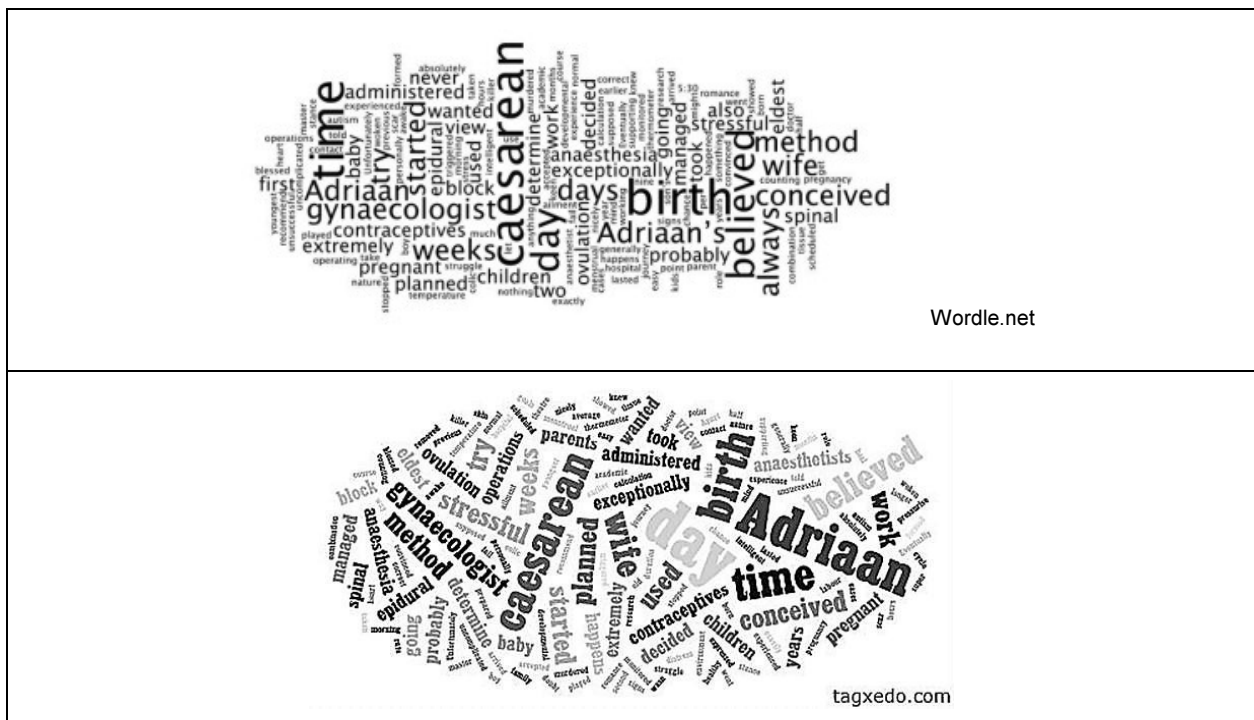


FIGURE 2: Word clouds from the first set of parental narratives in Chapter 4

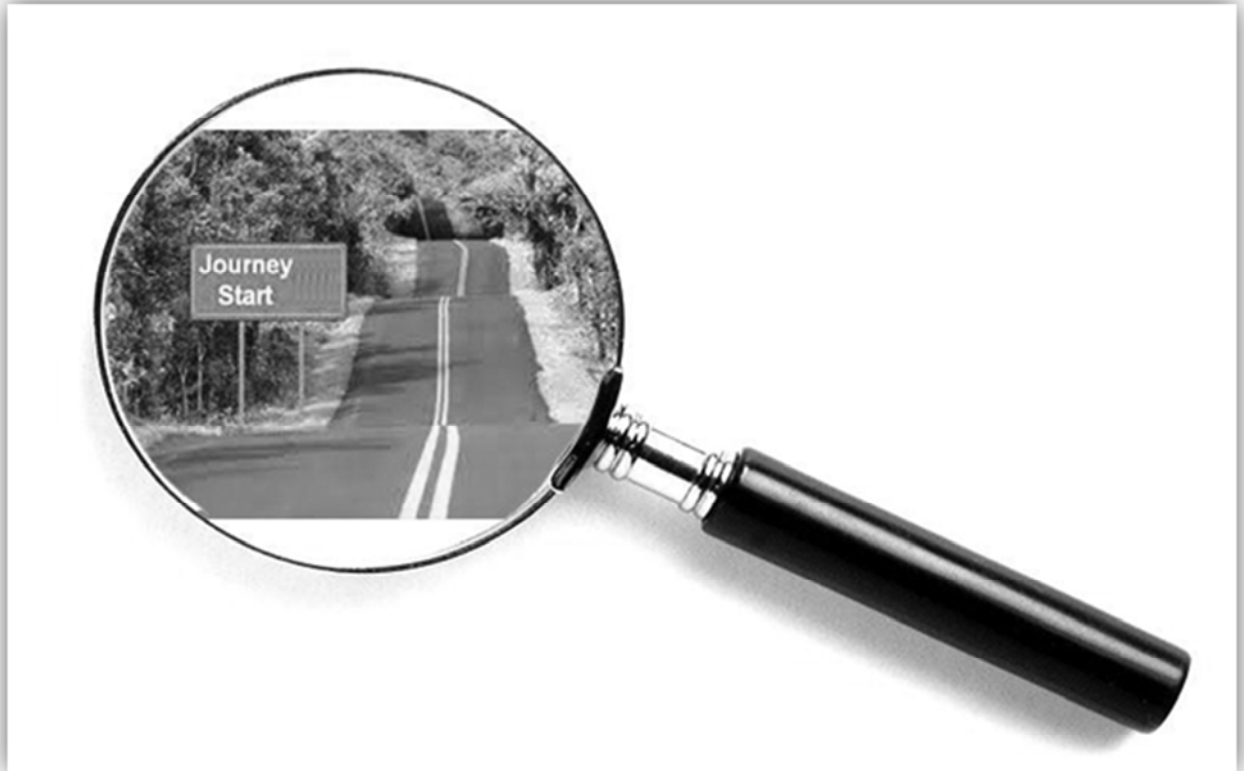
The artefacts that were analysed included a poem written by my husband. Sherry and Schouten (2002, p. 219) propose that “science and poetry are kindred enterprises” and that poems “serve to locate the researchers emotionally” within a study. They further state that poetry, in contrast to other narrative methods, expects the audience members to draw on their own imaginations, knowledge and emotions to “read between the lines” and to find their own truth. Other artefacts that were included as data, and utilised in the completed narrative, were a radio interview transcription, e-mails and letters. Letters have often been used as data in historical writings. Vietzen (1999) states that letters not only describe events, but also give insight into the writer’s thoughts and feelings.

The dialogue and co-construction sessions followed the framework presented on the next page:



FIGURE 3: The dialogue and co-construction session framework

Analysing the parental narratives enabled me to draw a map of the routes we travelled in finding appropriate educational support for Adriaan. In doing so, routes that were previously less travelled are shown as possible alternatives for consideration by other parents of children with special educational needs.



To think about a story is to reduce it to content and (to) then analyse the content. To think with a story is to experience its affecting one's own life and to find in that effect a certain truth of one's life.

Frank, A.W. (1995, p. 23)

CHAPTER 4

A JOURNEY INTO THE UNKNOWN



No journey starts the moment you leave for your destination. Most journeys involve planning and route mapping. The different participants also experience and remember a journey differently. So where did it start for the two of us?



For me it started with Adriaan's birth. The pregnancy was uncomplicated and his birth was supposed to have been a planned caesarean at 39 weeks. Because we had used the temperature method to determine ovulation, I knew exactly when Adriaan was conceived (day nine of my menstrual cycle), but the gynaecologist used the generally accepted method of counting from day 14. I went into labour at 39 weeks and one day (my calculation), 6 days before the planned caesarean.

With my eldest son's birth I had a spinal block, as I wanted to be awake during the birth. When we arrived at the hospital for the birth of Adriaan, the gynaecologist personally administered epidural anaesthesia as all the anaesthetists were in scheduled operations. Unfortunately, as happens in some cases, the epidural was unsuccessful. While I was being prepared in the operating theatre, the gynaecologist managed to contact an anaesthetist who then administered a spinal block.

The caesarean took longer than normal as scar tissue that had formed from the previous caesarean, had to be removed first. Adriaan's heart rate was monitored throughout and he showed signs of distress before he could be taken out. I have always believed that the combination of anaesthesia and the duration of the caesarean triggered Adriaan's autism.



For me the journey started much earlier. I am probably not the first parent who believed that he would be blessed with super kids. From an intellectual point of view both my wife and I are probably way above average. I always wanted children and to me there was absolutely no doubt in my mind that my children would be extremely intelligent.

Before we started with a family, my wife's doctor expressed the view that he believed she might struggle to get pregnant. We therefore decided not to pressurise ourselves and to let nature take its course. Within two months of going off contraceptives, my wife was pregnant and nine months later a healthy baby boy was born. Apart from the 11 weeks and three days of colic and a skin ailment that took almost a year to heal, he was an exceptionally easy baby. He also murdered all the developmental goals and it seemed that my master plan was working out very nicely.

By the time my eldest was about two and a half years old, we decided to try for our second. My wife stopped taking contraceptives, but this time nothing happened. Eventually she convinced me that we should use a thermometer to determine the correct time of ovulation. I wasn't keen at all and I told her that we could try it once, but that, should it fail, there was no chance that we would try the method again.

If ever there was a passion killer, this was it. My youngest was conceived after I was woken at 5:30 in the morning. I found the whole experience exceptionally stressful and something that I would definitely not recommend to other parents. At the time when Adriaan was conceived, I was also in a very stressful work environment and my work days lasted anything from 12 to 14 hours. I have always believed that the stress that I experienced during that period played a role, but I never managed to find any research supporting my theory.



To date, the medical fraternity has not been successful in isolating the causes of autism and we might never know what caused Adriaan's autism. Although both parties have wondered what the contributing factors were, it was never discussed until it came up during one of the sessions where these narratives were compiled. This thesis presented me with an opportunity to further examine the literature on probable causes for Adriaan's autism.

In animal models, a review of literature on stress and mutations found that, in mice and rats, DNA recombination and chromatin structure were affected by psycho-

emotional stresses (Daev, 2007). However, little research has been done on the influence of stress on the DNA in developing human male spermatozoa, as most studies focus on sperm structure, motility and quantity. Collodel, Moretti, Fontani, Rinaldi, Aravagli, Saragò, Capitani and Anichini (2008) though, did report that emotional stress in males disrupts the meiotic process in developing spermatozoa. Their finding supports the possibility that stress in males can be a contributing factor in autism.

Baron-Cohen, Bolton, Wheelwright, Scahill, Short, Mead and Smith (1998) proposed that parents of children on the autism spectrum, to a lesser degree, share the cognitive phenotype of those children, namely exceptional talent in physics related skills, with relatively impaired social abilities. These parents would therefore be more likely to be in an engineering field than any other career. In 2001 Wheelwright and Baron-Cohen confirmed that, whereas 5% of typically developing children had fathers who were engineers, 12.5% of children on the autism spectrum had fathers and even grandfathers who were engineers (Wheelwright & Baron-Cohen, 2001).

Glasson and Petterson (2004) examined Western Australian children, born between 1980 and 1995, who were diagnosed with an autism spectrum disorder. They identified foetal distress and delivery by an emergency caesarean section as common obstetric factors in their case children, while the use of epidural caudal anaesthesia was found to be one of the obstetric factors identified in the mothers of these children. My hypothesis is also supported by Loepke (2010) who, in a review of literature, found that exposure of neonatal brains to anaesthetics in developing animal models, caused neuronal cell death.

Whatever our own private thoughts were about the role the other party played in producing a baby with autism, there was no justification for blaming each other for contributing to Adriaan's autism. Our focus was on supporting our son to reach his full potential. Any attempt to apportion blame would have been to the detriment of his educational journey.

The fact that our eldest son's developmental journey had been exceptionally easy, left us totally unprepared for Adriaan who, from the start, was very different to his brother.



It is almost impossible for me to comment on the first two years of Adriaan's life. In many respects, I was an absent father during that period. I had, what I perceived to be, a hugely stressful job, but I would lie if I say that I did not enjoy every minute of it. I worked long hours and I did not spend nearly enough time at home. And then there was another hugely contributing factor.

When my eldest was born, we lived in Kuruman in the Northern Cape. My job was anything but stressful and I was fortunate to spend a lot of time at home. For some reason my eldest formed an immediate emotional bond with me, not with his mother. When he cried, I was the one who calmed him. I could see that my bond with my eldest actually bothered my wife.

When Adriaan was born, everything was different. As so often happens, I ended up spending more and more time with my eldest, to compensate for the inevitable lack of attention by his mother (due to the new baby in the house). There was absolutely NO emotional bond with my youngest. To me it felt as if he rejected me completely, and, as a result, I elected to spend more time with my eldest. To a large extent, Adriaan was an intruder in my perfect world. We were left with a situation where my eldest was my child and my youngest was my wife's child. My wife tried her best to be a good mother to both children. I cannot honestly say the same about me.



Once again, what seemed like a very familiar piece of the road to us, turned out to be unfamiliar, looking through the other's eyes. Although I was aware that Henré paid more attention to our eldest, that he was working extremely long hours and that he was often away from home, I never fully realised that he felt Adriaan intruded into our lives. Nor did I feel alone or feel left to deal with Adriaan on my

own. Bochner (1997) warns autoethnographic researchers and readers not to add meaning or feelings to events after the event, or as Edmund Shneidman (2004) wrote:

Hindsight is not only clearer than perception-in-the-moment, but also unfair to those who actually lived through the moment.



I still remember the first time I was allowed to hold Adriaan. It was about 4 hours after his birth. I had suffered complications from the anaesthesia and only when I was taken back to the maternity ward, could I finally hold him. Whereas my eldest son had been calm and attentive when I first held him, Adriaan was different. The moment I picked him up, he pulled up his legs in a foetal position and clung to my chest. I held him close and, although there were no other outward signs, I immediately felt that something was not right. I convinced myself however, that I was just emotional and tired after the stressful birth and that he would be fine.

As a new-born, Adriaan's brother had colic for almost 12 weeks, but Adriaan seemed to be what many would consider a dream baby who only cried when he was hungry. I still had this niggling feeling that something was wrong, though. Adriaan showed no interest in anything. Loud noises did not make him react, he did not follow me with his eyes when I moved around his cot, and he made no attempt to imitate any facial gestures. As is standard procedure in private hospitals in South Africa, Adriaan's hearing was tested when he was 3 days old. We were asked to have him reassessed at 6 weeks, as their testing had been inconclusive. The follow-up test concluded that he probably had normal hearing.

When he was 2 months old, Adriaan joined his older brother at a day-care centre when I had to return to work. Watching the other babies at the day-care centre, it was even more apparent to me that Adriaan was still behaving like a new-born baby. From about 4 months of age he started having unexplained screaming bouts. He would lie peacefully and smiling, fixated on a spot on the wall, and then, without warning, he would start screaming at the top of his voice while his face first turned red and then purple. Nothing, and no one, could succeed in calming him when he screamed like this. A few minutes into the screaming bout he would abruptly stop and would start smiling again. These episodes were nerve wrecking for us, the day-care centre staff and the other children in their care. The head of the day-

care centre repeatedly requested that we take Adriaan away, as she simply was not able to cope with him. When our eldest son had to move to a crèche, we moved Adriaan, aged 10 months, with him.

Adriaan also started having trouble sleeping. It seemed as if his internal clock just stopped working. He would easily stay wide awake until 02:00 or 03:00 in the morning, before suddenly falling asleep for two or three hours. In an attempt to allow us some sleep, Henrié installed a television and video machine in Adriaan's room. We tried to keep him occupied, so that the rest of the family could sleep, by playing children's videos that were about 50 minutes long. Adriaan announced the end of each video with a spine chilling scream and Henrié and I took turns inserting new videos. Within seconds he would stop screaming and a new 50 minute cycle would begin.

During this time I started a new job, teaching at an all boys' secondary school about 45 km from our home. I was tired all the time, since I left home at 06:20 and only returned home at 18:00. After tending to my family responsibilities, I still had to prepare for the next day's classes before going to bed at around midnight. Despite repeated visits to the doctors, they could not find any explanation for Adriaan's lack of sleep and screaming bouts. Both family members and doctors pointed out that boys usually develop slower and that we should take care not to overreact. We knew something was wrong with our son, but we had no idea how to address the situation. Our struggle for a diagnosis had begun.



In a review of articles on sleep problems in autism, Richdale (1999) found that children with an autism spectrum disorder often suffer from severe sleep difficulties, but that the aetiology was unknown. She also reported that sleep difficulties could not be related to intellectual functioning. Schreck and Mulick (2000) did a comparative study on children with and without an autism diagnosis, and found definite differences in their sleep patterns. Similarly, Honomichl, Goodlin-Jones, Burnham, Gaylor and Anders' (2002) research findings showed that, in a group of 100 children with pervasive developmental delays, all displayed longer sleep onset times and sleep fragmentation in relation to age-matched community norms. When a child suffers from sleep difficulties, it also directly influences the caregivers' sleeping patterns. Gallagher, Phillips and Carroll (2010) investigated the sleep

quality of caregivers of children with developmental disabilities and found that, compared to caregivers of typically developing children, parental caregivers slept less, struggled more to fall asleep, and had poorer sleep quality. All these factors lead to increased daytime dysfunction. This was also the case with Adriaan, whose sleep difficulties not only affected his own daytime functioning, but also ours.



