

**AN EXPLORATORY STUDY OF THE EXPERIENCES OF CARE-GIVERS OF CHILDREN
WITH AUTISM IN KWAZULU-NATAL**

by

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Declaration

Submitted in fulfilment of the requirements for the degree of Master of Social Science in the Graduate Programme in Anthropology, School of Social Science, College of Humanities, University of KwaZulu-Natal, South Africa.

I declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged. I confirm that an external editor was not used and that my supervisor was informed of this. This dissertation is being submitted for the degree of Master's in Anthropology in the School of Social Science, College of Humanities, University of KwaZulu-Natal, Durban, South Africa. None of the present work has been submitted previously for any degree or examination in any University.

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ABSTRACT

The term ‘autism’ was first used in 1906 to describe a condition in adults. The term was later used again in 1943 and 1944 by Leo Kanner and Hans Asperger respectively who used the term to describe symptoms found in children. Autism was a relatively unknown condition until the 1980s and 1990s when research on the condition began to increase. The increase in research and availability of information lead to a better understanding of autism and related disorders and there has since been an increase in the number of people diagnosed with 1 in 150 children being diagnosed with autism in South Africa. Autism manifests before 36 months of age with males being four times more susceptible to Autism Spectrum Disorders than females. Research available on autism and related conditions has focused largely on scientific studies in the attempt to discover a cause for the disorder and a cure for it. In recent years there has been an increase in parents writing about their experiences with their children who have autism, however very little literature is available on non-kin care-givers and their experiences in working with children with autism.

This thesis provides a view into the world of the non-kin care-giver through research carried out at two school sites in the KwaZulu-Natal region. This research through participant observation and interviews aims to fill the gap in the literature regarding non-kin care-givers of children with autism. The study looks at why non-kin care-givers choose to work with children with autism, the stress and challenges associated with working with children with autism, the highlights and personal impacts of working with children with autism and why non-kin care-givers continue to work in this field. In addition this thesis looks at the experiences of parents of children with autism and as such aims to describe a symbolic journey that parents and non-kin care-givers embark on with autism. In order to understand

this symbolic journey this thesis has used the theoretical framework of van Gennep's (1960) *Rites de Passage* and Goffman's (1969) Spoilt Identity and Stigma, analysing each stage of the participants involvement in relation to the concepts of *separation*, *transition* or *liminality* and finally *incorporation*. By using these theories to analyse the research findings this thesis argues for the formation of a group identity through shared experiences and understandings of autism and in this way for the creation of an Autism Community.

Key Words: Autism Spectrum Disorders, parents, non-kin care-givers, care-giving, community, culture.

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CHAPTER ONE: INTRODUCTION

“Autism is something I cannot see... Autism is like a seesaw. When it is up or down I cannot see a whole life. When it is passing through the middle I get to see a glimpse of the life I would have if I were not autistic... Autism is just an information-processing problem that controls who I appear to be. Autism tries to stop me from being free to be myself. Autism tries to rob me of a life, of friendship, of caring, of sharing, of showing interest, of using my intelligence, of being affected... it tries to bury me alive” (Williams, 1994: 223 – 224).

1.1. Understanding Autism

Autism, a relatively unknown condition until a few decades ago, was first described by Leo Kanner, a psychiatrist and Hans Asperger, a paediatrician, in 1943 and 1944 respectively. Golding (2006) tells us that the term ‘autism’ was first used by Eugene Bleuler, a Swiss psychiatrist, in 1906 when describing a condition existing in adults. Kanner, then a child psychiatrist at John Hopkins University, later used the term to describe symptoms in children. In a study Kanner conducted of eleven ‘severely disturbed children’, Golding states that he observed ‘unusual characteristics’ and diagnosed these children as suffering from “Autistic Disturbances of Affective Contact” or “Early Infantile Autism” (2006: 2).

The word autism, Golding (2006) states, originates from the Greek word ‘autos’ meaning ‘self’. Accordingly, Kanner used the term to describe “that state when children seem to be withdrawn into themselves, apparently uninterested in other people and unaware of their own identity” (Golding, 2006: 2). While Kanner originally termed the condition ‘Early Infantile Autism’, Golding (2006) explains that this is because it was not understood at the time that autism exists on a continuum and thus that children with autism would continue to live with the disorder for the rest of their lives, growing into adolescents and then adults with autism.