Adriaan's first birthday was emotionally draining. I remember standing in a toy store, staring at all the toys that were supposed to be perfect for a one year old, knowing that there was no way Adriaan would be interested in, or know how to play with, any of those toys. The only items I could consider buying were all for new-borns. Most of the time I could pretend that he was just developing a bit slower than his brother, but standing there in that toy shop, I had the sudden realisation that there was a major problem with my son's development. I rushed out of the store, got into my car and just sat there crying, amazed that everyone around me was carrying on with their daily routines while mine had come to a complete stop. I couldn't phone Henré, as he was on an incentive trip in France at the time, and I could not go home without a present. I eventually went back into the store and bought a soft toy. The rest of Adriaan's first birthday remains a blur.



I don't think I was a bad father and I certainly did well at hiding the complete lack of an emotional bond with my youngest, but I spent a lot of time at work or away from home. I missed Adriaan's first birthday due to an incentive trip to France. The following year I missed my eldest son's birthday due to a trip to Nigeria.

When, at age 18 months, Adriaan was admitted to hospital with viral meningitis, the paediatrician mentioned that he believed there was something wrong with our son. However, he left it at that and said that we had to wait until Adriaan was three before taking any further steps. Shortly after this we had Adriaan's hearing tested again, because he displayed an almost complete lack of response to loud noises. When his hearing was found to be normal, I mentioned to my wife that I believed that our youngest might be autistic. I still don't know why the paediatrician was not willing to at

least elaborate more on his suspicions. When Adriaan was eventually diagnosed by a different paediatrician at age 3 years and 10 months, her comment was: "It is a pity that he is only diagnosed now. We have already lost a lot of time."



At the time of Adriaan's birth in 2001, medical professionals worldwide were hesitant to diagnose developmental delays before standardised tests could be done at age three. It was only in 2005 that Zwaigenbaum, Bryson, Rogers, Roberts, Brian and Szatmari (2005) described markers for detecting possible autism in infants, namely infrequent eye contact, not smiling in response to others, passivity and extreme irritability, and a tendency to fixate on objects.



Adriaan loved music and would turn the volume on the radio to full blast, placing his hands against the speakers to feel the vibrations. At 20 months I took him to an occupational therapist for an assessment. He was not copying sounds or actions like other children, including his cousin who is 6 months younger than he is. He was still sleeping for very short periods only, and occasionally, he was throwing 40 minute long tantrums. The occupational therapist observed him and asked us to complete a Winnie Dunn Sensory Profile¹¹ (Dunn, 1999) as well as a De Gangi's Infant-toddler Symptom Checklist¹² (DeGangi, Sickel, & Wiener, 1995). She concluded that Adriaan had problems with sensory modulation, advised us to have his hearing tested again, and suggested occupational and speech therapy. Again Adriaan's hearing tested normal. We started taking him to occupational and speech therapy sessions once a week. At last it felt as if we were doing something, even though we weren't seeing much progress. The speech therapist struggled to get any kind of response from Adriaan and, although he gradually began to interact with the occupational therapist, he still wasn't copying or attempting speech. Despite all the other signs, I did not agree with Henrié that Adriaan might be autistic, as he was, for the most part, a happy little boy who loved being hugged and cuddled. To me autism conjured up images of stern faced children who avoided physical contact.

¹¹ A parent-reported questionnaire that assesses a child's sensory processing abilities.

¹² A parent-reported checklist for symptoms of sensory processing problems



Brill (2001) reports that, because of the unavailability of precise clinical tests for diagnosis, autism is frequently mistaken for deafness. He is supported by Tomchek and Dunn (2007) who found that nearly 80% of toddlers on the autism spectrum appeared to “tune out” language. This could be related to the auditory processing deficits commonly associated with autism and explains why we, as well as the occupational therapist, believed that Adriaan had a possible hearing deficiency.

In the autism spectrum community there is an often repeated saying about the variety of symptoms found on this spectrum: “If you’ve seen one autistic child, you’ve seen one autistic child”. This, of course, further complicates the task of diagnosing children on the autism spectrum. Tomchek and Dunn (2007) also found that more than 90% of the toddlers with autism spectrum disorders they had tested, showed either under-responsive or sensation-seeking behaviour. Adriaan’s love for vibrations, hugging and cuddling could probably be classified as sensory seeking behaviour.



It wasn't a single event that changed my relationship with my youngest and I am not exactly sure when it happened, but I believe that it was when Adriaan was about two years old. A comment that my eldest made towards his grandmother had a huge effect on my outlook on life. She jokingly said to him that he must come to stay with her. When his response was "yes" she backtracked and mentioned that his dad would miss him too much if that should happen. My eldest, the one that I once had such a close relationship with, responded: "Dad won't miss me. He works too much." I did not know what to do, simply that I had to do something. If I did not act, I would have lost my family.

Shortly after my return from Nigeria, I resigned from my job and accepted a new position. The new working environment was more conducive to family life and the stress was substantially less. I will always believe that I did not pull my weight during

the first two years of Adriaan's life and I will always feel guilty about it. But I am also hugely proud of what I have contributed since.



Before we had Adriaan, we loved camping and spending time with friends and family. Adriaan's condition changed a lot of that. It was easier to simply stay at home than to explain to family, friends, waiters and strangers why our son behaved so badly. Adriaan's frustration levels could explode into a tantrum without any warning. In restaurants strangers would comment on how "undisciplined" our son was, clearly blaming us for his behaviour.

By the end of 2003 the stress of coping with Adriaan, interrupted sleep and working so far from home, became too much for me to handle. I resigned, despite not having another position lined up. I was lucky to find employment at a new private school close to our home. Our eldest started school in 2004. I was apprehensive about how his new friends would react to Adriaan, but as luck would have it, he made friends with a boy who had an older sister who is also on the autism spectrum. The friend did not think Adriaan was strange at all.

Attending our eldest's school events were exhausting affairs. One of my most vivid memories is of trying to catch a glimpse of Adriaan's brother playing rugby, while walking round and round the rugby field, simply because Adriaan could not stand still for a second. On another occasion, we had to attend a parent braai (barbeque) at the school. I had to carry Adriaan upside down the entire evening, as he would start screaming the moment I tried to turn him face up.

In April 2005 my husband won his third motor industry incentive prize. The prize consisted of an eight day all expenses paid trip to Singapore, Malaysia and Thailand. Although my husband had been overseas a number of times, I never had the opportunity to join him. For me, it was the opportunity of a life time. Neither my parents, nor my widowed mother-in-law, were prepared to look after both children. They eventually agreed that my mother-in-law would look after my eldest, and my parents would care for Adriaan while we were away. It would be the first time since Adriaan's birth that he would be away from home. The trip turned out to be more than I could ever have hoped for. Looking back, I am extremely grateful that we had that one week break before Adriaan was finally diagnosed.



Miller, Buys and Woodbridge (2011) investigated the impact a grandchild with a disability has on the grandparents of the child. They found that most grandparents described support as their main role.



Although Adriaan's grandparents showed some concern for his developmental delays and attempted to provide emotional support, they did not offer any physical support in the time before he was diagnosed. We were mostly left to deal with the situation on our own.



Unfortunately I do not agree with my wife, as I believe that she is completely understating the lack of support we experienced. Our families did not even admit that there was anything wrong with Adriaan. If there was nothing wrong, then there was certainly no need for support. This did not even change immediately after Adriaan was diagnosed.

As mentioned earlier, it took me almost two years to form an emotional bond with Adriaan and I believe it took six to seven years for my mother to form that bond. I don't blame her, since I believe that she simply did not know how to handle him. Once Adriaan was able to verbally communicate with her, everything changed.

For the first seven years of Adriaan's life we got very little support. Babysitting only became an option when there was no other alternative, as was the case with our trip to Singapore. Never did any of our family members offer to look after our children for even a few hours to allow us a break. My mother lost her husband when I was only four years old and she did an exceptional job of raising four children alone. She once stated that she had done her fair share and that her responsibilities lie primarily with her children, not her grandchildren. I find this understandable, but I will always feel that we were let down at a time when we really needed support. I am not even mentioning the lack of support from my in-laws, since my own relationship with my mother-in-law has always been something between strained and non-existent.

After our return from Singapore, my mother-in-law told us, for the first time, that she believed that there was something wrong with Adriaan. A few days later my wife, accompanied by her mother, took Adriaan to see a new paediatrician. After completing the assessment, the paediatrician referred him to a psychologist. At that stage we had no idea that her diagnosis was autism, although it is not impossible that she perhaps used the term PDD.

Adriaan was assessed by the psychologist on 19 May 2005. She forwarded her report to the paediatrician, the occupational therapist and the speech therapist. She also suggested that the occupational therapist and the speech therapist visit us at our residence to discuss the diagnosis. This was possible since they both lived in close proximity to us. I am not 100% sure of the date, but I believe that they came to see us on Monday, 23 May 2005.

That evening they informed us that Adriaan was autistic. I asked them to be honest with us; to call a spade a spade. When I asked whether Adriaan would ever be able to speak, they responded by saying: "Probably not". They also informed us that he would never be able to attend a mainstream school. According to them, the only real option was to enrol him in a school for autistic learners in Cape Town. To be accepted at this school involved a drawn out process. They therefore suggested that, in the meantime, we enrol him in a local centre for children with severe mental disabilities.

I don't remember the rest of the conversation and I don't even remember them leaving. I was probably too shocked to show any emotion. Although I always suspected that there was a major problem, and despite the fact that I was the first one to actually suspect that Adriaan was autistic, the final diagnosis came as a huge shock.

Somehow, I survived that night. The next day the managing director of the company I worked for, called me to his office. I can't remember if he specifically asked what was wrong, but I do remember breaking down completely when I informed him about the

events of the previous evening. I went home and cried for the rest of the day. That was, to the best of my knowledge, 24 May 2005. The next time I cried about my son was on 17 January 2008.

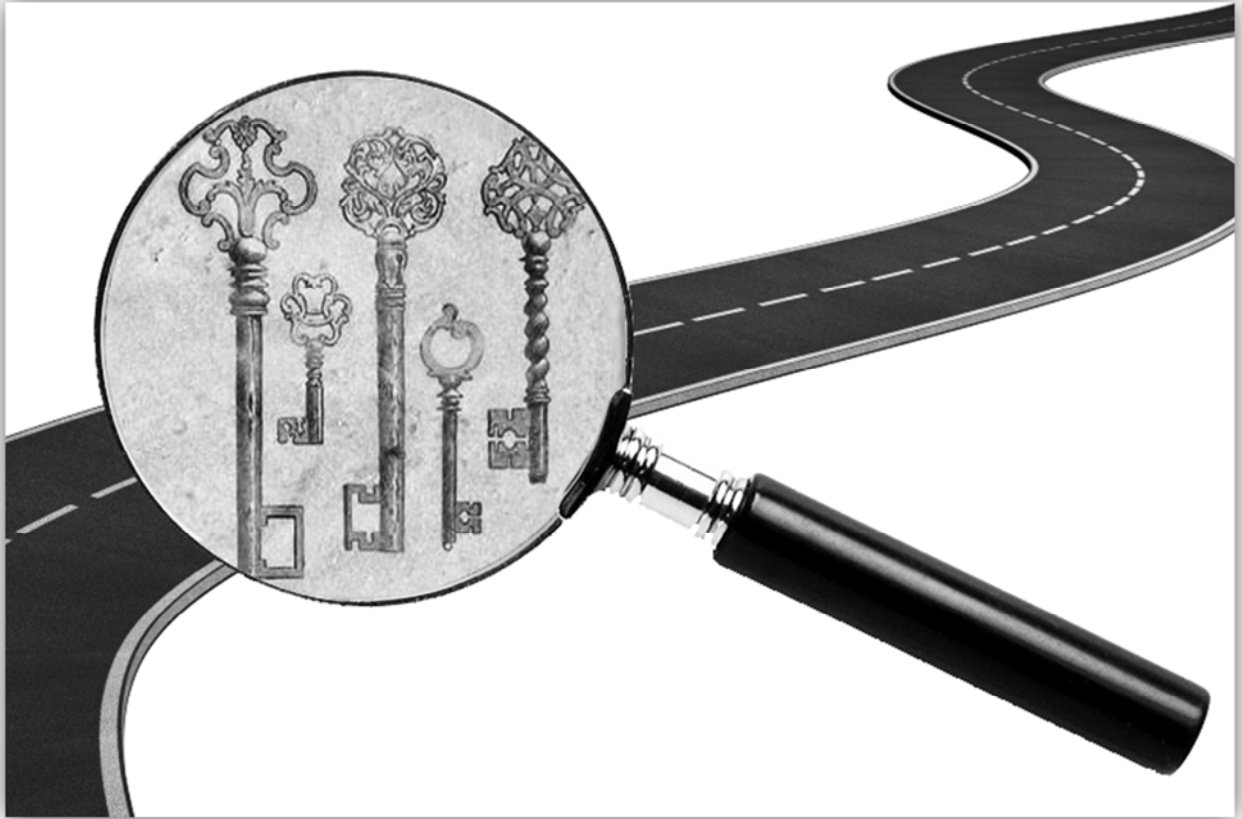


I agree that the journey would have been much easier had we received more support from our families. At times I even got the impression that they became irritated when we spoke about Adriaan's problems. I do think though, that our families' lack of support had less of an impact on me than it had on my husband. He had grown up in a more closeknit and interdependent family than I had, which meant that I probably had less expectations of support than he did.

The diagnosis also came as less of a shock to me than to my husband. For nearly four years I had spent every waking moment, except during working hours, with Adriaan. This meant that, although I did not have a name for what was wrong with him, I was constantly aware of, and had to deal with, his problems. It broke my heart to hear the diagnosis and their prognosis, but at the same time I experienced a sense of relief to finally know what was wrong with my son. I had already spent hours crying before that day. After hearing the diagnosis, all I wanted to know was how we could best support him. What I found disappointing was that Adriaan was given a "death sentence". I suppose medical professionals do not want to create an expectation of false hope, but I find their method of crushing all hope, totally unacceptable.



Adriaan's diagnosis concluded the first stage of our journey, a stage in which we, at times, were completely lost. At last we knew exactly where we were on our map. Now we could start planning routes, despite not knowing exactly where we would end up.



There is no chance, no destiny, no fate
that can circumvent or hinder or control
the firm resolve of a determined soul.
Gifts count for nothing; will alone is great;
All things give way before it, soon or late.
What obstacle can stay the mighty force
of the sea seeking river in its course,
or cause the ascending orb of day to wait?

Wilcox (1888, p. 145)

CHAPTER 5

FINDING AND MAKING KEYS: RECOLLECTIONS



With a map containing the route suggested by the medical professionals, we started a new phase in our journey. We soon realised that we would encounter many locked doors.

*Some people see a closed door, and turn away.
Others see a closed door, try the knob,
if it doesn't open... they turn away.*

*Still others see a closed door, try the knob,
if it doesn't open, they find a key,
if the key doesn't fit... they turn away.*

*A rare few see a closed door, try the knob,
if it doesn't open, they find a key,
if the key doesn't fit... they make one.*

<http://www.oafccd.com/lanark/poems/keymaker.htm>

Key 1: It is a solid door – accept it



It might seem strange, but my husband and I never discussed the day that Adriaan was diagnosed. We also did not discuss the roles each of us would play in finding him support. Both of us assumed that I would do the research and that he would manage the process. I literally spent hours doing research on possible interventions. Once I found something that I believed could help Adriaan, my husband and I would discuss it. If he agreed, he took over and ran with the idea.

Probably the only advantage of Adriaan being diagnosed at such a late stage, was that we never doubted the diagnosis, although we strongly disagreed with the medical professionals on the prognosis.



No father wants to learn that his child is physically or mentally impaired, but along with the shock of Adriaan being diagnosed with autism, there was a sense of relief. Suddenly this "monster" which affected every part of my son's life, had a name.

After crying for the most part of 24 hours, I decided to do something I knew I was good at: fight. The decision to fight was probably selfish to a large extent, since I said to myself that, if I look into the mirror in ten years' time, I needed to be able to live with the image and that there should be no regrets.



Nissenbaum, Tollefson and Reese (2002) reported on the contrast between parents' and medical professionals' perception of a child's prognosis. They found that medical professionals tended to focus on the possible negative outcomes, whereas parents' focus was on finding interventions that could facilitate the child's potential for improvement. Their findings are supported by De Alba and Bodfish (2011) who interviewed 438 parents of children with an ASD. They found that, at the time of diagnosis, most parents were more interested in possible interventions to support their children, than information about the causal factors of the disorder. Although some medical professionals describe parents' more positive attitude as denial or even as dysfunctional, Kearny and Griffen (2001) suggested that a positive attitude can be a powerful resilience factor for parents of children with disabilities.

Key 2: Some days the door will seem unmovable



It is impossible to describe to people who do not find themselves in a similar situation, what a parent of a child with special needs goes through. For a long period I lived with a tremendous fear of death, not because of concerns relating to religious issues, but simply because I wanted to provide a future for Adriaan; a future that I was convinced nobody else could provide. This fear of death, and the uncertainty about my son's future, completely dominated my thoughts and emotions. In order to cope I allowed myself the odd "down" day, but most of the time I tried to focus on the task that lay ahead.