When looking at the family, Kanner believed that the mothers of the children from his original study group had an ‘intellectual approach’ to parenting and thus the term ‘refrigerator mothers’ arose. The term ‘refrigerator mothers’, argues Grinker (2007), arose from the belief that parents (mothers) took a stance of parenting that was emotionally ‘frigid’, that mothers were emotionally unavailable to their children and were thus, in some way, ‘responsible’ for their child’s autistic tendencies. As a result of the stance adopted by Kanner, a divide was created between parents and professionals, a sentiment which Grinker (2007) has echoed. Golding (2006) elaborates on the understanding of the family and the role that it plays in the life of a child with autism. She states that Kanner believed that if the way in which the family functioned was changed or treated (via family counselling) then the child’s experience of autism would alter and improve, thus leaving a ‘healthy child’.

At the time that Kanner proposed the diagnostic category of autism the condition was considered to be “extremely rare” (see Grinker, 2007) with only a few children ‘fitting’ the diagnostic criteria. However, during the 1980s and 1990s a wealth of information became available through an increase in research and publications. This increase in information meant a better understanding of autism and led to, in recent times, specifically since the 1990s, people being diagnosed as autistic in ever increasing numbers. As Grinker (2007: 4) notes “there are more people with a diagnosis of autism now than at any time in history resulting in autism being recorded as a major public health concern”.

Recent studies (see Sutcliffe, 2008; Koudstaal, 2010) indicate that autism manifests usually before 36 months of age in a child, but it has also been known to manifest later. According to

London and Etzel (2000) during the 1960s and 1970s prevalence of autism was around 2 - 5 in 10 000. Since 1985, the rate of diagnosis has increased with current prevalence rates sitting at 1 in 150. According to Autism South Africa (2010), autism affects 1 in every 150 children in the country, a significant increase from the previous statistic of 1 in every 300 live births (Grinker, 2007). Hertz-Picciotto et al (2006) state that males are four times more susceptible to Autism Spectrum Disorders (ASD) than females, however, Le Blanc (2011) states that there may be more females with autism, but they may not be as severely affected (they may have high functioning Asperger's Syndrome for example) and therefore may not have been formally diagnosed. In the province of KwaZulu-Natal, the province where the research for this dissertation was conducted, Ord (2010) estimates there to be around 90 000 people, of both sexes, living with autism.

1.1.1. Autism Spectrum Disorders (ASD)

The concept of autism being a spectrum of disorders rather than a singular diagnostic category came much later, during the 1970s, with the publication of the Camberwell Study in 1979 by Drs Lorna Wing and Judy Gould. The Camberwell Study served to clarify the diagnosis of autism. This is echoed by Koudstaal who states that Autism Spectrum Disorders (ASD) refers to “a broader conceptualisation of autism” (2010: 307). What is important to take away from this notion of a spectrum of disorders is that the manner in which the typical features of autism manifests in children varies in its severity from child to child.

Children with classic autism are more affected by developmental impairments than children with Asperger's Syndrome, Pervasive Development Disorder (PDD) and Pervasive

Development Disorder – Not Otherwise Specified (PDD-NOS). Children with Asperger’s Syndrome, PDD and PDD-NOS can be schooled in mainstream schools. This is not to say that children with spectrum disorders are not affected, but rather they are not as severely affected by developmental impairments as children with (classic) autism. Children with Asperger’s Syndrome, PDD and PDD-NOS may, for example, still be socially awkward/inappropriate, have difficulty in conveying their emotions and thoughts and experience difficulty in interacting socially. Koudstaal states that children with Asperger’s Syndrome will also be in need of “consistent support, structure and adapted curriculum, to prevent and address learning breakdown” (2010: 310).

Jordan (2006), in response to the acknowledgement that autism incorporates a host of varying conditions as opposed to a singular all-embracing disorder, brings to our attention the need to categorise and label in order to better aid development and the ability to access rights within society. While the concept of labelling individuals with a disorder may not appeal to everyone as it may result in negative consequences (for instance bullying or stigmatizing), Jordan (2006) finds labelling to be important in the sense that individuals can use the label to help identify themselves and subsequently successfully navigate their way through the world around them. Labelling helps the individual to identify with other individuals who are similar, and this allows for a larger support base to be reached, whereby groups may help each other to find their way through the world collectively, (see Jordan, 2006), and thus can cater for their specific needs.

In accordance with this more varied conceptualisation of the condition, Koudstaal recently defined autism as a “complex, variable, biologically based, pervasive development disorder (PDD) which influences both the development as well as the functioning of the brain” (2010: 307). Hinged on this premise, classic autism and its less severe counterpart Asperger’s Syndrome, PDD and PDD-NOS are represented as separate from each other, however, they share a number of central characteristics and all conditions fall into the realm of ASD as per WHO (1992) and the American Psychiatric Association DSM-IV-TR (2000).

1.1.2. Autism and Impairments Associated with the Condition

Koudstaal (2010) argues that a developmental disorder such as autism, which originates early in life, may cause difficulties in learning for the child at the start of the learning process. In comparison to their neurotypical (NT) counterparts, children with autism develop skills and abilities in an uneven manner and these abilities may not develop spontaneously. Children with autism may display behavioural impairments, however, these are outward manifestations of internal factors. Hence it is not their behaviour that is impaired rather there is an impairment in their neurological behaviour.

Dr Lorna Wing identified what is known as a triad of impairments. This triad, as explained by Koudstaal (2010), brings our attention to three important dimensions common in children on the autistic spectrum. The three areas of development have been identified as (1) impairment of reciprocal social interaction, (2) impairment of language and reciprocal communication, and (3) impairment of imagination and social understanding (Koudstaal, 2010: 309). These areas do not stand alone, rather they may overlap with each other in various ways, and since

they represent impairments on the spectrum, they manifest in varying degrees in individuals. Dr Wing's triad breaks down the impairment experienced by individuals with ASD into parts which can be more easily understood.

1.1.2.1 Impaired Social Interaction

Individuals with ASD may come across as socially inappropriate and this is caused by impairment in social interaction as a result of being unable to positively navigate their social sphere. Difficulties arise in terms of relating to others as well as in taking the first step toward interaction in a socially acceptable manner. Some examples of manifestations of odd behaviour identified by Wing are "aloof and indifferent behaviour, passive behaviour, and active but odd behaviour" (1995: 4).

A child with autism may be thought to be difficult, stubborn or withdrawn/ unsociable. This is not however always the case, as Koudstaal (2010) brings to our attention, as children with ASD often want to interact with people but do not understand how to read social scenes by initiating and responding to social situations and acting in a socially acceptable manner. Their inability to interact appropriately will vary depending on how severe their autism is and, for example, one may be faced with a non-verbal child who throws a tantrum in an attempt to get his/ her request across. Thus, while individuals with autism may appear to be rigid and emotionless (see Golding, 2006) and as lacking the desire to communicate with others, this is often more to do with a lack of understanding of social cues than with a will to simply not communicate. Koudstaal (2010) states that as a result of impaired social cues people with autism may not realise how they affect people around them and the inability to

understand social rules during interaction may impact on their ability to actively engage with people. Something as simple as a facial expression, for example a frown, which we take for granted, may not be understood in the same way, or as easily, by an individual with autism.

1.1.2.2 Language and Communication Impairments

Along with the difficulty of interacting easily on a social level is the impairment of language usage and communication. Koudstaal (2010) argues that difficulties are experienced by children with autism from an early age, in varying degrees, and that impairments include not only “a lack of joint attention, poor understanding of reciprocity, low frequency of initiating communication” but also an “impaired ability to understand the meaning of language and communication and to control situations and experiences” (Koudstaal, 2010: 312). Individuals with autism lack the necessary skills (both verbal and non-verbal) to communicate effectively and thus their execution, for example greeting someone (even if they are familiar with the person), may come across as overly formalised to the NT person. Depending on the level of severity, an individual with autism may find a way to communicate in alternative ways. They may, as Koudstaal (2010) describes, take a person to an object of their desire, or they may use whatever language they have available to them to tell others what it is they want. While some individuals may display a wide usage of language, their understanding of language in a conversation is often limited (Koudstaal, 2010). When they do show an understanding of language, it is often taken very literally. A metaphor, for example, may not be understood the way it is intended, rather, it is likely to be understood in a concrete manner and this may cause an individual to experience anxiety and confusion, argues Koudstaal (2010). Simple, straightforward sentences which lack the use of idioms and metaphors therefore work best when communicating with children with autism. However, as

individuals with autism do not always grasp the use of language and the associated non-verbal cues through the process of natural assimilation they may have to learn social cues and skills in a different way to NT individuals.