*My husband and I shared the physical journey and discussed possible treatments and support, but we rarely discussed our emotions regarding Adriaan or the journey. John Gray, in his 1992 book **Men Are from Mars, Women Are from Venus** uses the metaphor of a Martian caveman to describe how men react to, and deal with, stress:*

When a Martian gets upset he never talks about what is bothering him. He would never burden another Martian with his problem unless his friend's assistance was necessary to solve the problem. Instead he becomes very quiet and goes to his private cave to think about his problem, mulling it over to find a solution. When he has found a solution, he feels much better and comes out of his cave.

(Gray, 1992, p. 24)

Although I know when my husband is stressed or feeling down, I rarely know exactly what he is feeling or what triggered a specific emotional response. Not being the confrontational type, I also do not “nag” my husband to talk about his feelings or problems.

One evening, after returning from Newlands in Cape Town, Henré went straight to our study and asked me not to bother him. To this day I do not know exactly what happened. All I know is that my husband took Adriaan along to watch a rugby match. They had tickets in a private box belonging to one of his suppliers. After spending about two hours in the study, Henré gave me a poem to read. He did not say much; only that the poem reflected exactly what he felt and that it was impossible for him to word it any better. I read the poem and, for the first time since Adriaan was diagnosed, I got a glimpse of what my husband was thinking and feeling. For the first time I realised that we shared many fears; fears and thoughts that I had been too scared to voice, thinking that it was wrong to have them.

*The dream is shattered,
my life in tatters.
I'm living the loving hell.*

*An emotional flood
of tainted blood.
I'm living the loving hell.*

*A God up above?
With endless love?
I'm living the loving hell.*

*Fill the grey with colour,
the dark with light.
I'm living the loving hell.*

*Give him a future bright,
not the black of night,
nor this painful loving hell.*



Frank (1995) described chaos narratives as reflections on chaos that find no purpose for suffering. My husband's poem was motivated by the chaos he experienced: a father's love for his son versus the pain and confusion that raising a son with barriers to learning, evoked. Krajewski (2005) stated that special needs fathers (SNFs) struggle to express their feelings and my husband is no exception. His poem was the key that opened the door to sharing our emotions.

Key 3: Get to know the door and keys used by others



When the paediatrician diagnosed Adriaan, she prescribed Risperidone in an attempt to address his sleep difficulties and temper tantrums. I really do not believe that the temper tantrums were any better after we started with the medication, but the sleep difficulties completely, and almost immediately, disappeared. What was disappointing, however, was that our medical aid refused to pay for the medication. If the same medication is prescribed for schizophrenia, medical aids in South Africa cover it under chronic medication, but when Risperidone is prescribed for autism, it is not covered. When I mentioned this fact to the managing director and financial director of the company I worked for at the time, they immediately offered to pay for the medication. I stayed with the company for another year and a half. My employers never renege on that promise and a few days before I left their service, they paid the last bill.

As recommended by the psychologist, we placed Adriaan at a centre for children with severe mental disabilities. The aim of the exercise was twofold. Firstly, the placement at the centre gave the speech therapist and the occupational therapist the opportunity to work with Adriaan during the daytime, and secondly, the staff at the centre was given the opportunity to potty train Adriaan.

I took control of this phase of Adriaan's development. I dropped him at the centre every morning and picked him up most afternoons, since the centre was only about 500 meters from my workplace. Any possible lack of an emotional bond with Adriaan that might still have existed at the time, was eliminated. Suddenly I had the opportunity to spend more time with my son than my wife could. I really don't know whether it was simply the drastic change in circumstances, but without ever speaking about it, my wife and I assumed new roles. She assumed the role of researcher and I took control of managing Adriaan's education and medical treatment.

In retrospect, it was a shockingly bad decision to enrol Adriaan at the centre. The decision was based solely on the advice of the psychologist. If anything, Adriaan regressed. In my opinion they were not interested in his development at all. The only positive about the period at the centre was that it gave us the opportunity to make other plans. As per the recommendation by the psychologist, we arranged to have Adriaan assessed by the school for autistic learners in Cape Town. My wife was not keen on the idea, but I convinced her to be open-minded and to give the school a chance.

I think it was June 2005 when we took Adriaan for the assessment in Cape Town. As we entered the main building we noticed a sign that read: "Autism is a life sentence". Another sign exclaimed: "Autism cannot be cured". I asked myself how it was possible for the school to provide in the needs of the learners if they saw the children as a burden to society, children sentenced to a life with autism. Right there my mind was made up. I allowed them to continue with the assessment, but I knew that there was

no way that the school was the right place for our son. One positive aspect was that the school psychologist confirmed the autism spectrum diagnosis.



Those were probably the last words I expected to read at a school for autistic learners. Despite hearing the same prognosis from the medical panel and frequently reading it on the internet, it still came as a huge shock to read it on their wall. I wondered what the learners thought when reading those words. If Adriaan and I had gone alone that day, I would have left right there and then. Something else I noticed was the marked silence; learners passed us with their heads bowed. How could our son learn social skills in an environment where all the learners struggled to socialise?

My husband and I already knew that the care centre Adriaan was attending was totally wrong for him. He started to repeat some of the odd sounds the other children were making and it seemed as if no cognitive progress was made. Because the facility was a care centre and not a school, their focus was solely on caring. We needed to find a place that could support Adriaan to reach his potential, whatever that turned out to be. At that stage we took the risky decision to ignore the medical professionals and “go it alone”, at least for a period of about a year.

In an attempt to find strategies and treatments that had worked for other children with an ASD, I spent hours reading books and articles on the internet. When I came across an interesting treatment, I first attempted to find peer-reviewed research to validate the parents’ findings, or at least some research indicating that the treatment could not harm our son. I would then present my findings to my husband and we would decide whether to attempt the treatment or not. During the next year we attempted the gluten-and-casein-free diet, explored chelation therapy, bathed Adriaan in Epsom Salt and even tried a new kind of food supplement that cost us R1 700 per bottle per month. Most of the treatments made no difference to Adriaan’s behaviour or autistic traits, except for the gluten-free diet that he is still on today. At the time the paediatrician told us that there was no scientific evidence of the gluten-free diet having any positive effect on children with pervasive developmental delays, but that it could do no harm. After about a week on the diet Adriaan seemed to start noticing the world around him and, although he still did not attempt to be part of it, he

started to react to sights and sounds that he previously seemed impervious to. The diet was by no means a cure, but it definitely made a positive difference.



Hanson, Kalish, Bunce, Curtis, McDaniel, Ware and Petry (2007) examined the prevalence of complementary and alternative medicine (CAM) use by children diagnosed with an ASD. They reported that nearly 75% of the families they investigated used CAMs, mainly due to concerns with the side effects and/or safety of prescription medications. We accepted right from the start that there was no cure for autism and that there was a place for prescription medication in Adriaan's treatment. We explored CAMs to address our son's autistic traits (symptoms) and not as an alternative to prescription medication.

Gluten is a protein mostly found in wheat, oats and barley. It can, when improperly digested, produce toxic peptides (Knivsberg, Reichelt, Høien, & Nødland, 2002). Sun and Cade (1999) observed that, when injecting rats with one of gluten's resulting peptides, β -casomorphin-7, they displayed autistic behaviour. This behaviour normalised when the rats were taken off the injections. Research has also shown that gluten-free diets decrease urinary peptide levels (Knivsberg, Reichelt, Høien, & Nødland, 2003). Extensive research into the use of a gluten-free diet as therapy or cure for children diagnosed with an ASD, has however been inconclusive (Mulloy, Lang, O'Reilly, Sigafoos, Lancioni, & Rispoli, 2010). This is mainly because of the complicated research design needed to exclude all other contributing factors, and the variability of symptoms within the autism spectrum. Hague (2011) is of the opinion that multiple case studies, and a decrease in urinary peptide levels, show probable promise for the use of the gluten-free diet in addressing some of the symptoms of autism.



By October 2005 Adriaan had made no progress at the centre for children with severe mental disabilities. When I confronted the staff on why they still had not attempted to potty train him, they simply said that it was still too cold and that they only attempted potty training in the summer months.

During this period we heard about a private institution for learners on the autism spectrum. I arranged a meeting with the principal and we went to see her one evening after work. For the first time it seemed as if somebody was willing to listen to us. The principal quoted what was apparently a well-known saying: "If it walks like a duck, talks like a duck and acts like a duck, it's probably a duck". In other words, if an autistic child can be taught to act and communicate in a way that could be considered normal, he himself could probably be considered to be normal.

That day in October 2005 had a huge effect on Adriaan's development. The principal was the first person to give us hope and her program kick started our son's educational development. Without her, our son would not have been where he is today. Since then, a considerable rift has developed between the principal and me, but let me give credit where credit is due.

The logistics behind taking Adriaan for treatment at the new institution was an absolute nightmare. Adriaan still remained at the centre for children with severe mental disabilities, but twice a week I would pick him up at 13:00, drive the 40 km to the private institution, drop him off and rush back to work. At 16:00, my wife would leave her work, drive the 40 km to the institution, pick him up and drive back home again.

By November 2005 we decided to sell our house in an attempt to move closer to the new institution. It also afforded us the opportunity to free up some cash to pay for Adriaan's treatment. And boy, did we need cash! The fees charged by the private institution were and still is, in my opinion, exorbitant. In my mind it places a huge damper on the good work they are doing there.



I did not spend hours on the internet searching for a cure; I was searching for hope. The medical professionals' prognosis might have killed the dreams I had for Adriaan, but they could not erase the feeling that, somewhere inside my frustrated little boy, there was

more than the eye could see. There were, of course, times that I wanted to give up. Every time I walked into the care centre and saw the older children, I wondered whether the future had something similar in store for Adriaan.

In October 2005 we found a private school for autistic learners who claimed that children on their programme had learned social skills and progressed into mainstream schools. My husband and I took Adriaan for an interview. The principal was the first professional to give us real hope. Tutors worked one-on-one with learners and each child had his own program, apparently tailored to his specific needs. We were hooked, despite the astronomical fees. We could not afford to enrol Adriaan full-time, so we opted for two afternoon sessions a week.

I was tasked with fetching Adriaan in the afternoons. Some afternoons, when I did not have extramural activities, I would arrive at the school while the tutor was still busy with him. They worked in a little room with a small one-way window in the door. This allowed the principal, other tutors or parents to observe the session. It was heart breaking to watch my son yelling and screaming for minutes on end when he did not want to co-operate. I was slowly starting to see progress though, and stopped myself from rushing into the room to comfort Adriaan. He was starting to point at things he wanted and even started to use single words, although very sparingly. Every tiny step forward seemed like a miracle.



Until October 2005 we were unable to find appropriate educational support for Adriaan. The centre for children with severe mental disabilities focused on care giving and the facilitation of minimal self-care skills. The private school for autistic learners was the first institution that focussed on our son's potential and not on his disabilities. In other words, they gave us hope. Similar to many parents in our position, hope was a commodity we were more than willing to pay for.

Snyder (2002) referred to the two components of hope. The concept of "hope agency" refers to the motivational role of hope, whereas the concept of "hope pathways" refers to the thought processes involved in attaining one's goals. The private school became our agent of hope, motivating us to keep on searching for keys to unlock our son's potential.

Key 4: You can't unlock all the locks at once



By January 2006 we were advised to increase the amount of treatment sessions. Three sessions of three hours per week would have amounted to R7000 per month. I said to my wife that, for the same amount of money or even less, we could appoint a full-time au pair.

We knew a woman who worked at a crèche in the Helderberg area. She was a bit of a rough diamond, and from a logical point of view there wasn't a single reason to appoint her. We weren't sure whether she ever finished school, she lived 35 km from us, she had never driven a motor vehicle in her life and she was over 50 years old. However, she had met Adriaan more than three years earlier when he was transferred from the day-care centre to the crèche. She immediately took a liking to him; in fact, I believe she loved him.

At the time Charlene¹³ earned R1500 a month. I arranged a meeting with her and offered her a starting salary of R3000 a month. I also told her that she had three months to obtain her driver's license and that her salary would increase after the three months. In the meantime, I paid for her train ticket to get to our house and back. We could finally take Adriaan away from the centre for children with severe mental disabilities.

By this time our own approach regarding Adriaan's education, had changed. We were of the opinion that speech was paramount to any further development. Charlene's main task was therefore to focus on Adriaan's speech. Social interaction could be addressed at a later stage.

With Charlene's appointment a new chapter was starting for Adriaan. I took Charlene for her first driving lesson at a local shopping centre on a Sunday afternoon. After

¹³ A pseudonym is used to protect the identity of the individual

less than an hour, I took her straight onto the public roads. It came as no surprise that, after that specific episode, she kept her part of the agreement and managed to pass her driver's license test within three months. I kept my promise and raised her total remuneration to R4500 per month.

Once Charlene could drive, we arranged for her to receive training at the private institution that Adriaan was attending. By this time they had started their own crèche and Charlene was utilised as the class aid. From the information I received, it appeared as if she did not really get on well with the rest of the staff. I have met few people more stubborn than Charlene and I have no doubt that she was mostly to blame for the problems that cropped up. For starters, she did not believe in what she called rough handling of the learners and I have no doubt that she would have made her viewpoint abundantly clear to the other staff members.

When eventually Charlene informed me that my son was force-fed after refusing to eat his food, I decided to take him out of the school. I made an appointment with the principal and told her that I was taking Adriaan out of the school. She told me that I was not acting in the best interest of my child and that I would, one day, pay the price. I would like to believe that I remained calm and simply walked away.

We now placed all our trust in somebody with little formal training, but someone who we never doubted had our son's best interests at heart.



The private institution that Adriaan attended twice a week, attempted to address all his developmental delays simultaneously. Although he made noticeable progress, he still had almost no speech, could not be taken to public places and was not potty trained by the time that Charlene started working with him. We were of the opinion that it would be better to follow a baby-step approach by firstly focussing on his speech. We believed that, once Adriaan was able to communicate properly, it would be much easier to address his other developmental issues. I planned activities for Charlene to develop Adriaan's speech. She

was however, very creative in finding ways to stimulate speech acquisition. She talked to Adriaan incessantly while preparing his food, playing with him or attempting the planned activities. She named every appliance/resource she used during the day, even if it meant repeating a label twenty times. Charlene had a natural knack with Adriaan. Whereas he would start to scream when I asked him to complete a puzzle, he would gladly struggle with one if Charlene asked him to do it. She started taking him to the shops, all the time giving running commentary and rewarding him if he managed to avoid throwing a tantrum.

Slowly but surely Adriaan started to communicate. It started with single words and gestures, but soon two word sentences followed. He struggled to understand questions, often simply repeating some of the words of the question. But Adriaan was quick to learn the meaning of the word “no”, using it often. In fact, it became his default response to any question! Charlene managed to trigger Adriaan’s will to communicate. She did not only support our son’s development, but she gave us our lives back. Her outings to the shops had taught Adriaan how to control his frustration levels and for the first time in five years we could visit fast-food outlets or friends without fear of unpredictable tantrums. There were still times when his inability to understand or communicate properly led to tantrums, but it became far less frequent. Usually, we could also pick up the cues that pre-empted the tantrums and could subsequently remove Adriaan from the public setting as quickly as possible.

We had taken a huge risk appointing Charlene and she wasn’t the easiest employee to have around, but she had done what the medical professionals could not do – she managed to get Adriaan to speak. For that I’ll be eternally grateful to her.



By the middle of 2006 I was approached by the company I worked for previously. They made me an offer that was simply too good to resist, but I almost did. My employer at the time had been hugely supportive at a stage that was probably the worst period of my life. Eventually I had to take emotion out of the equation. I realised that the financial gain would ease the huge financial burden of Adriaan’s treatment, and I therefore accepted the new position. They say that you have to buy a dog if you want loyalty, but the gesture of paying for my son’s medication disproved that point to me. I found it extremely difficult to leave my employer at the time.

From time to time I still drop in on the managing director and financial director. They were, and remain, amazing human beings.

With a great deal of the financial burden taken care of, we entered a relatively calm era in Adriaan's development. In 2007 the paediatrician suggested that Adriaan's lack of concentration be addressed by the use of Ritalin. We were not crazy about the idea, because we believed that Ritalin was prescribed far too often, but eventually we agreed. Within a few days our son became psychotic. Amongst other things, he became obsessed with washing his hands. When my wife took him back to the paediatrician, she observed that people with epilepsy at times displayed a similar reaction to Ritalin. She immediately suggested an E.E.G. Adriaan was diagnosed with absentia, a form of epilepsy. If memory serves me right, the E.E.G indicated misfiring in the brain every two minutes. The decision was made to administer Carbamazepine twice daily.

The medication had an immediate effect on Adriaan's language development and by the third quarter of 2007 Adriaan had developed quite an extensive vocabulary. His sentences now contained up to five words. We now felt the need for him to interact with other children. It became evident to us that Adriaan was ready to go to a school, but we had no idea what setup would be suitable for his educational needs. After an unfortunate incident where our eldest son's cell phone was taken from our house, I had no alternative but to terminate Charlene's employment. I want to make it clear that she was not involved, but one of her acquaintances was. However, she did have instructions not to let the specific person into our house.

Suddenly we were back to square one. We thought that Adriaan was perhaps ready to join the day-care centre that his brother went to every day after school. It turned out to be a nightmare, for Adriaan as well as his brother. Adriaan was simply not ready and was bullied by some of the other kids. It did not take long for my eldest to resort to his fists to stop the bullying and we had to remove Adriaan from the centre. There

were only three months left before the end-of-year holiday period, but we had nowhere to take Adriaan. Eventually we had no choice but to take him back to the centre for children with severe mental disabilities, the same centre that he had left almost two years earlier. It was a bitter pill to swallow. We had hoped that my recently widowed mother-in-law would have offered to look after Adriaan until the end of the year. She was a house wife and had not worked for more than 20 years. We never directly asked my mother-in-law, and reflecting on it now, it was perhaps a mistake. Maybe she would have looked after Adriaan, but if you are made to feel like you are infringing on somebody's private space by asking them a favour, you get to a stage where you simply stop asking.

Fortunately, the process of finding a school for Adriaan had started months before, but we were suddenly faced with the daunting reality of having to find our son suitable placement within four months, before the start of the new school year. We encountered a road block. We found ourselves in a situation where we were forced to find a new route in order to get to our destination.

CHAPTER 6

FINDING AND MAKING KEYS: CONTINUED



In many democratic countries parents of neurotypical children take for granted their right to choose the correct educational context for their children. They have a choice between state schools, private schools and home schooling, and this choice is seen as a very personal and private decision. When your child is not neurotypical, every choice you make is scrutinised by professionals who appear to believe that they, because of their academic background, are the only people capable of making the correct decision about a child's education.

For a period of almost two years, Adriaan appeared to make huge progress, despite fierce opposition to our chosen educational program by almost every medical professional we dealt with. With the termination of Charlene's employment, it suddenly felt as if we were back at the starting point of our journey. To an outside observer, Henré's decision to terminate Charlene's employment may appear to have been impulsive and not in Adriaan's best interest.



I am the first person to admit that I can be impulsive at times, but the decision to dismiss Charlene was not. I was furious about the cellular phone incident and wanted to be 100% sure that my eldest had not merely misplaced his phone. In the discussions that followed, he informed me about another incident where my children's safety were in jeopardy due to Charlene's conduct. This made the final decision an easy one.

There were also other factors that influenced my decision; factors that were directly related to Adriaan's education. Most people will probably classify me as a strict parent. I believe in discipline and I certainly do not consider my household to be a democracy. When it comes to the education of our children my wife and I make the decisions and we do not see the need to debate this with anyone. After working with Adriaan for about a year, Charlene increasingly questioned our decisions and at times ignored our instructions.

As in any marriage, my wife and I do not always agree on all issues. One such issue relates to discipline. Very often Charlene started an activity with Adriaan. If he did not want to do the activity, she moved on to the next one. If he did not want to do that activity either, she once again moved on to another one, and so it continued until he finally found something that he was willing to do. At least she eventually returned to the skipped activities. My wife was of the opinion that it did not matter, as long as the activities were eventually completed. I strongly disagreed and believed that Adriaan had to do what he was asked to do, when he was asked to do it.

Shortly before the termination of Charlene's employment, I arranged to have Adriaan reassessed by the occupational therapist who treated him earlier. She noted that there was a marked improvement, especially with regard to language acquisition. However, she was quite outspoken in her criticism of both Charlene and my wife's way of handling Adriaan. Adriaan did not want to do any of the assessments that the occupational therapist had planned for him. Charlene kept on asking her to move on to the next activity and when eventually Adriaan had an outburst, my wife tried to console him. The assessment was a complete failure and I was hugely disappointed. I so desperately wanted to show the world that our decision to have Adriaan educated at home was the right one, but I was convinced that the occupational therapist formed completely the opposite impression. Shortly afterwards, I arranged to have the assessment redone. This time, however, I took Adriaan myself. The assessment went rather well and Adriaan completed most of the tasks.

In my opinion, discipline is an absolute necessity. If you are strict with a neurotypical child, you need to be twice as strict with an autistic child. This is the one area where the father should play a crucial role. For most mothers, their motherly instincts take over whenever their child becomes upset. I believe that it is easier for a father to remain emotionally detached from the situation.



In South Africa, there has always been a perception that Afrikaner families have a stronger focus on discipline than many other families. When I grew up, my family was no exception and the rule that ‘children should be seen and not heard’ was definitely applicable. My family did not believe in a physical show of emotion and I was expected to fight my own battles whenever a problem arose at school. I believe that this background, combined with a mother’s urge to protect her child, especially when that child has a disability, probably clouded my judgement on the matter of disciplining Adriaan. Watching him struggle to build a puzzle or a tower of blocks broke my heart. I knew I had to be stricter with him, but I simply could not get myself to do it.

The visit to the occupational therapist was a nightmare. I knew Adriaan could complete many of the tasks the therapist had set him, but I could see that he was scared and confused. I knew that, if I had rephrased her questions, he would know what to do, but I was only allowed to observe. So I did what most mothers would have done by hugging him and trying to calm him down. I could not bear to watch him fail another test. We had come so far and now we couldn’t prove it to the therapist.

In a way, I blamed myself for Adriaan’s lack of progress. If only I knew how to work with him, like Charlene did. I had often read about mothers who had abandoned their careers to work with their autistic children full-time. Financially we could not afford me staying at home, but I also have to admit that I enjoyed having a career. To be able to cope with Adriaan I needed some time away from him, no matter how selfish that might sound. Adriaan required full-time attention. I was even too scared to take an afternoon nap. Charlene gave me some breathing space, but at the same time I felt guilty about not being one of the perfect mothers one often reads about.



Baumrind (1991) described four types of parenting styles, namely authoritative, authoritarian, permissive and disengaged patterns. Both authoritative and authoritarian parents are strict and use direct, forceful, consistent and firm discipline, but authoritarian parents also use domineering and arbitrary discipline. According to Baumrind, Larzelere and Owens (2010) the authoritative parenting style results in increased self-discipline and emotional maturity in children, whereas

authoritarian parenting styles lead to children who lack adequate behavioural inhibition and who are less emotionally mature. Permissive parenting refers to a more lenient and non-confrontational style of parenting, whereas disengaged parents offer minimal support and may even neglect their parental responsibilities (Baumrind, 1991).

In a study comparing parenting styles of parents of children with autism spectrum disorder with parents of typically developing children, Rutgers, Van Ijzendoorn, Bakermans-Kranenburg, Swinkels, Van Daalen, Dietz, Naber, Buitelaar and Van Engeland (2007) concluded that parents of children with an ASD were less likely to use an authoritative style of parenting. Osborne, McHugh, Saunders and Reed (2008) suggested that the most important parenting behaviour is effective limit setting and that it directly correlates with fewer child behaviour problems in children with an ASD. My husband and I believe in limit setting and strict discipline, and mostly follow an authoritative style with both our sons, although I find that I resort to a permissive style with Adriaan during assessment sessions, and my husband, at times, may show tendencies of an authoritarian style.

Tsai, Tsai and Shyu (2008) advise medical professionals to take into account that mothers of children with an ASD have to integrate their roles as nurturer and trainer. These two roles differ in expectation and can cause conflict and stress in mothers. Shearn and Todd (2000) reported that mothers of children with disabilities felt that a career outside of their homes “provided an alternative focus for their thoughts and energies” and assisted them in maintaining an identity other than just that of the mother of a child with a disability.



By September 2007 we were once again without a suitable educational option for Adriaan. I became totally obsessed with finding him a school. Through one of the medical professionals, we heard of a general special needs school not too far from our home. At that stage the school catered mostly for high functioning Down syndrome learners. My wife was convinced that Adriaan would be perfectly suited to the school. I therefore took it upon myself to get him admitted.

I arranged an appointment with the principal. She made it clear that they do not cater for children on the autistic spectrum and suggested that we enrol Adriaan in their home program. Soon afterwards, my wife took Adriaan for his first session. Once again it turned out to be a bit of a nightmare, and once again I arranged to personally take him for the follow-up session. It went much better the second time. The therapist was brilliant and, in my opinion, she had a real passion for her job. I know that it is impossible to generalise, but in this field of education somebody who works for the public sector certainly does not do it for the money. There was an enormous sense of relief. I said to myself that the admission to the home program was a huge step in getting him admitted to the school.

From the first day I walked into the school, I experienced a completely different attitude. Everybody there seemed to care about our predicament, but it still took some convincing to get Adriaan admitted. Every time I phoned I was informed that the school was not geared to deal with autistic children, and every time I ignored the comments. I wish that I had kept record of the number of phone calls I had made to the school and the number of visits to the principal's office. To the credit of the principal, I never got the idea that she did not want to help us. I was convinced that she would eventually admit our son, so I just kept on contacting her.

By the end of 2007 Adriaan had still not been accepted into the school and we had no idea what lay ahead of us. My father-in-law had passed away a few months earlier and left a considerable amount of money to my mother-in-law. At that stage my relationship with her was probably the best it was ever likely to be. She told me to tell the school that, should they admit Adriaan, she would donate the sum of R50 000 to the school. This is the part where I would love to say that I refused the offer based on ethical considerations, but the truth is that ethics did not even come into play. If I had been in a position to make a considerable donation to the school myself, I would not have thought about it twice. After very seriously considering her offer, I eventually

refused, simply because I wanted to prevent a situation where my wife and I would be continually reminded that my mother-in-law's money got our son into the school.

The first school day of 2008 was an emotional shocker. We had to witness thousands of grade ones starting their school careers, amongst them Adriaan's younger cousin. The following day, a Tuesday, the principal of the general special needs school phoned me and advised me that they were willing to give Adriaan a chance. The plan was to let the therapist work with him on a one-on-one basis and to slowly introduce him to the classroom environment.

On Thursday, 17 January 2008, I dropped Adriaan off at the school. I did not even make it to the car before the tears started flowing. Almost three years of pure hell seemed to be at an end; three years during which I never allowed myself to cry, three years during which I fought with everything I had in me to obtain appropriate support for our son. It must have been quite a sight for motorists. By the time I stopped at my office, almost 30 km from the school, I was still crying. I cannot describe the sense of relief that Adriaan's admission to the school brought. Although money was seldom a consideration, this was a state run school and the fees seemed ridiculously low compared to other institutions. I was on an emotional high. We had done it! Our son had a school. About a year after Adriaan was admitted, the principal jokingly said to me that she simply admitted Adriaan to stop me harassing her. I believe that she tried to hide the truth with a bit of humour. I did harass her and, if necessary, I would gladly do it again.

Fathering is the single most creative, complicated, fulfilling, frustrating, engrossing, enriching, depleting endeavour of a man's life.

(Pruett, 1987, p. 282)



Kearney and Griffin (2001) proposed that parents of children with disabilities find themselves on a constant pendulum between “joy and sorrow” and “hope and no hope”. This is not necessarily negative, as, according to Fleischmann (2004), most of these parents perceive themselves as “daring mountain climbers” rather than victims. My husband, by nature and occupation, has what Calbrese and Davidson (2009) describe as an engineering personality who enjoys handling emergencies and solving practical problems, are good fixers and want instant results. Although I will not go as far as to say that he enjoyed the trials and tribulations of persuading the school to accept Adriaan, it was the kind of challenge that he excels at.

Key 5: Sometimes the unwanted key fits



Looking back, it was a brilliant decision to enrol Adriaan in the general special needs school and, to be totally honest, the decision was not mine. My wife did the research and came up with the idea. I immediately agreed and took it upon myself to make it happen. In fact, I did not even think about the pros and cons. I just ran with the idea. My sometimes impulsive nature probably assured that I made the correct decision for our son. If I had really thought it through properly and had spoken to other people, it might not have been such an easy decision.

I grew up in an average middle class white Afrikaner family at a time when the colour of my skin certainly gave me opportunities that other people did not have. Although we were not rich, we had everything we needed, despite the fact that my mother single-handedly had to provide for four children. From a political point of view we were probably much more liberal than the typical Afrikaner household. No, we were not political activists, but my mother always taught us to respect other people, no matter what their skin colour.

Despite this background, I cannot even describe how I felt the day of Adriaan's first athletics meeting at the school. There I was with my white skin, my high income job, my fancy company vehicle and my prejudices, and I felt completely and utterly out of

place. It is not as if I was the only white person there, but, based on first impressions, few of the white people that were present would have been candidates for my social circle. I could see that I was not the only person struggling with the situation. There was a white lady who grabbed her laptop and headed for the furthest corner of the pavilion. At least I have always known how to hide my true feelings. She did not even try to fit in. So to call a spade a spade, my feelings came down to what I perceived as me being at a numerical disadvantage in terms of race and social standing.

My reaction came as a complete surprise to me. I had a coloured friend at university, even before the change of government in 1994. At the time that Adriaan went to the school (2008), I also had two very good coloured friends. Sitting at the athletics meeting, there was this clash between my liberal upbringing and a society where white was mostly regarded as affluent and intelligent. Mentally impaired did not fit into the picture I had of the typical white family. I had to tell myself that this was not about me, nor my snobbish tendencies. It was all about our son's best interest.

We are all products of our societies. What I have always been able to do is to suppress any "inbred" tendency due to the knowledge that something is not morally justifiable. If I find it difficult to change, I can only think how difficult it must be for somebody who grew up in a more typical white household in the "old" South Africa: difficult, but not impossible.



Gibson and Claassen (2010) commented on trends in racial prejudice in South Africa from 1994 till 2004. They found that, because of an increase in contact between minority groups (Whites, Indians and Coloureds¹⁴) since 1994, their social integration had also increased, leading to a decrease in prejudice between these groups. Less contact between the majority Blacks and the minority groups has however lead to increased prejudice. Gibson and Claassen therefore proposed that increased contact between different groups leads to decreased prejudice. Seekings

¹⁴ A classification system originating from the Apartheid era

(2008) noted that South African schools are the places where most interracial interaction of middleclass children take place, as racial integration in most residential areas are still limited.

My husband's reaction to the athletics meeting might seem out of character, given his upbringing and the social environment in which he has operated during his adult life. Most of the parents at the athletics meeting were coloured, an ethnic grouping to which my husband has had a lot of exposure; not black. I agree with Gibson and Claassen (2010) that increased social contact between minority groups leads to a decrease in prejudice between these groups. However, I also believe that, for many white people in South Africa, the acceptance of other minority groups have been easier, since the white population form the majority in this new minority grouping. A typical example would be the following: five children of ethnic African origin are admitted to a class with 20 white, Afrikaans speaking pupils. The classroom culture is determined by the majority (in this case white and Afrikaans). This greatly increases the possibility of acceptance of the five ethnic African children by the white, Afrikaans children. I believe that my husband's reaction was typical of what many white people might experience if they suddenly find themselves in the minority within their social environment. The inequalities of the past and the subsequent social imbalances, have sheltered most white people from this scenario.

I also believe that many South Africans from across the racial divide developed a coping mechanism for the changing times. After 1994, they replaced discrimination based on race by discrimination based on social standing and economic factors. They became classists instead of racists. Many people will tell you that they are not racist, but I believe that most people are classist. Knowing my husband and knowing the way he has always treated people from across the racial divide, I believe that his response at the athletics meeting was classist and not racist in nature.



It is not that I did not notice that the race compilation at the school was completely different to what the accepted norm in our community was, as I was subjected to the same prejudices as my husband. In fact, I come from a considerably more conservative family. The difference, however, was the fact that I, as a teacher, had more widespread exposure to

multicultural working environments. Ironically, the one fear that I always had, was a fear of having to deal with people with a mental impairment.

When I was at primary school, there was a bus stop just outside the school premises. This was used as a drop-off point for a nearby school for children with mental and physical disabilities. I felt extremely uncomfortable being around the children and avoided contact with them as far as possible. They did not repulse me, but I had a fear of having to communicate with them. I also feared ever having a child with a mental impairment.

When Adriaan was at the centre for children with severe mental disabilities, I avoided dropping him off or picking him up as far as possible. I probably experienced the centre in a manner similar to how my husband experienced the school, although it had nothing to do with race or social standing. The first time I went there, a group of small children greeted us with smiles and waves. They were so friendly, but they were different, and I felt out of my comfort zone. It was not easy to accept our situation and it did not happen overnight, but today I can honestly say that the fear has gone.

Dread refers to the "prospect of being overwhelmed by anxieties that reach to the very roots of our coherent sense of being in the world."

Giddens in Hughes (2007)



Hughes (2007) states that many non-disabled people fear becoming physically frail, having a bodily difference, or being socially vulnerable. They then project this fear onto the disabled. Fear as a reaction to disability and illness is, according to Fleitas (2000), a realistic response in children, as the fear is usually related to the concern of exclusion from a peer group. Growing up I feared, and often experienced, exclusion. I always perceived myself as different from my peer group. I had to wear high strength spectacles, was the shortest in my class and was socially inept. Having to fight for Adriaan has in some sense given me the confidence to stand up for what I believe in, and to define myself not by what I perceive others think of me.



The general special needs school was exactly what Adriaan required. Because of it being a state run school, the school fees were considerably less than anything we had paid up to that point. This meant that we could afford the private speech therapist who treated children at the school. This therapist was the first medical practitioner who was willing to express the opinion that Adriaan had the ability to fully master basic language skills.