1.1.2.3 Impairment of Imagination and Social Understanding

The third impairment on the triad, as outlined by Koudstaal (2010), is the impairment of imagination and social understanding. This can be seen in the individual's resistance to accept change in any form. Individuals with ASD, argues Koudstaal (2010), are often unable to foresee the consequences of their actions or to imagine what may happen as a result of a certain action, and thus, if change occurs, it is unexpected and may result in repetitive behaviours being adopted as a defence mechanism. This is one explanation for the need to maintain a routine so often observed in people with ASD; if the same thing is being done repeatedly then the response will remain the same, and the risk of something new and not yet understood is averted. Movement such as hand or finger flapping or rocking may thus be resorted to, because, as Koudstaal (2010) points out, it leaves the individual with a sense of predictability in line with routine, order and security. Sutcliffe describes "repetitive, stereotyped and obsessive-compulsive-like behaviours" (2008: 208) to be prominent features associated with autism.

This limit on imagination makes it difficult to place the self in a situation and limits the individual from generalising an experience and response from one situation to another. It also impairs individuals with autism from being able to reflect and recall lessons which they have learned. Koudstaal further explains that "play behaviour is affected on all levels" (2010: 314).

This is a serious concern because children learn through play interaction and by use of their imagination. Play, Koudstaal (2010) argues, is meant to be imaginative, however, in individuals with autism it becomes a guided action and learners are instead taught to play in much the same way as they are taught verbal and non-verbal communication strategies.

Other commonly associated features which Koudstaal (2010) argues to be extended manifestations of the triad are; sensory motor development, odd movements, sleeping and eating disturbances, mood, attention and concentration deficits. These will be expanded on at a later stage when discussing how care-givers deal with these features and the impact these features have on them.

1.1.3 The Causes of Autism

There has been on-going research in the area of the causal factors of autism. The ‘nature vs nurture’ debate continues to stir up more and more questions, but not enough answers. A single cause for autism has yet to be found and Koudstaal (2010), Sutcliffe (2008) and Hertz-Picciotti (2006) argue for a multifaceted aetiology to be considered. There are arguments for both biological and environmental causal factors. Environmental factors are those factors that are external to the body; such as toxins, viruses and vaccines and London and Etzel (2000) use the rubella virus as an example of an external force which may cause autism. Hertz-Picciotto et al (2006), like London and Etzel (2000), suggest that external factors such as prenatal exposure to thalidomide, valporic acid or rubella, may impact on the aetiology of ASD; however, this is not conclusive. Sutcliffe (2008), for example, states that environmental exposure to particular variables during the course of pregnancy may cause or contribute to

autism, while simultaneously, like London and Etzel (2000) and Koudstaal (2010), alludes to the concept of an autistic gene. Although no 'autistic gene' has been discovered, there has been research around the concept of susceptibility genes for autism. A possible biological factor considered by London and Etzel (2000) are lesions formed on the brain. This does not, however, answer the question as to how children are able to begin communication and then regress. There is also no evidence to suggest how the lesions may have occurred and what caused them. Neural tube closure is a hypothesis put forward by Rodier, cited in London and Etzel (2000), as another biological casual factor while Sutcliffe (2008) argues that 'genes' disrupted by chromosomal abnormalities may play a role in one's susceptibility to autism. Sutcliffe (2008) further brings attention to the concept of deletions and duplications of the deoxyribonucleic acid (DNA) which have been found in individuals with autism. Hertz-Picciotto et al (2006) note that structural changes in the brain found during autopsies indicates neuro-atypical differences in information processing between children with neurotypical development and children with ASD.

An outright consensus has evidently not been reached about the possible causes of autism and the 'nature-nurture' debate continues. What is clear though, argues Koudstaal (2010), and this is echoed by Miller (2006), Hertz-Picciotto (2006), Grinker (2007) and Sutcliffe (2008), is that there is no evidence to support the earlier theory hypothesised by Kanner (1943) that parents, and especially mothers, play a role in causing autism.

1.1.4 Debates Around Care Provision for People with Autism

Jordan argues that “those with ASD will have needs in common with the rest of humanity, they will also have individual needs but, unlike other special needs areas, those individual needs cannot be accurately identified and met except through an understanding of the condition” (2006: 1).

Diagnostic categories and symptoms are better understood and information on autism is more widely available and understood by doctors today than in the past. This, Grinker (2007) argues, means that doctors are more aware of the condition and symptoms exhibited by individuals and are thus better equipped to diagnose autism than was previously the case. Not only is there much more information available to professionals for diagnostic purposes, there has also been advancements in the technology available to assist individuals with autism in their learning processes and in their lives (Golding, 2006). Given the increased numbers of people diagnosed with autism coupled with the sentiment of incorporation into mainstream society (see for example Golding, 2006 and Koudstaal, 2010), debate has been fuelled over the ideal care for individuals with autism.