During the first year at the special needs school, Adriaan's language improved dramatically, as did his social behaviour. "No" was still his default answer, but we started to realise that, most of the time, it did not mean "no". It meant "wait, give me a chance to think". If you waited long enough after the emphatic "no", he would attempt to answer the question. I remember one day in a local grocery shop where I asked Adriaan if he wanted a packet of chips. He emphatically answered "Nee!"¹⁵ [No!], held up his hand like a traffic officer and said "Wag, ek dink" [Wait, I'm thinking]. The staff in the shop, who knew Adriaan and his tantrums well, burst out laughing. My son was thinking about his thoughts! I was ecstatic.

My husband and I agreed that the fact that Adriaan was on the autism spectrum did not mean that we should allow him to be rude or undisciplined. In our minds there was a huge difference between being autistic and being naughty and rude. We practiced rituals where he needed to say please and thank you. Adriaan always loved his rooibos tea and would say, "Tee hê" [Want tea]. We would respond with, "Nee, hoe vra 'n mens?" [No, how should you ask?]. In turn, he would respond with "Kan ek tee kry, asseblief?" [May I have some tea, please?] and we would answer with, "Ja, jy kan" [Yes, you may]. This ritual soon became way too tedious for Adriaan, so in one very fast, monotonous, unpaused sentence he would say: "Tee hê waar vra mens kan ek tee kry asseblief ja jy kan" or "Want tea where should you ask may I have some tea please yes you may". This phrase became a huge hit with friends and family.

Adriaan still confused words like what, where, why and how, but at least he attempted socially acceptable verbal communication. We had to learn to wait until he had completed a sentence before answering or correcting him, otherwise he would become severely agitated.

¹⁵ Afrikaans

He would then restart the sentence. This could become a very time consuming and frustrating exercise, especially if we were in a hurry.

Key 6: Only you can turn the key



A vehicle can only be driven by one person at a time. To complete a long journey, designated drivers need to replace one another to prevent fatigue. Without realising it, we did exactly that. At any given time only one of us was in control of Adriaan's educational journey, though we frequently had to swop roles. This was probably crucial in being able to go the full distance.



By the middle of 2008 Adriaan had settled in well at the school. I helped him with his school work and after the tremendously stressful experience of getting Adriaan admitted to the school, my husband could afford to stand back. I suppose he found it difficult not to be involved in some sort of battle, so he joined the school governing body. In August 2008 the school started the first state supported autistic unit in the northern suburbs of Cape Town. The entire process was driven by the principal of the school and my husband. Even before planning the unit, it was understood that Adriaan would not be transferred to the autistic unit, as he had adapted well in the foundation phase class. My husband's primary reason for assisting the school was to thank them for the opportunity they gave Adriaan.



The background surrounding the establishment of the autistic unit at the school does not really fall within the scope of this thesis, but there are two events that I would like to expand on. The first was a meeting between me, the principal of the school and senior representatives from the Western Cape Education Department (WCED). I was shocked to hear that there were children who simply had no school to go to. I made the statement that I was under the impression that the right to education was one of the basic pillars of the constitution. One of the WCED officials replied that this was indeed the case, but that this basic right was suppressed by a lack of funding. This lack of funding was mostly due to the need to correct the severe inequalities that existed under the previous dispensation.

Schools, like many private businesses, need to justify their staff numbers. In practice this meant (at that time, anyway) that WCED schools had to submit learner numbers by the first of September every year. These numbers were then utilised to determine staffing requirements for the following year. The official gave us a lifeline and said that, if we could start the unit on our own before 1 September 2008, the WCED would take over the salaries of the teacher and the class aid as from January 2009. After raising more than R120 000, we opened the doors of the autistic unit on 1 August 2008, one month ahead of schedule. The WCED kept their promise and took over the financial responsibility the following year.

The second event that I want to illuminate was a meeting between the school, parents of autistic children who required placement, and other stakeholders. This happened shortly after the meeting with the WCED. The principal was out of town and I was tasked with leading the discussions. After a brief outline of our plans, I made the following statement: "I want to make it clear that neither the WCED, nor the school is going to start this unit. We as parents will have to do it." All hell broke loose. I was flabbergasted at the reaction. It took almost half an hour for things to settle down. Stakeholders in the private education industry had themselves invited and did their best to disrupt the meeting. Eventually less than half the parents were willing to even discuss the issue any further. The other half came up with a million excuses, amongst others the fact that they did not want to get their hopes up, only to have it shattered when all our plans were to come to nothing.

The two incidents proved to me that most people simply want everything in life for free. It is always somebody else's responsibility. You frequently hear how useless all government departments are, but our experience with the WCED was very positive. All they wanted was some sort of commitment from the parents before getting involved. Most parents however, were simply not willing to make any contribution, be it financial or simply time and effort. Many of those parents probably went home that evening and prayed for a solution to their problems. In my opinion you cannot cross an obstacle on

your knees. If you find consolation in faith, by all means pray, but realise that you will have to cross the obstacle yourself.



The general special needs school gave Adriaan a solid pre-school foundation, but the area where he progressed most was in his social development. His teacher for the first two years had a son with Down syndrome. To me it seemed obvious that we were dealing with somebody who had a real understanding of our situation; an insider and not an outsider.

The other learners, mostly with Down syndrome, included Adriaan in their games and did not seem to mind the times when he was irritable or when he chose to ignore them. There was a real family feeling at the school and every child was made to feel welcome and appreciated.

Key 7: Learn the locksmith's trade



At the beginning of 2009, I accepted a position at the Institute for Mathematics and Science Teaching at the University of Stellenbosch (IMSTUS). Instead of teaching children, I was now doing in-service teacher training. The work was fulfilling and one major advantage was that my evenings were not filled with lesson planning and marking. I now had the opportunity to spend more time with Adriaan and to give him better assistance. Later that year a colleague brought me a newspaper clipping where a Master's Degree in Educational Support at the University of Stellenbosch was advertised. She asked me if I wanted to join her. I have an Honours degree in Genetics and had always assumed that any further studies would be in that field. It dawned on me that, at age 39, I finally had the time and a topic for further study: Adriaan. However, the prospect of becoming a student again, 17 years after completing my higher diploma in education, was a daunting one.

In May 2010, as part of my master's degree studies, I attended a guest lecturer's presentation on dynamic assessment. I was hooked. Someone finally echoed my sentiments that an IQ test could not determine Adriaan's learning potential; it only indicated what he was not yet capable of doing. I could not stop talking about dynamic assessment and structural cognitive modifiability (Feuerstein, Rand, & Rynders, 1988). I kept on nagging my husband to allow me to take Adriaan for an assessment. He was not keen at all, probably because of the substantial costs involved. He eventually agreed however, and in July 2010 I took Adriaan

for the assessment. I was extremely nervous, as Adriaan had never responded well to the stress associated with assessments, but the lecturer managed to get Adriaan's full cooperation. I was allowed to observe the assessment and was amazed at what Adriaan was able to do and learn over the two days. The third session was a feedback session where the lecturer requested that my husband and Adriaan's teacher also be present. Adriaan's teacher was stunned by what Adriaan had been able to learn in only two days. The lecturer's only concern was about Adriaan's level of mathematical understanding. He commented on our son's ability for analogical reasoning (needed for higher order thinking) and his above average visual memory. As was the case with other assessors, he commented on Adriaan's dependence on me for reassurance during the testing, but he saw it as a positive attribute that helped Adriaan cope with stressful situations. He tested Adriaan's letter recognition and blending skills and advised Adriaan's teacher to focus on his reading, as he had already shown all the basic skills needed to be able to read.



The lecturer, who acted as the assessor, did not use the words "above average visual memory skills". He actually said that he hated the word "gifted" because many parents get carried away by the term, and that any gift means nothing at all if it can't be properly utilised. For lack of a better term however, he considered Adriaan to be gifted with regard to his visual memory. That evening I said to my wife that, if Adriaan was gifted in terms of visual memory, I could see no reason why he could not learn to read. Up to that point the school had done some basic reading and writing with him, but it seemed that they had no intention to up the pace. I also told my wife that Adriaan's education was not the school's responsibility, nor that of the government, the church or even God. It was our responsibility.



According to Feuerstein, Rand and Rynders (1988), cognitive modifiability refers to a lifelong, integrated alteration of personality traits, thinking abilities and levels of competencies. The theory of structural cognitive modifiability (SCM) states that the brain can be structurally modified and that this can be achieved despite severe barriers that the individual might be facing. I therefore believed that, with the

right input and training, I could modify the structure and functioning of Adriaan's brain.

Draganski, Graser, Kempermann, Kuhn, Winkler, Büchel and May (2006) found that extensive learning of abstract information can trigger changes in the brain. Brain imaging of German medical students, three months prior to their medical examination and immediately after the examination, were compared to imaging of the brains of students who were not studying for the examination at that time. Draganski et al. found significant increases in grey matter in parts of the cortex during the students' learning period. Brain imaging after the subsequent three month semester break showed no significant decreases in grey matter. Draganski et al. proposed that the human nervous system possesses the characteristic of modifiability to assist it in coping with changes in the environment. These findings support Feuerstein, Rand and Rynders' (1988) theory of structural cognitive modifiability.

There are many different types of assessments used when cognition is assessed. According to Lidz (1991) the type of assessment depends on the diagnostic question. She states that norm-referenced assessments, e.g. IQ tests, are used when students' current levels of performance are compared with those of their age or grade peers, whereas developmentally referenced assessments are used to determine where a student's skill or developmental accomplishment is located within a predetermined hierarchy. Criterion- or curriculum-referenced assessments are used when a student's specific knowledge base must be determined. Dynamic assessment aims to determine how responsive a learner is to intervention, how easily the learner acquires problem solving processes and how modifiable a learner's cognitive structures are.

Freeman and Miller (2001) evaluated UK Special Educational Needs Co-ordinators' (SENCOs) relative familiarity with, and perceived usefulness of, norm-referenced, criterion-referenced and dynamic assessments. Although most SENCOs were more familiar with norm-referenced assessment, they perceived dynamic assessment as the more useful tool to understand learners' barriers to learning and to use this as basis for planning suitable educational support.

Not only did dynamic assessment reveal that Adriaan's potential to learn showed little correlation with his norm-referenced GQ testing, but it also highlighted the need for us to re-focus our expectations of suitable educational support. Adriaan now needed support that focussed more on academic skills.



I've always disliked the concept of sight reading, also referred to as whole word recognition, and believed that the only proper way to teach a child to read was through phonics or letter recognition. Both the school and my wife tried to teach Adriaan how to read utilising phonics, but despite recognising the individual sounds, he struggled to put the sounds together to make words. I told my wife that I would make it my project to teach him how to read utilising sight reading. I was not sure whether Adriaan would be interested in the typical children's book, so I created his own reading book called "My story". Initially it consisted of four A4 pages typed in a 14 point font. As can be deducted from the title, the book was about Adriaan. It told his story, including when and where he was born, the names of his family members, the professions of his parents and detail about his school. Within three weeks, Adriaan could read all four pages. By the time I stopped teaching him, the book consisted of 12 pages and Adriaan could read all of it. I changed the order of pages, pointed at individual words and at times reprinted pages with minor changes to try to establish whether he was not perhaps memorising the entire story. He always got it right.

By this time, Adriaan had been in the general special needs school for two and a half years and in our opinion his academic progress became stagnant. We needed the school to focus more on his academic development, but we realised that they simply did not share our belief that Adriaan could do more than basic foundation phase education. We believed that the school followed what I called the "bum-wipe principle": there was no focus on academic development, only on teaching the child to cope and to be able to look after himself (to wipe his bum).

I recorded a video clip of Adriaan reading the four pages of his book and gave a copy to the school. I asked them politely to look at it. After three days the DVD was still lying in the office. I phoned Adriaan's teacher and asked her to please watch the DVD. It took two more days before we got any response: "Oh, it's a miracle of GOD!" Nonsense, this was not about God, it was about two parents who were not willing to give up on their child. I told my wife that the major advantage of attributing the progress to God was that it took any responsibility to continue the work that I had started away from the school. Slowly but surely we realised that our search for appropriate educational support for Adriaan was not over. And then, for some reason, we backed off. I still don't know why. As 2010 drew to a close, Adriaan was still at the general special needs school.



At the time, I felt a bit offended by my husband's statement about whose responsibility Adriaan's education was. Faith and prayer have always been a part of who I am and of the way I confront life's hurdles, but I also believe in the old saying that God helps those who help themselves. My faith has carried me through this journey and I felt that Henré's statement was a bit blasphemous. After reflecting for a while, I came to realise that I was in agreement: Adriaan's education was our responsibility. I still believe, however, that Henré could have phrased it differently.

At the 2010 end of year carols-by-candlelight function, Adriaan was dressed up as a little sheep and participated in the nativity play. Suddenly one of the "cows" pulled up a chair and a guitar. The teacher handed Adriaan a microphone and my son stood up in front of the audience and sang a Christmas carol, accompanied by the "cow" on guitar. Adriaan remembered all the words and although he was slightly out of tune at times, to me it was perfect. I was so proud of my son and so grateful that his teacher gave me this surprise performance.

My husband could not attend the nativity function due to work commitments. When I told him about Adriaan's performance I could see that, although he was proud of Adriaan and made a big fuss about him, something was bothering him. The next day my husband told me that he

was worried that our son was becoming a bit of a marketing tool for the school. We had heard previously that prospective parents were taken to Adriaan's class and that he was asked to either sing a song or show the parents his work. I suppose that this fact, along with the performance at the nativity play, triggered my husband's concern. As long as Adriaan was making progress and enjoyed being the centre of attention, I was not overly concerned. Despite it bothering my husband, he never raised the issue with anybody at the school. By that time our son had been at the general special needs school for three years and the paediatrician expressed the opinion that Adriaan displayed almost no further autistic traits with regard to his social behaviour. The only question that remained was whether the school would be able and willing to assist Adriaan in developing his emerging academic skills.



Excellence is the result of caring more than others think is wise, risking more than others think is safe, dreaming more than others think is practical, and expecting more than others think is possible.

Howard Schultz in Canfield, Hansen, McNamara, & Simmons (2007)

CHAPTER 7

CLOSING IN ON OUR DESTINATION

Key 8: A key might need replacement



Sometimes when a key is used frequently, it wears out and has to be replaced by a new one. The general special needs school had been a fitting key to address Adriaan's social skills development, but by the middle of 2010 we started to realise that a change was perhaps necessary.



At the end of January 2011 we received a text message from somebody known to us. The person stated that it was not in the continued interest of Adriaan to remain at the general special needs school, but no further information was given. We took note of the text message, but did not immediately address the situation. Our main consideration, when choosing the school back in 2007, was that it provided the best educational placement to support Adriaan's social development. In that regard the school had achieved more than we could ever have hoped for: our son was doing well in the classroom situation, he interacted socially with other children and he had become very independent. However, we were disappointed that the school did not really attempt anything more than foundation phase education. After three years at the school, the level of reading and writing taught in the classroom was nothing more than grade one level in a normal primary school. On a personal level though, both my husband and I had only the highest regard for the principal and every single staff member that we had ever dealt with, and we were not willing to spoil the relationship we had with the school. Another reason for not immediately taking action could have been that we were simply not ready to start the journey all over again.

By March 2011 it became increasingly clear that Adriaan's education was stagnating and that it was time to act. My husband told me that he would make an appointment with the principal to discuss Adriaan's future. We felt it appropriate that the school be afforded a fair opportunity to address Adriaan's educational needs, even if it meant changing their curriculum. Henré went to see the principal early one morning in March 2011. When he phoned me after the meeting, he told me that Adriaan was finishing up at the school at the end of that term. He had no idea where Adriaan was going to, simply that the time had come

to move on. I was concerned about moving Adriaan again, but I also knew that if my husband had made up his mind, nothing and nobody was going to stop him.



The meeting with the principal of the general special needs school was as open and honest as all our previous dealings had been. In fact, in the more than three years that we were involved with the school, I cannot remember a single occasion where a harsh word was spoken between the principal and me. I told her that my wife and I were convinced that Adriaan had the ability to do more advanced academic work and stated that his reading skills proved our point. She agreed to an extent. Her only concern was whether Adriaan really comprehended what he read. She also said that they probably had two or three other children who also had the ability to move on, but that the school was simply not geared to provide for these children. I told her that I fully understood her predicament, but that she had to understand why I had no option but to move Adriaan to a new school. The last thing I wanted was to appear ungrateful for the work the school had done. Both parties understood the situation and with that a mutually beneficial relationship came to an end.

Once again I was entrusted with the responsibility of finding Adriaan a school. This time round however, it felt a lot easier. I suppose practice makes perfect. I contacted six schools in total: three mainstream schools who all had separate ELSEN units, one state run school for learners with disabilities and two private schools. When I made enquiries, the reaction of the individuals I spoke to at the schools varied from blatantly rude and unhelpful to "we understand your predicament, but we cannot assist you". There were only two exceptions: one private school and one mainstream school.

At the time, I had a very clear idea of what I believed the correct educational context was for our son. Back in the days when I was at school, almost every primary school had a special class. Yes, there was quite a stigma attached to the children in the special class, but they were still considered to be part of the school. I now wanted our son to attend one of these classes. When I started enquiring about special classes, I

was informed that it was done away with under the new dispensation and that the ELSEN units replaced the special classes. Despite the bad news, my wife and I decided to visit one of the mainstream schools that operated their own ELSEN unit. The staff members were really helpful and the setup was very good, but there was no noticeable difference in academic focus between their ELSEN unit and the school that Adriaan attended at the time. Simply because I was so impressed by the staff and the setup, I decided not to leave it at that and I wrote an e-mail to the school. In the mail I gave a rundown of our experiences with Adriaan and what we were looking for. Below is an extract from the e-mail:



"In a discussion with the WCED in 2008, I mentioned that I believe that every person has a constitutional right to education. The response was that this right is suppressed by the lack of funding caused by the need to rectify the shortcomings that existed in previously disadvantaged education. I still believe that my son is entitled to be educated and that this education involves more than just basic foundation phase education. He must be able to learn about the life cycle of the frog, even if he does not grow up to be a biologist. From what I have seen thus far, (name of school) is far closer to this dream than any of the special needs schools."