Historically, people diagnosed with autism were institutionalised; being forced to live away from mainstream society in spaces devoid of everyday dyadic contact with parents and significant others (Grinker, 2007). Prior to the term ‘autism’, or ASD being used, Golding states that children were diagnosed as having “childhood schizophrenia”, as being “psychotic children” or as having “atypical ego development” (2006: 3). However, with increased prevalence and awareness there has been a change in the way autism is perceived.

Accordingly, the care-giving role has shifted from institutions to parents, close relatives, facilitators, domestic workers, teachers and therapists (Darula, 2010) with care-givers being regarded as integral to the process of holistic care within mainstream society (Miller, 2006). Providing care to a child with autism can however be physically and emotionally draining and may place enormous strain on the family and the care-giver. While this stress is acknowledged by Grinker (2007) and Miller (2006) it becomes tangible in the statement by Collins (cited in Ord 2010) that 80% of parents with an autistic child separate.

1.2. Aim of research

This research looks into the world of care-giving to expose, from the care-givers¹ (both kin and non-kin) perspectives, their experiences in caring for children with autism. Care-givers have, for the purpose of this research, been separated into categories of kin (parents) and non-kin (educators and facilitators). The role provided by care-givers is an important one that shapes the way in which these children learn and interact in the world in which they find themselves. A relationship is formed between the care-giver and the child and this relationship mutually impacts on the lives of those involved (see Miller, 2006). With the incidence of autism on the increase, the issue of care-giving is frequently recognised as being central to autistic children's ability to learn, adapt and survive in mainstream society. However, care of the child with autism has been largely overlooked within the social sciences as a whole, leading Grinker (2007) to argue that more research is required in this field.

¹ Care-givers for the purpose of this study comprised of parents, educators and facilitators.

This study which focuses specifically on care-giving of children with autism highlights the importance of the non-kin care-giving role and the impact that caring for a child with autism has on the non-kin care-givers and on their lives. Through detailing experiences of care-givers in KwaZulu-Natal, the research examines the stresses care-givers face and the strategies they employ and thus serves to narrow the gaps that exist in the literature by providing detailed insights into the care-giving experience.

1.2.1. Rationale for Choosing the Topic

A key reason for choosing to conduct research into autism and care provision was fuelled by a chance encounter with an autistic adult and his elderly parents. Witnessing the interaction between this man and his parents made me think about the type of care necessary for a person with autism and how this man's parents coped with caring for him. It was only upon delving deeper into the topic that I became aware of the noticeable gaps in the literature on care-giving (and most noticeably non-kin care-giving) despite the fact that the role of the care-giver (both kin and non-kin) is vital to the well-being of people with autism. Grinker (2007) and Miller (2006) both state that autism is a lifelong condition which frequently lessens in severity with age, and thus the focus of this research is on the child as it is at this stage that the condition is most pronounced and thus the need for care-giving is intensified.

1.3. Research Problems and Objectives: Key Questions Asked

Anthropology seeks a holistic understanding of phenomena and in terms of the analysis of the care-giving experience the categories of care-givers utilised are broad enough to encompass as many forms of care-giving as possible. During the course of the research process I have

looked at the interactions that occur between teacher and child, facilitator and child, as well as parent and child. Central to these interactions and experiences are the reasons why care-givers have come into this line of work, why they have remained in the field and their corresponding experiences. Accordingly, the research addressed the following key issues:

- The main factors which influence paid care-givers in Durban to work with children with autism.
- The highlights experienced by care-givers.
- The challenges which care-givers of children with autism face on a daily basis.
- How care-givers cope with the challenges they face.
- Whether the personal lives of care-givers have been affected in any way by working with children with autism on a daily basis.
- The emotional requirements a care-giver needs to have in order to live/ work with children with autism.
- The key motivating factors driving paid care-givers to continue to work with children with autism in the long-term.
- Whether living with a child with autism affects family relationships.