The principal of the mainstream school responded positively to my mail. He arranged for our son to be assessed by a teacher at the school.

The day before the scheduled assessment, I also went to see the principal of a private remedial¹⁶ school. The classes were small and, despite following the normal curriculum, the school deviated from the curriculum to address individual learners' needs. I told the principal that I wanted to enrol my son, only to be told that the minimum admission requirement was an IQ of 70 points. I mentioned the possibility of having Adriaan reassessed, but I was not overly concerned since I really looked forward to the

¹⁶ Although the term "remedial" has fallen into disrepute within the social psychological model, in this instance it forms part of the school's official name.

meeting at the mainstream school the following day. In my mind I had no doubt that the mainstream school would accommodate Adriaan.

The next day I took Adriaan for the assessment. We had learnt the hard way that Adriaan performed much better in assessment situations when I was present, than when his mother was present. This time nobody except me was going to take him. While waiting for the teacher, the principal introduced himself to me. I know that it is wrong to generalise, but my experiences with principals in public schools have not been too positive. But this one was different. I cannot really point to anything specific, but I sensed compassion, and I immediately liked him. I have never seen him since that day and my contact with him was limited to two minutes, but in my mind he is the best principal I've ever met.

When the teacher arrived, she asked to speak to me before the assessment. She said that they sincerely wanted to help me, but that their setup was not what I was looking for. Then she asked me whether I had ever considered (name of school) Private Remedial School, the same school that I had visited the previous day. I mentioned to her that I had visited the school and that it was a consideration. She told me that she was convinced that the private remedial school was the right setup for Adriaan and that I should do my best to get him admitted. She also said that, should I fail to get Adriaan admitted, they would enrol him in their ELSEN unit. We decided not to proceed with the evaluation. Now I had no doubt in my mind. The private school simply had to admit our son, despite me not having any intention to have his IQ retested.

I cannot remember if, during my first visit to the private remedial school, I left them a copy of the DVD containing the footage of Adriaan reading his book. I phoned the principal and told her that I could not believe that a person with an IQ of less than 70 could learn to read in three weeks. To my huge surprise she informed me that she had visited Adriaan's school after our first discussion and that she had inspected his work books. Already at the first meeting, I mentioned that I was of the opinion that

Adriaan was at grade two level with his reading and that I thought it best to enrol him straight into the grade two class, despite other academic shortcomings.

That day in March 2011, the principal informed me that she was willing to take Adriaan for a two week observation period, starting on the first day of the second term. She agreed to admit him as a grade two learner, but we also agreed that, should he not succeed, the school had the right to move him to their own ELSEN unit. I never had any doubt that the observation period would turn out to be a mere formality. In my mind we had reached our destination. I now shifted almost all the responsibility to ensure that Adriaan remain in the grade two class, to my wife.



When I accompanied Henré to the ELSEN unit at the state school I was both excited and scared. I had, up to that point, forced myself to accept that Adriaan would never attend a mainstream school, but dreams die hard. The school's website stated that the ELSEN unit was an inclusive entity and that they had a strong academic focus. I did not believe that Adriaan was ready for a mainstream class, but I believed that this unit could perhaps bridge the gap between the special needs school and a mainstream classroom. The unit was beautiful and well equipped, and the teacher experienced and enthusiastic. However, despite the unit being within the mainstream school, it was not an inclusive setting, nor was the academic focus different to that of the special needs school that Adriaan was attending at the time. I was very disappointed.

My husband told me about the visit to the private remedial school, but because they only admitted learners with an IQ above 70, I had not given it a second thought. It therefore came as a huge surprise when my husband phoned me at work to inform me that, not only would they accept Adriaan for a two week observational period, but he would be attending the mainstream grade two class.

After I spoke to Henré, I completely succumbed to my emotions in the privacy of the cloak room. I was extremely excited and extremely scared at the same time. Adriaan was being given the chance of a lifetime, but would he be able to cope? What if he wasn't ready yet?

Would the other children accept him? Would the teacher understand him? Except for reading and counting, Adriaan had no academic background. His language skills were only on a five or six year old level, and when he became excited or agitated, his speech would deteriorate. I wanted to jump for joy and run away scared at the same time. I went back to my office and blurted the news out to everyone, whether they were willing to listen or not!

The day Adriaan started at the private remedial school was one of the best days of my life, and certainly the best since Adriaan was diagnosed with PDD-NOS. My husband and I both took some time off from work to accompany Adriaan to his new school. During the preceding school holidays we had prepared him for the move and that morning he couldn't wait to see his new school. The grade two teacher came to fetch him at the entrance. He confidently greeted her, briefly said goodbye to us and accompanied her to his new classroom. I was immensely proud of him.

While we had been waiting on Adriaan's teacher, two other new learners arrived with their parents. I might be wrong, but to me the reactions of the other parents were in stark contrast to ours. To us this moment had been the "cherry on top", but to the other parents it seemed as if it was an emotionally taxing morning. Their children probably moved from mainstream schools to the remedial school, and the look on their faces told me that this was the last place they had ever thought their children would end up at.

The move to the remedial school placed a huge responsibility on my shoulders. In line with the unspoken agreement between my husband and I, the responsibility to assist Adriaan with his academic work now rested solely on my shoulders. My husband got Adriaan into the school and my job now was to ensure that Adriaan received the support he needed to benefit from this opportunity.



According to the Department of Education (2010), 19 034 learners in ordinary schools in South Africa are taught in separate special needs classes and a further 96 535 learners are in special schools. Motshegka, in Walton (2011), reported that, since the promulgation of White Paper 6 (Department of Education, 2001), country wide only eight schools have been converted to full-service schools catering for the needs of all the children in their communities. The White Paper 6 proposes that

inclusion of learners with barriers to learning should only be attempted after their completion of the Foundation Phase. Most special needs classes therefore restrict their curriculum to the Foundation Phase curriculum. As most learners in these units are never mainstreamed or included into the rest of the school, they consequently spend their entire schooling career in the Foundation Phase.

The private remedial school, on the other hand, caters for a range of learners, from those with average to above average intelligence, who experience barriers to learning because of an Attention Deficit Disorder, to those who struggle to progress academically and follow a vocational programme that includes the Intermediate and Senior Phase. The school is therefore, although not a full-service school, more inclusive than the typical South African special needs class or school.

Key 9: Not all keys are made from the same material



For the first time since starting in a formal school setting, Adriaan received homework. It is the remedial school's policy that, daily from Monday to Thursday, all learners review work that was done in the classroom. There is no homework over weekends. Adriaan started at the remedial school on 11 April 2011. He had to learn the spelling of about 10 words every day. At that stage he could write his own name and he was very good at copying words or phrases from magazines, but he never had to write words that were read to him. Initially it took Adriaan forever to write down a word that I read to him and when he made a mistake he refused to rewrite it.

When checking Adriaan's homework book on the evening of 13 April 2011, I noticed that the homework included a spelling test. Adriaan was only three days into the observational period. What if he failed? Would the school ask us to take him out? That night Adriaan and I spent two hours in our study practicing and arguing. I was at my wits end. It seemed as if he would never manage to learn all 20 words. For the first time I wondered whether I was expecting more of him than he was able to achieve. Adriaan left the study fuming and I broke down crying.



It is not often that my wife completely breaks down, especially not in front of anybody else, including me. From the lounge where I was sitting I could hear every angry word that was spoken. As Adriaan walked through the lounge with his cellular phone (used solely as a toy), I asked him to fetch his spelling book. He sat next to me on my recliner chair. One by one I read the words to him and one by one he typed all the words on his phone. He got it all right, despite the phone being one of the older generation phones where one key accounts for three or four letters.

The next day Adriaan got full marks for his spelling test. Well, almost. The teacher wrote a note at the bottom of the test stating that she helped him with two words. The rest he managed on his own.



Adriaan loved his new school. The concession we made by allowing him to practice his spelling words on his cellular phone made the homework sessions considerably less stressful. Mathematics however, was a huge stumbling block. His class had just started with multiplication, while Adriaan was still struggling to add and subtract numbers. He quickly learned to count in 2's and 10's, but he struggled to understand the concept of multiplication. I spent hours with him counting on his fingers and practicing the multiplication problems. In May he wrote his first mathematics test – it was a disaster! During the test Adriaan wrote down any numbers that came to mind, and consequently got zero for the test. His teacher was very supportive and left us a note saying that we should not give up hope. She also said that she would spend more time helping him.

For the next mathematics test two weeks later, Adriaan did not get zero. It wasn't that much more than zero, but it was not zero. We celebrated! My eldest son thought that my husband and I had gone insane and jokingly bemoaned the fact that we would reprimand him for getting less than 70% for any test. Since then Adriaan has written many spelling and mathematics tests and he has even done two oral presentations. The spelling tests have gone exceptionally well and we survived the oral presentations, but mathematics remains his nemesis. Luckily he has a very experienced teacher who, after realising that there were a few learners in the class who were losing faith in their abilities, promptly handed the struggling

learners calculators; her motivation being that most grownups use a calculator and that a lack of mathematics ability should not hold back a child's progress. Adriaan has since passed quite a few of his mathematics tests. One of the major advantages of the remedial school is that they are able to cater to the individual needs of learners. By using a calculator Adriaan was able to, at least partially, overcome his fear of mathematics.



In many Hollywood movies, including *Rain Man* (Johnson, 1988) and *Mozart and the Whale* (Dimbort, Heid, & DeMartini, 2005), the perception is created that individuals on the autism spectrum are mathematical geniuses. This is very far from the truth. In a review of literature on the mathematical skills of individuals with high functioning autism, Chiang and Lin (2007) found that, although a small minority of these individuals were gifted in mathematics, the majority had average mathematical abilities. Williams, Goldstein, Kojkowski and Minshev (2008) found that, in individuals with high functioning autism, at least 25% had poor arithmetic skills. The use of a calculator can obviously not improve abstract thinking or problem-solving skills, but Martinez and Pellegrini (2010) have shown that Down syndrome learners with a weakness in numeracy, who were allowed to use calculators as an assistive device, showed significantly improved mathematical skills. Whether Adriaan's problems with mathematics are only numeracy related or more complex, still remains to be seen.

Key 10: A key may open more than one door



When Adriaan started at the remedial school he was a diligent and well-mannered little boy. I have come to realise that part of becoming more neurotypical and less autistic, includes testing boundaries. In the beginning Adriaan was happy to sit down and do his homework every evening, but as the year progressed it became more and more of a struggle. He also started to copy his peers' habits, the good and the bad ones! At first I was upset about losing my "perfect little gentleman" as someone had once referred to him, but I now realise that, if I want my son to behave more neurotypically, I have to accept both the positive and negative behaviours as part of his growth curve. Of course Adriaan, like neurotypical children, also had to learn that negative behaviours have negative consequences. Fortunately, in that respect anyway, he is a fast learner.

I was immensely proud when, at the school's annual prize giving ceremony for 2011, Adriaan walked onto the stage to receive a reward for diligence and reading. Yes, the school believes in rewarding all the children with a certificate, but in order to receive the certificate, Adriaan still had to succeed academically. As I watched him walk confidently up those stairs, my thoughts went back to the day he was diagnosed and I realised that I wasn't sad or scared anymore. Sitting there, I wasn't concerned about the future. My son had become so much more than just his diagnosis. We had not completed the journey, but the road ahead looked so much brighter than the roads travelled.



It is now November 2011, more than six years since Adriaan was diagnosed. As my wife stated, we are not at our destination yet, but I am relatively happy to be where we are right now. Maybe we need to clarify exactly where that is.

We started off with a boy who, in terms of being able to live a value adding life, was given no chance by many medical professionals. Now, at age ten, our son is relatively well adjusted in terms of social behaviour, and he is only two years behind his age group in terms of academic placement. Speech remains a big issue. His Afrikaans vocabulary is quite extensive, but at times he struggles with syntax. His two best friends at school are both English speaking and he has no problem communicating with them. Another area that remains a problem is his inability to grasp figurative or abstract language. The biggest obstacle to a mainstream schooling career, however, is his poor mathematical skills.

I still experience the odd day when my concern about Adriaan's future seems unbearable, but these days are few and far between. Earlier this year I took Adriaan to a gift store and told him to choose whatever he liked. After spending almost an hour in the store, he emerged with a hardcover counter book. I asked him to choose something else, but he only wanted that empty counter book. It took us almost 15 minutes to walk to the car. Adriaan's eyes remained fixated on one of the pages: an empty white page. He did not look up once the entire way. I asked myself if that

empty counter book represented my son's future. No words can describe the emotions I experienced that day. A seemingly meaningless incident took me to a point where I almost felt that life was not worth living.

Will Adriaan eventually obtain a matric certificate? I don't know, but, to be totally honest, I would have to say that I doubt it. I am not even sure whether he will pass grade three next year. The one lesson we have learnt is to take things one step at a time. We rejoice at things other people take for granted. At the end of this year (2011), we will probably receive a report card stating that our son has passed grade two. In my book, that achievement will be bigger than anything that my wife and I have achieved in our lives.

CHAPTER 8

KEY MAKERS TRANSFORMED

*We must be willing to get rid of the life we've planned,
so as to have the life that is waiting for us.*
(Canfield, Hansen, & Thieman, 2008)



People ask me whether the journey with Adriaan has changed me. Of course it has, but I have to be careful not to attribute all these changes to this journey. I might have experienced some changes anyway, whether I had Adriaan or not.

After losing my father when I was only four, I was raised by my mother, and also by my grandmother, who stayed with us until I was nine years old. My mother never remarried and devoted her life to her children. Being forced to fend for myself, I probably wasn't the easiest person to get along with. I always wondered why I was not popular in school. During my first year at university, my roommate spelt it out for me: I was always right and always wanted to get the last word in. Up to that point, the world was against me. Everybody else was wrong and I was right.

I grew up in the Dutch Reformed Church and by age nineteen religion played a major role in my life. It filled a gap at a time when I needed an anchor to hold onto. After my roommate's unambiguous words, I made a concerted effort to change. It certainly did not happen overnight, but after about two or three years I actually became quite popular and easy-going. I had many friends and I was happy. As my happiness increased, my dependence on religion decreased. I also started to question existing concepts, more specifically the existence of God and life after death. By the time Adriaan was diagnosed, religion did not play a major role in my life, but I still considered myself to be a Christian. The final progression to the stage where I am now, was partially brought on by the circumstances surrounding Adriaan, and partially by being a scientifically orientated person. Questioning things, things that simply do not make sense to me, has always been a part of who I am.

Many years ago, on a plane from Johannesburg to Cape Town, I started talking to the lady sitting next to me. When she asked me in what grades my children were, the subject started to revolve around my son's autism. After telling her about some of our ordeals she responded by saying: "Oh, God knew exactly which parents to give such a child to". My response was: "Well, then you believe in a sadistic God, because I do not wish what my wife and I have gone through, onto my worst enemy". As soon as I said that, the lady sitting right in front of me turned around, stood with her knees on her chair and started preaching to me. When the plane eventually landed both ladies told me that they were going to pray for me so that my faith could be restored! Since then I have heard similar comments on at least three occasions, but I simply do not bother to respond anymore. On another occasion a well-meaning gentleman said to me: "You must bring your son to our church. Our pastor will heal him". I find comments like that hugely offensive. If there is a God and if he wanted to "heal" my son, it would not have been necessary for intervention by a faith healer.

Our household is now quite an interesting place. My wife has never lost her faith and the journey with Adriaan has brought her closer to her God. I, on the other hand, struggle to accept the concept of an almighty deity who will reward me with everlasting life if I live according to a set of guidelines established almost 2000 years ago. I prefer to believe in the concept that God is within all of us and that it is our duty to bring the Godliness inside of us to the fore. I have been verbally crucified for my viewpoints, especially since I do not refrain from airing them. In a sense, I envy people who have an unrelenting faith in God, because I believe that their lives are so much simpler than mine.

The journey with Adriaan was probably not the main reason for my spiritual transformation, but it has played a huge role in justifying my beliefs. I can never accept the concept of a God who only rewards one group of people with everlasting life; people who live according to the "correct" religion. What is the "correct" religion? I live according to the same set of principles most Christians follow. But unlike some

Christians, I know that I have made a real difference in this world. Through the continuous struggle with an inflexible system and with, at times, inflexible people, I have managed to help people outside my family circle. The journey became a quest, and that quest has given new meaning to my life.

The quest to find Adriaan suitable support, has taken complete control of my life. I have fought with everything at my disposal to give my son the best possible chance at a brighter future. In the process I have become considerably more emotional, compared to the time before Adriaan was diagnosed. I have always struggled with my short temper. By adding emotion to the equation, it has become a recipe for disaster. During this journey I have stepped on people and I have alienated people that were once close to us. I have lost friends, because they now consider me to be narrow-minded and obsessed. Maybe they are right, but sometimes I wish that their eyes will open up to the world around them. They live in their seemingly perfect worlds, with their seemingly perfect children, completely ignorant of the plight of others less fortunate.