1.4. Research Problems and Objectives: Broader Issues Investigated in the Study

As stated, research on the care-giving of autistic children is a relatively new area of study in the social/ human sciences. As a result, there is minimal research available on the actual experiences of care-givers, (including physical, emotional and psychological), the way in which they cope and the strategies which they employ. To this end, the broad issues in this particular study sought to:

- Gain a perspective of what the care of children with autism entails.
- Understand whether care needs differ according to the severity of the condition.
- Identify and explore the everyday role of care-givers working with children with autism.
- Understand the needs (emotional and psychological) of care-givers.
- Investigate the nature of the relationship between the care-giver and the child.
- Explore the strategies which care-givers embrace in working with children with autism.
- Understand the coping strategies/mechanisms of care-givers.
- Examine the similarities and differences in experiences between the different categories of care-giver.

1.5. Research Methods

Research for this thesis was conducted at two schools which provide care and education for children with autism in KwaZulu-Natal as well as with parents outside of the school environment. The research that was undertaken, both at the Durmstrang Institute for Remedial Studies and Beaxbatons Academy for Children with Autism², was of a qualitative nature, with varying degrees of engagement respectively. Research was conducted at each school once a week for most of the morning and this spanned a six month period. Further research was carried out on a number of other occasions that were out of the school setting which involved parents; namely at support group meetings and at an Action in Autism walk. The research methods that were utilised were qualitative in nature and included participant observation, in-depth semi-structured interviews and unstructured, informal interviews. A combination of these methods enabled me to compare the information provided by research participants during the interview process against their actual behaviour, leading to the emergence of pertinent themes from the data.

Qualitative research, as described by Babbie et al is the attempt to “study human action from the perspective of the social actors themselves” (2006: 270). Anthropologists refer to this as the emic, or insider perspective, a key part of which is participant observation. The aim, argues Babbie et al (2006), is to describe and understand the experiences of the research participants rather than to simply explain human behaviour.

² Pseudonyms have been used to protect the identity of the schools.

Some key features of qualitative studies are; research is conducted in the natural environment of the research participant, the view of the research participant is emphasised, in-depth (thick) description and understanding of the research participants and key events are important, understanding the research participant in a specific setting is a central aim and the researcher is seen as the main instrument in the research process (Babbie et al, 2006). The research setting in this case was that of two schools, and the observation was of non-kin care-givers in their natural environment (the classroom) focusing on the relationship that they nurtured with the children in their care.

Having more than one research site allowed for access to a wider range of people who provide care for children with autism, both experts and non-experts, thus allowing for a more diverse range of information. The dual-sited approach coupled with the use of qualitative methodology also allowed me to see and experience first-hand the different forms of care provided for children across the continuum of the autistic spectrum. Although children formed part of the research and were pivotal to the construction of an analysis of the experiences of care-givers, the children themselves were not interviewed during the research process. In terms of observation of care-giver interactions, the children who formed part of the study were under the age of 15.

1.5.1. Participant Observation

A research method unique and primary to anthropology is that of participant observation (Dewalt and Dewalt, 2002). According to Bernard (1994) participant observation allows the researcher the opportunity to listen to, observe and participate in the research. Through the

use of participant observation, gaining entry to schools with an autistic unit allowed me to spend time in the natural environment of the care-giver and child and therefore observe, first hand, the relationship that is created and exists between them, their interaction and the experiences non-kin care-givers face on a daily basis. Participant observation was used in varying degrees at the research sites and allowed me to obtain rich, qualitative data and to assist with the formulation of a research schedule. By observing the interaction between non-kin care-giver and child I was able to develop questions which suited the research and I was able to pinpoint areas of the research that I wanted to bring attention to.

The use of participant observation further allowed me to gain insight into the world of the care-giver from the emic, or insider's perspective. Where I was allowed to interact with the children, it brought a better understanding of the role provided by care-givers and the importance attached to this role. Where possible, I participated during the class, for example, during 'circle time' when songs were sung. Here, I attempted to do the actions that were part of the song. I also assisted children with their tasks during 'puzzle time' and 'table games'. While the use of participant observation allowed me to witness first-hand the interaction and the relationship between the non-kin care-giver and child, it also allowed me to experience some of the emotions that non-kin care-givers themselves later brought to my attention during the interview process. This was crucial to the research process as it ensured significant rapport to be built with the research participants as I could, in some way, identify with their experiences.

1.5.2. Interviews: Semi-structured and Unstructured

While participant observation was the central method utilised, this was supplemented with and analysed against interviews. In-depth semi-structured and unstructured interviews were utilised for this purpose. These methods are important because they allow for free flowing conversation between the researcher and research participant (Bernard, 1994). According to Denscombe (2007) semi-structured interviews allow respondents to develop their ideas and speak more widely on issues they believe to be of importance as they are not limited in any way by rigid and inflexible questions.