Many people have told me that they do not know how my wife and I have managed to do what we have done for Adriaan. My default response has always been that every parent would have done the same. After writing these narratives, however, I realise that this is not the case. We have done more than many people would have done and that gives me a tremendous sense of accomplishment. I can look into the imaginary mirror and I have absolutely no regrets.

Despite my liberal upbringing and the fact that I have always treated people of all races with respect, the journey with Adriaan has had a profound effect on the way I look at myself and at other people. I can try to sugar coat things, but the reality is that, for a long time, I felt ashamed about having a child with a mental impairment. The situation surrounding Adriaan's education forced me into a social environment where I felt out of place. I considered myself better than other people who were in a similar position. It wasn't easy to change, but today I am a far better human being. I

do not look down on others anymore. My priorities have also changed drastically. I will always appreciate material gain and success, but these days my first and only priority is my family. I adore my children, both of them, and their wellbeing is what I live for.

Would I have chosen to be the parent of a special needs child? Certainly not, but if I find myself in the same situation once again, I will do things in exactly the same manner as before. A few years ago I bought a CD of the South African artist Brandon October. It contains a very famous song that I had heard hundreds of times before, but I had never taken notice of the lyrics up to the day that I played that CD for the first time:

The Quest

To dream the impossible dream

To fight the unbeatable foe

To bear with unbearable sorrow

To run where the brave dare not go

To right the unrightable wrong

To love pure and chaste from afar

To try when your arms are too weary

To reach the unreachable star

This is my quest to follow that star

No matter how hopeless, no matter how far

To fight for the right without question or pause

To be willing to march into hell for a heavenly cause

And I know if I'll only be true to this glorious quest

That my heart will lie peaceful and calm when I'm laid to my rest

*And the world will be better for this
That one man, scorned and covered with scars
Still strove with his last ounce of courage
To reach the unreachable star
To fight the unbeatable foe
To dream the impossible dream*

Leigh & Darion (1965)



Some of the changes I have experienced during the journey could probably be attributed to growing older, and hopefully wiser, but I am convinced that, if Adriaan had been neurotypical, I would have been content to stay just the way I was. Before Adriaan's birth I had a happy and stable marriage, an intelligent and well-mannered child and a job I enjoyed. There was no reason for me to have strong viewpoints on anything. Reflecting on our journey has made me realise just how unprepared I had been to raise a child with special needs. To begin with, I knew very little about autism and I was scared of people with disabilities. Confronting the unknown was something I actively avoided up to that point in my life. I feared confrontation and consequently, I would rather change my viewpoint on a subject to blend in, than to stand up and fight for what I believed in. In short I was a bit of a coward, with a fragile self-esteem.

My parents divorced when I was two years old. My mother and I lived with her parents until she remarried when I was six. My mother and I have never had a typical mother-daughter relationship. I know that she loves me, and I have come to accept that she had tried her best to be a good mother to me, but I never felt that I could live up to her expectations. My mother is attractive, strong willed and socially ambitious. She knows how to make a good impression in any situation. I was also told that she excelled at sport in her youth. I, on the other hand, was always plain looking, useless at sport and socially inept. Wearing thick spectacles as a child did nothing to improve my self-esteem. At some point during my teenage years, I realised that the easiest way to avoid confrontation with my mother was to pretend to agree with everything she said and to never voice my own opinions. It became a habit not to think too much about anything. If I did not have critical thoughts, I could not voice an opposing opinion. My husband frequently commented on how I seemed to change into a completely different person when we visited my parents. With Henrié I could at times

allow myself to voice an opinion, but as soon as I walked into my parents' house, I took on the role of the submissive and dutiful daughter.

In a sense, Adriaan gave new meaning to my life. I suddenly had a real purpose in life – to help my son reach his full potential and be a happy and well-adjusted human being. Maybe that is a selfish way of looking at it, but it sure beats looking at him as punishment from God or a freak of nature. I believe in a loving God who created mankind, but who does not, like a puppet master, manipulate humans to do what He wants them to do. I do not believe that my God specifically choose for human beings to experience painful situations, or that He protects us from experiencing them. I rather believe in a God who supports us and carry us through everything we are faced with in our lives. At the beginning of the journey with Adriaan, my faith was more of a ritual than a belief, but as the journey progressed my faith grew deeper. Without my faith in God, I would not have been able to walk the distance. I have found strength and hope to deal with anything life throws at me.

The journey also made me realise how precious human life is, whether it is a child with a disability or someone with a different skin colour or culture. It has made me think more carefully about people's motivation for doing the things they do, something that has helped me tremendously with my work in previously disadvantaged schools. I have come to realise that, for me to be happy with who I am, I needed to sacrifice my life long need to please everybody around me. I had to make peace with the fact that I could not afford to waste energy on individuals who did not share my vision for Adriaan, or who refused to support my husband and I on our journey.

I like to socialise in pairs or small groups and to share my experiences with others, but with regard to my emotions, however, I am an extremely private person. It has therefore been a disconcerting experience sharing, reviewing and commenting on my emotions throughout this journey, be it through the lense of researcher or participant. The journey has also forced me to become more assertive. Once, while standing in the queue at our local grocery store, Adriaan was crying incessantly. There was only one person in front of me. I needed the items in my grocery basket and could not simply walk out. I tried to ignore Adriaan's crying, knowing from past experience that talking to him or picking him up would have set off a screaming tantrum. Suddenly a lady at the back of another queue loudly proclaimed: "That is what you get for raising a child psychologically!" Instead of picking Adriaan up and

leaving the shop, my usual way of dealing with confrontation, I turned around and replied “My son is autistic and mentally challenged; you are welcome to take him home and attempt to cure him with a good hiding!” It felt good to have found the courage to defend my son. I was no longer afraid to speak my mind, especially when it concerned my son’s well-being. I do not care whether people think that I am a bad mother, but I do care when they make comments about my son without knowing all the relevant facts. I have since realised that I have been guilty of the same offence on a number of occasions. Before we had Adriaan I often looked at ill-mannered children and I had exactly the same thoughts as the lady in the grocery store. The only difference is that I never felt the need to express my opinion publicly.

In a sense, the journey to find educational support for Adriaan strengthened our marriage, as we are dependent on one another to fulfil our different roles. On the other hand, we also grew apart, as neither of us is the same person we were when we got married. This thesis not only gave us the chance to reflect on the different thoughts and emotions we experienced during the journey, but also forced us to confront and acknowledge our resulting differences. In many respects my husband and I differ radically, and although I love my husband dearly, I cannot say with certainty that our marriage of eighteen years would have made it, had it not been for the challenges we had to face together. For a mother, quitting is seldom an option, but so many fathers take the easy way out. To the best of my knowledge this was never even a consideration for my husband.

After Adriaan’s diagnosis, I momentarily believed that my life had come to an end. I was going to have to care for a child with special needs for the rest of my life. Images of repetitive caregiver tasks, boredom, isolation and hopelessness clouded my thoughts. As the journey progressed, I have found the complete opposite to be true. I now tend to look at friends with neurotypical children and believe their lives to be quite ordinary. I am however not implying that I would not swop my life for theirs in an instant, if it meant that Adriaan could be neurotypical. I have learnt to find pleasure in the small and sometimes different things, such as Adriaan’s very first lie. Children on the autism spectrum are supposedly not able to tell lies!

I have learnt to enjoy taking on new challenges, especially the role of lifelong learner. Adriaan’s diagnosis led me to research every piece of information and explore every possible avenue in order to assist him. The more I investigated PDD-NOS, the more I

realised that there was a total lack of information on the subject. I had never really considered furthering my studies after getting married, despite my husband frequently prodding me to do so. I'll always be grateful to him for encouraging me to enrol for this master's degree, although it has been extremely difficult to balance studying with work and family commitments.

The journey to find educational support for Adriaan has made me realise that, in order to be happy and fulfilled, I do not have to be what others want me to be. I just need to feel good about what I am doing with my life right now. I have finally realised that I am good enough for me.

CHAPTER 9

A HAND FULL OF KEYS, A LIFETIME OF MEMORIES

“Life should not be a journey to the grave with the intention of arriving safely in a pretty and well preserved body, but rather to skid in broadside in a cloud of smoke, thoroughly used up, totally worn out, and loudly proclaiming “Wow! What a Ride!”

Anonymous

9.1 A TRAVELLER’S REMINISCENCES

This thesis was framed by the question: How did my husband and I experience the journey to find an educational niche for our son with PDD-NOS within the South African special needs landscape? The quote above not only sums up our experiences to find an educational niche for our son, but also the journey of writing this thesis. I have identified key themes to share with other parents and the research community, and attempted to reduce ten years of fragmented, entangled memories and emotions into one meaningful whole.

The key themes that emerged from the co-constructed narratives focussed more on how we tackled the journey, than only on our experiences of the journey.

Knowing is not enough; we must apply. Willing is not enough; we must do.

Goethe

The first key theme is acceptance; not only acceptance of our son’s diagnosis and acceptance that we as parents are responsible to find him appropriate support, but also the acceptance that we are human and that there will be times when raising a child with a disability simply seems too heavy a burden to bear.

There is also the key theme of knowledge acquisition. We had to investigate what other parents and professionals had attempted before us in finding the best possible support for their children. Our investigations included scientific research, gathering

of word of mouth empirical data and attending courses on alternative support strategies.

The key theme of taking baby steps was obtained through the realisation that our son's educational support needs were extensive and that we could not address them all at once. We needed to prioritise his needs and focus on them one-by-one. Speech was our first major focus area, followed by social skills development.

We had to acquire the key of flexibility by learning to step outside our comfort zone and to face our fears, especially when those fears provided further obstacles in obtaining appropriate support for our son. We also came to realise that appropriate support was a changing concept, and that our son's progress inevitably led to a need for changing support strategies. Flexibility also meant applying alternative solutions when barriers seemed insurmountable, as was the case in addressing our son's adverse reaction to assessment situations.

The most important key theme however, is the theme of hope; hope that the medical professionals were not prepared to give; hope that kept us going. Not a misguided hope that our son will one day be neurotypical, but a hope that, if we as parents keep on fighting for our son, he might have a functional and bright future.

9.2 THE VEHICLE REVISITED

Gaitán (2000) poses three possible reasons why readers should read autoethnographies on health or disability issues. The first is to gain an understanding of the impact that bureaucratic decisions and policies can have on patients' lives. In this thesis the reader was introduced to policies and decisions of medical professionals and educational support structures. As parents we do not only have to deal with our son's barriers to learning, but also with a system not geared for his needs. Gaitán argues that traditional research reports cannot have the same impact.

Gaitán (2000) further reasons that, in an autoethnography, the reader and author are equals, as the author is insider to both the experience and the discipline. The text of

this thesis aims to be accessible and pertinent to both a parent of a child with a pervasive developmental delay, and an educational support researcher. To create that same accessibility in a traditional research report would be almost impossible.

As a third reason, Gaitán (2000) poses that autoethnographies not only aim to produce new knowledge, but also attempt to allow readers to imagine themselves within an unknown situation, or gain a better understanding of a similar experience. I have allowed a few good friends and family members to read parts of the narratives, and on more than one occasion the comment was made that the specific person had no idea of what my husband and I had gone through.

Although the main purpose of this research is to inform parents of special needs children, medical practitioners and educational support specialists, the autoethnographic format also makes this research accessible to parents of neurotypical children. I wanted to create a better understanding in the neurotypical community, of the plight of special needs children and their parents.

9.3 TRAVELLERS TRANSFORMED

The most striking fact about the disabled population is that it is the most inclusive. I will never be black, and I will never be a woman, but I could become disabled on the drive home tonight.

George Will in Canfield, Hansen, McNamara, & Simmons (2007, p. 152)

Transformation is a continuous process, but the rate of transformation varies. Writing this thesis accelerated this process of transformation. Both my husband and I were able to critically reflect on a period of more than ten years.

Before our son was born, we had no idea of what having a child with a disability entailed, and we had no motivation to find out either. Retracing my steps and being a previous version of me, even only for a while, were at times interesting, at times humorous, but mostly stressful and painful. These varying emotions were brought on by reading the medical professionals' reports and by reliving events that I had

done my best to forget. The most difficult, but also the most insightful period, started with the co-constructing phase. My husband and I would remember detail differently and often realised that we had misinterpreted each other's emotions along the way.

When we started writing the narratives, we had no idea of how we would remember all the finer details, since neither of us had kept a diary. However, as soon as we started writing, the memories returned. The requirement by the South African Revenue Service to keep all medical documents for a period of at least five years, proved to be a blessing in disguise. My husband's tax records not only contained copies of all the relevant invoices, but also copies of every single report by a medical practitioner.

Initially I found it difficult to relive the emotions and to write my narratives, whereas my husband seemed to excel at writing his. I believe that my husband allowed himself to be emotional at times, and in doing so, he enabled himself to move on. I have a tendency to suppress my emotions. During the co-construction phase, I therefore not only had to relive emotions, but in some cases I had to discuss these emotions for the first time. For my husband, it was mostly a case of simply writing a story; a story containing facts and a description of emotions experienced years ago, and dealt with at the time.

Right from the start we agreed to be brutally honest and not to hide any emotions. In the narratives we raised issues that we were unhappy about, the most important being the lack of support from our families. Some of the issues we raised, led to unhappiness in our family circle. However, since we cannot change our perceptions and reactions to situations at the time, it would be wrong to alter the narratives. At least the narratives provided an opportunity to discuss these long overdue issues, and in the process a mutual understanding was reached and old wounds were healed.

Although I will always remain more of an introvert, the journey taught me to stand up for what I believe in and act accordingly. My husband is an independent and success driven individual, but he had to change his concept of success for our youngest son. Whereas he expects academic excellence from our eldest, he had to

learn to find the same joy in our youngest son learning to read or just managing a pass mark in mathematics. When I completed my teacher's diploma, I thought that I had completed my studies, but now I find myself being a lifelong learner, constantly seeking new ways to support my son's educational needs. The journey also transformed our beliefs. I have grown increasingly dependent on the belief that there is a God who supports me every step of the way, whereas my husband has found it increasingly difficult to accept the existence of God. Whereas I look upwards, my husband looks inwards in finding God.

9.4 THE LIMITS OF THE VEHICLE

I want you to feel what I felt. I want you to know why story truth is truer sometimes than happening-truth.

(O'Brien, 2009, p. 171)

The main limitations of this study are posed by the nature of autoethnography. Because the narrative is limited to one set of parents, generalisation in the traditional social-scientific sense is not possible. According to Ellis, Adams and Bochner (2010), the focus of generalisability in an autoethnography is with the reader, who has to determine whether a story speaks to an experience the reader has lived, or illuminates an unfamiliar cultural fragment, such as parenting a child with disabilities. The single parental set also raises the question of validity. Ellis, Adams and Bochner pose that an autoethnography is valid if a coherent story is presented and the reader experiences the narratives as "lifelike, believable, and possible". Both generalisation and validity are therefore open to reader interpretation.

9.5 MORE AND DIFFERENT JOURNEYS

There is a need for more caregivers to give voice to their experiences in finding educational support for children with pervasive developmental delays within the South African context; the aim being to inform medical and educational professionals

on how to improve their support to caregivers, and to increase the knowledge resource base available to caregivers.

In writing this thesis, I have also attempted to convince medical professionals to abstain from the practice of painting the darkest possible picture, thereby minimising the risk of them being held responsible for a child not fulfilling the potential outlined by a more positive diagnosis and prognosis. With more caregiver voices propagating for hope, the likelihood of medical professionals giving more positive prognoses might increase.

By his own choice, a voice that remains unheard in this journey is that of our eldest son. Petalas, Hastings, Nash, Dowey and Reilly (2009) found that most research focussing on siblings of children on the autism spectrum are quantitative in nature. They also found that the research questions utilised, assume a negative impact on the siblings' emotional and behavioural development. I therefore believe that there is a definite need for qualitative, narrative research into sibling journeys.

9.6 TRAVELLERS AT REST

Our journey has not ended. This paragraph is therefore not a conclusion, but merely represents a resting place along the way. With this thesis my husband and I took a short break to remember and reflect on our lived experiences and emotions. Our parental narratives and researcher reflections were used to share, with the reader, our physical and emotional journeys in finding educational support for our son with Pervasive Developmental Delay – Not Otherwise Specified. Themes were discussed, limitations addressed and new journeys suggested.

The process of writing this thesis has been hugely therapeutical. Looking back, we stand amazed at what we had gone through, and the future seems far less daunting. We took a detour from a sometimes bumpy and dark road. Now, after completing this thesis, we hope to continue our journey on a highway: a highway to a brighter future.

On 9 December 2011, a few weeks after the majority of the co-constructed narratives were completed, we received Adriaan's grade two report card. Our son had been promoted to grade three.