The use of informal interviews is a method that is suited for the beginning of participant observation. Bernard (1994) states that this method is used to settle in to the field and to get to know the surroundings one finds oneself in. Informal interviews may take the form of casual conversation whereby the researcher gains insight into the world of the research participant through every day conversation. This, Bernard (1994) argues, allows the researcher to build a stronger rapport as well as to aid in finding topics of interest that might otherwise be overlooked.

Unstructured interviews played an important role in this research context in getting research participants to open up and talk about their own experiences at their own pace. This provided research participants with a sense of security as they felt in control of the type of information that they conveyed. Unstructured interviews help to build rapport with research participants and this plays a significant role in the following semi-structured interview process and leads to more honest research results. Bernard (1994) further points out that unstructured

interviews aid in the development of a research schedule for semi-structured interviews by allowing the researcher to pinpoint topics of interest.

In-depth interviews (whether semi-structured or unstructured) are important as they allow one to collect information on “opinions, feelings, emotions and experiences” (Denscombe, 2007: 175). This allows for detailed responses by research participants, thus providing more holistic research outcomes than questions which illicit one or two word answers. Semi-structured interviews have a clearly defined set of issues that need to be addressed, but as Denscombe (2007) points out, they also allow for flexibility in the interview process as the research participant is allowed to develop his/her thoughts and ideas and may draw upon other aspects of the research which had not occurred to the researcher. The research participant is the focus of the interview while the researcher guides the process with open-ended questions.

The interviews were conducted on a one-on-one basis at the respective research sites. The interviews that were conducted with parents were done at the parent’s leisure, in their home or at a place of their choosing. This ensured that the key informants were in a space that they were familiar with and that they had privacy during the interview process.

In the case of educators and non-parental care-givers, interviews were conducted outside of the school day so as not to interrupt the learning process. Interviews were scheduled at the availability of research participants. Interviews were recorded using a Dictaphone upon consent from the research participant. This is helpful because it means that the researcher is not distracted during the interview process by writing notes and can focus on the interview

process and pay full attention to the research participant. After the interview the recordings were transferred to a personal computer and transcribed in order to sieve through and extract the valuable information.

A total of twenty interviews were conducted and the questions were designed (and altered) specifically for each group with regard to the particular role that they play.

An important part of the research process is the use of field notes. Fetterman describes field notes as “the brick and mortar of an ethnographic edifice” (2010:116). Throughout the observation period it was important that I had a detailed account of the data I had collected. The field notes comprised mainly of recordings of informal unstructured interviews and the days observations. These field notes, as put forward by Fetterman (2010), contain the raw data that is then used for analyses at a later stage of the research process. Writing field notes, according to Fetterman (2010), is an important research technique as one cannot expect to remember everything that happens during the research period in great detail. To remember events, actions, thoughts and behaviours and to then bring this information to life during the write-up stage was thus assisted by maintaining a field note record.

1.6. Anticipated Problems Prior to Entering the Field

Due to the sensitive nature of the research and in terms of the involvement (albeit indirectly) of children with a disability, I was aware that gaining access to a research site may be problematic. Upon making contact with the relevant gatekeepers I provided a clear outline of

what my research concerned, and where it was required, I made my research proposal available for a further, in depth understanding of what my research entailed.

Once the research sites were approved I was concerned that the research participants would think that I was there to find out information on how they performed and to possibly use this information against them by passing my observations on to their superiors. I was concerned that this would also affect my ability to establish a strong rapport with the research participants as if they were suspicious and 'on guard' it could hamper the research by preventing them from going about their day in the manner in which they normally would. Furthermore, this could potentially impact on the collection of data during the interview process as research participants may not want to be completely open in their responses.

I was also aware that my presence in the field (in this case the classroom) would be noticed by the children. A key part of the research was to observe the natural relationship between the non-kin care-giver and child and this could be disturbed by the obvious presence of an outsider. Children with autism prefer routine. They react to anything new in the environment and I was anxious that the presence of a person unknown to them would impact on them negatively or distract them from their lessons. I did not want to get in the way of teachers and hinder the class in any way, but I was aware that my presence would cause some form of distraction.

Being a person who is calm and patient is very important in this line of work and I learnt that on my first day at Beaxbatons. I found that being the type of person who is not usually calm

or patient at all, I had to force myself to slow down and go at the pace of the child who was with me rather than try to do the task, for example a puzzle, for them. This took a lot of hard work and restraint on a personal level.