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Addendum A
Letter of ethical clearance



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Approval Notice New Application

17-Nov-2011
Hanekom, Pauline PW

Protocol #: HS653/2011

Title: The journey to find an educational niche for our son with pervasive developmental delay-not otherwise specified

Dear Mrs. Pauline Hanekom,

The **New Application** received on **19-Jul-2011**, was reviewed by Research Ethics Committee: Human Research (Humanities) via Committee Review procedures on **28-Jul-2011** and has been approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **17-Nov-2011 -16-Nov-2012**

Present Committee Members:

Van Wyk, Berte B
De Villiers, Mare MRH
Hattingh, Johannes JP
Theron, Carl CC
Somhlaba, Ncebazakhe NZ
Viviers, Suzette S
Bitzer, Elias EM
Van Zyl, Gerhard Mkhonto

Standard provisions

1. The researcher will remain within the procedures and protocols indicated in the proposal, particularly in terms of any undertakings made in terms of the confidentiality of the information gathered.
2. The research will again be submitted for ethical clearance if there is any substantial departure from the existing proposal.
3. The researcher will remain within the parameters of any applicable national legislation, institutional guidelines and scientific standards relevant to the specific field of research.
4. The researcher will consider and implement the foregoing suggestions to lower the ethical risk associated with the research.

You may commence with your research with strict adherence to the abovementioned provisions and stipulations.

Please remember to use your **protocol number (HS653/2011)** on any documents or correspondence with the REC concerning your research protocol.

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

After Ethical Review:

Please note that a progress report should be submitted to the Committee before the approval period has expired if a continuation is required.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

National Health Research Ethics Committee (NHREC) number REC-050411-032.

This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant parties. For approvals from the Western Cape Education Department,

contact Dr AT Wyngaard (awyngaar@pgwc.gov.za, Tel: 0214769272, Fax: 0865902282, <http://wced.wcape.gov.za>).

Institutional permission from academic institutions for students, staff & alumni. This institutional permission should be obtained before submitting an application for ethics clearance to the REC.

Please note that informed consent from participants can only be obtained after ethics approval has been granted. It is your responsibility as researcher to keep signed informed consent forms for inspection for the duration of the research.

We wish you the best as you conduct your research.

If you have any questions or need further help, please contact the REC office at 0218089183.

Included Documents:

Application Form HS653/2011

Research Proposal HS653/2011

Sincerely,

Sidney Engelbrecht

REC Coordinator

Research Ethics Committee: Human Research (Humanities)

Investigator Responsibilities

Protection of Human Research Participants

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

1. Conducting the Research. You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research. You must also ensure that the research is conducted within the standards of your field of research.
2. Participant Enrollment. You may not recruit or enroll participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use. If you need to recruit more participants than was noted in your REC approval letter, you must submit an amendment requesting an increase in the number of participants.
3. Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the REC-approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (5) years.
4. Continuing Review. The REC must review and approve all REC-approved research protocols at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the REC approval of the research expires, **it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in REC approval does not occur**. If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.
5. Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the REC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written REC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.
6. Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research related injuries, occurring at this institution or at other performance sites must be reported to Malene Fouch within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the REC's requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Research Ethics Committee Standard Operating Procedures. All reportable events should be submitted to the REC using the Serious Adverse Event Report Form.
7. Research Record Keeping. You must keep the following research related records, at a minimum, in a secure location for a minimum of five years: the REC approved research protocol and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the REC
8. Reports to Sponsor. When you submit the required reports to your sponsor, you **must** provide a copy of that report to the REC. You may submit the report at the time of continuing REC review.
9. Provision of Counselling or emergency support. When a dedicated counsellor or psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.
10. Final reports. When you have completed (no further participant enrollment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the REC.
11. On-Site Evaluations, Inspections, or Audits. If you are notified that your research will be reviewed or audited by the sponsor or any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.

Addendum B

Sample of the parental narratives before co-construction

Father:

No father wants to learn that his child is physically or mentally impaired, but along with the shock of Adriaan being diagnosed with autism, there was a sense of relief. Suddenly this 'monster' that affected every part of my son's life had a name.

To say that the day that my son was diagnosed was the worst day of my life, would be a gross understatement. My decision to fight was probably selfish to a large extent. I said to myself that, if I look into the mirror in ten years' time, I needed to be able to live with that image and that there should be no regrets. If I think back over the last six years I probably had about 7 or 8 of these 'down' days. Most of the time however, I kept my focus on the task at hand.

I will not say that we decided to blatantly ignore the medical professionals. We simply decided to get as many opinions as possible and we were willing to try EVERYTHING. This included food supplements, special diets and probably 4 million different educational programs (all with 4 letter acronyms).

Mother:

Listening to the panel giving us feedback on Adriaan's condition was surreal. Since he was only a few days old, Adriaan has reacted differently to stimuli compared to his older brother. I had accompanied him to all the medical tests, so I was fully aware of his developmental delays, but no one wanted to attempt a diagnosis until that day and to listen to someone condemning your son to an institutionalised life just didn't seem real. At least we finally had a diagnosis, something that we could tackle head-on. Prior to the diagnosis, I cried every time I drove back from yet another medical test. I wanted to appear calm, not weak and emotional, when giving feedback to my husband and the family.

Addendum C
Sample of the transcription of data

Interview by a community radio station DJ with the principal (P) of the special needs school Adriaan was attending at the time and Adriaan's father (F). Broadcasted live in September 2009

- 1 DJ: Nou, ek het gesê dat..uh..ek gaan..uh..van die personeel en ouers hê van die (skool naam)
2 skool in die ateljee saam met my en hulle is hier. Goeienaand aan...uh of goeie naa..goeie
3 goeie vroegaand aan uh P en ook aan..uh F.
- 4 F: Goeienaand, DJ.
- 5 P: Hallo, DJ.
- 6 DJ: Lekker om julle hierso te hê..saam met ons. Uhm nou (skool naam)...P ek gaan nou-nou met
7 jou gesels. Jy's die prinsipaal...en ons het 'n paar weke gelede met iemand anders van die
8 skool ook gesels so ons luisteraars is al wel bekend met (skool naam). Ek dink meeste mense
9 is in elk geval (stilte) Uh...oor die goeie werk wat julle doen, maar F ek wil graag by
10 jou..uh..begin. Nou jy is 'n ouer wat nou 'n kind by hierdie skool het. Jou
11 seun...is..uh..gediagnoseer met outisme ek wil net graag weet hoe oud was hy, hoe oud is
12 hy nou en wat is outisme?
- 13 F: Uhm..Hy is nou 8 jaar oud. Hy was 3 en 'n half jaar oud en ons het al van 2 jarige ouderdom
14 vermoed dat daar moontlike pro..probleem is. Outisme beïnvloed 'n persoon se vermoë om
15 met sy omgewing en die mense rondom hom om te gaan en te kommunikeer. Dis baie
16 belangrik...dit manifesteer nie as een of 2 simptome nie, dit is 'n..uh..hele spektrum van
17 simptome. So geen 2 kinders met outisme is dieselfde nie.
- 18 DJ: Jy sê julle het eers op omtrent 2 en 'n half...jarige ouderdom vermoed hy het outisme?
- 19 F: Twee! Ons het nie eers geweet wat dit was. Ons het gedink hy was doof, want hy't so in 'n
20 wêreld van sy eie geleef, hy't nie gereageer op die impulse van buite nie so ons het gedink
21 hy's doof. Nadat die gehoor getoets is, het ons vermoed dat hy dalk outisties is.
- 22 DJ: Hhm. So dit kan nogal..uh..ja...en dit het uit die aard van die saak seker 'n groot impak op
23 julle gehad, né?
- 24 F: Ja, jou..jou wêreld kom redelik tot 'n...tot 'n vinnige val.
- 25 DJ: Ja, ek sal jou...ek sal jou baie goed glo. Nou, hy is nou by...by (skool naam) ek wil ook net
26 weet wat beteken hierdie skool nou vir...vir 'n ouer soos jy wat wat 'n kind het...wat met
27 outisme gediagnoseer is..uh..uhm dis seker 'n...baie groot hulp?
- 28 F: Anton..ek..ja ek dink in om..ek kan dit seker nie sterker stel as om te sê die skool het werklik
29 vir ons, ons lewe teruggegee nie. Uhm..van 'n periode van ongeveer 3, 3 en 'n half jaar waar
30 ons uh grootliks op onself aangewese was. Uhm..in..uhm in die Suid-Afrikaans konteks is is
31 hulp regtig uhm baie moeilik om te verkry so jy moet heeltemal op jouself aangewese. Die
32 proses om 'n skool te vind vir die kind was 'n absolute nagmerrie wat geen ouer van 'n
33 normale kind kan besef waardeur mens deurgaang nie, want daar is doodeenvoudig nie

Addendum D
Samples of Audit Trail

Sample 1: Timeline

A rough timeline of the physical journey was compiled to guide us in writing the narratives.

Chapter 4

2001	<ul style="list-style-type: none"> • 19 July: birth • September: day-care • October: hearing re-test (6 weeks)
2002	<ul style="list-style-type: none"> • 10 months: move to crèche • 19 July: birthday = 1 (Henré in France) • 18 months: viral meningitis
2003	<ul style="list-style-type: none"> • April: Occupational Therapist (20 months) • 19 July: birthday = 2 • End of year: Pauline resigns
2004	<ul style="list-style-type: none"> • January: eldest grade 1 • 19 July: birthday = 3
2005	<ul style="list-style-type: none"> • April: Trip Singapore • May: Diagnosis

Chapter 5

2005	<ul style="list-style-type: none"> • 19 July: birthday = 4 • Centre for children with severe mental disabilities • State school for autistic learners • October: Private institution for learners on autism spectrum • November: Sell home • 24 December: Move closer to private institution
2006	<ul style="list-style-type: none"> • Appoint Charlene • 19 July: birthday = 5 • Henré new job
2007	<ul style="list-style-type: none"> • Adriaan diagnosed with Epilepsy • September: Charlene employment terminated • Eldest: day-care centre

Chapter 6

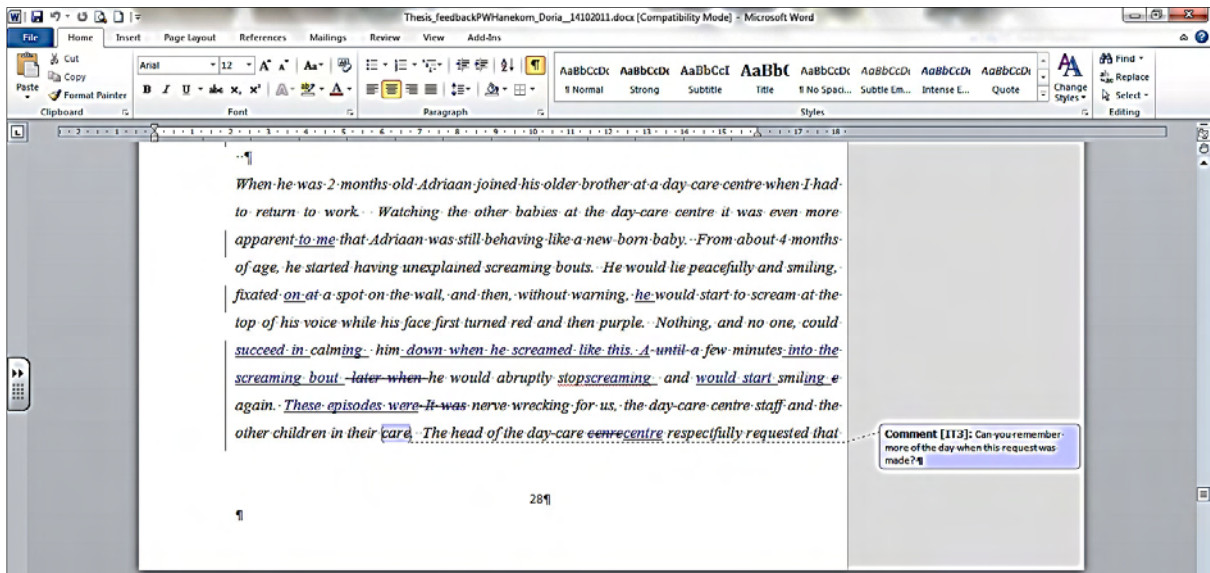
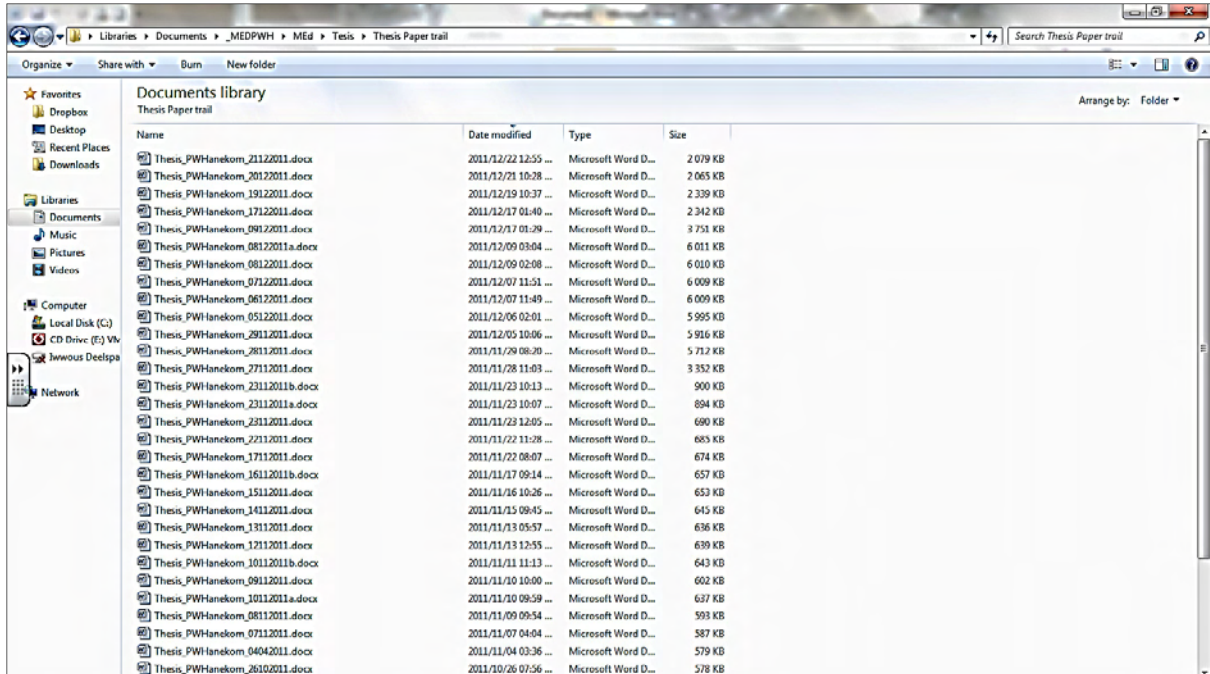
2007	<ul style="list-style-type: none"> • Retesting Adriaan – occupational therapist • Back to Centre for children with severe mental disabilities • October: Henré appointment at special needs school
2008	<ul style="list-style-type: none"> • First day schools open: Adriaan no school • Second day of school: Adriaan excepted at special needs school • 17 January: Adriaan starts at special needs school • August: Autism unit opens doors
2009	<ul style="list-style-type: none"> • Pauline starts at IMSTUS
2010	<ul style="list-style-type: none"> • Pauline starts Master's degree • May: Dynamic Assessment Course • July: Adriaan – Dynamic assessment • 3 weeks later: Adriaan reads • December: Christmas event

Chapter 7

2011	<ul style="list-style-type: none"> • January: SMS advises Adriaan move • Different schools visited • March: Remedial school appointment • 11 April: Adriaan starts at remedial school - 13 April: First test • November: Prize-giving ceremony
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Sample 2: File Trail

All drafts of chapters, as well as feedback from my supervisor, were kept as a file trail. Below are screenshots of parts of this trail:




Sample 3: Field notes


Notes were made during feedback conversations with my supervisor, and during narrative discussions with my husband. In the example below, comment [D3] was made by my supervisor. The handwritten comments are my own.

 *"No father wants to learn that his child is physically or mentally impaired, but along with the shock of Adriaan being diagnosed with autism, there was a sense of relief. Suddenly this 'monster' that affected every part of my son's life had a name.*

After crying for 24 hours, I decided to do something I knew I was good at: fight. That decision was probably selfish to a large extent. I said to myself that, if I look into the mirror in ten years' time, I needed to be able to live with that image and that there should be no regrets."

 Nissenbaum, Tollefson and Reese (2002) reported on the contrast between parents' and medical professionals' perception of a child's prognosis. They found that medical professionals tended to focus on the possible negative outcomes, whereas parents' focus was on finding interventions that could facilitate the child's potential for improvement. Their findings are supported by De Alba and Bodfish (2011) who interviewed 438 parents of children with an ASD. They found that, at the time of diagnosis, most parents were more interested in possible interventions to support their children than information about the causal factors of the disorder. Although some medical professionals describe parents' more positive attitude as denial or even as dysfunctional, Kearny and Griffen (2001) suggested that a positive attitude can be a powerful resilience factor for parents of children with disabilities.

Key 2: Some days the door will seem unmovable

 *"It is impossible to describe to people who do not find themselves in a similar situation, what a parent of a special needs child goes through. For a long period I lived with a tremendous fear of death, not because of concerns relating to religious issues, but simply because I wanted to provide a future for Adriaan. This fear, and the uncertainty the future holds, completely dominated my thoughts and emotions. I allowed myself to have the odd 'down' day, but most of the time I tried to focus on the task that lay ahead."*

↓ Poem follows.

- Ask H. to elaborate on his emotions
39 on the day he wrote the poem.
- Research: Special Needs Fathers?

Ask H: Why did you see this as selfish?

Comment [D3]: Why?