1.7. Overcoming Research Concerns

Once I had successfully been granted access to the research sites I was given a ‘tour’ of the facilities by the relevant gatekeepers and was introduced, from the start, to the teachers with whom I would spend the next few months working. I was open and honest about the research that I was conducting and about what I was doing at the schools. I made every attempt to answer all the questions that were directed at me so that research participants would feel more comfortable in my presence.

Establishing rapport with the research participants was important as this would impact heavily on the data that was to emerge, especially during the interview process. I had already met a teacher³ (now a member of staff at Beaxbatons) by chance, and this helped greatly in creating a good working relationship and in making staff feel comfortable with my being in their space. In addition to spending time at the research sites, during the research period I made myself available for other activities held by the schools so that I would be able to get to know the research participants on a less formal level and they would begin to know a bit more about me as well. This included attending walks that the schools held for awareness as well as a ‘costume contest’ held by Durmstrang to celebrate the new books that were received by the school library.

³ Who initially worked at a remedial school that was not part of the research sites.

While I was worried how the teachers would react to having me in their classrooms I was pleasantly surprised to find that at both schools, the majority of the teachers were very inviting and friendly and were curious about what my research entailed. I assured the teachers of their anonymity and that the final research write-up would be made available to the schools for their viewing. I made it clear to them that I did not want to hinder the learning process of the children in their classrooms and that if they were not comfortable with my presence they were aware that they could ask me to leave at any time. I was also surprised to find how inviting and accommodating the children were. During the course of the research period, I became a familiar face to the children and they became more relaxed around me. This made the process of participant observation much easier. I was able to observe what it is that the teachers do, how they interact with the children in their care, and most importantly I was able to observe the clear relationship that exists between teacher and child. During play breaks I would spend time with the teachers at Durmstrang watching the children as they played and this was an ideal opportunity to ‘hang out’ with the teachers on a more informal level and chat about everyday things. This helped me toward the end of the research process when it came to conducting more formal interviews with participants. Some of the research participants did feel a bit nervous at the start of the interview process but because I had insider knowledge of what they experienced they were comfortable enough to answer my questions. This helped to ease whatever tension there was between us and helped in building a relationship of trust and confidence.

During the interview process I also ensured all research participants that their personal information would not be made available to the public and that I would use pseudonyms for

both them and the schools they taught at. This allowed my research participants to be open and relaxed with the answers which they provided.

1.8. Moral and Ethical Considerations

In gaining access to the research site, I had to make it explicit that the children would not be a direct part of the study. As the focus of the study is on non-kin care-givers the children were not questioned or interviewed during the research process. Whilst not directly involving the children, the research process did, however, involve observation of the relationship and interaction between the various non-kin care-givers and children. Inevitably some form of contact with the children occurred; for example helping to take the children to the playground or a surprise hug from a child. Where permission was granted I was allowed to interact with the children and aid with basic tasks. This was, however, done under complete supervision as there was always at least two trained individuals with me at all times.

All participants in the study were provided with an informed consent form which explained the nature of the research and asked for their permission to take part in the research and have their interview recorded. Research participants were allowed to withdraw from the interview and were able to decline answering any question that they were not comfortable with. In addition to this, research participants were assured that where applicable pseudonyms would be used in the final dissertation. In instances where a research participant mentioned a child in an interview, a pseudonym has also been provided to ensure the respect and privacy of the child.

1.9. Chapter Outlines

This dissertation consists of seven chapters. Chapter One being the introduction to the research topic detailing the area of study, providing background information to the research question and outlining the research methods used in the study. Chapter Two consists of the literature review and theoretical perspective which details existing literature that relates to the research question and the theories that have been applied to the analysis of the data collected during the research process. Chapter Three then provides a background to the two research sites and details information regarding the non-kin care-givers involved in the research process. Chapter Four details the experiences and subsequent journey of non-kin care-givers in terms of the work they do with children with ASD. Chapter Five then moves on to detailing the experiences of parents in living with and ‘bringing up’ a child with ASD. Chapter Six analyses the data that has been collected using the theoretical framework outlined in Chapter Two and looks at the Autism Community and the relatively new concept of ASD as a culture. Chapter Seven forms the conclusion of the dissertation and provides recommendations for further research in the field of autism and care provision.

CHAPTER TWO: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

“What does it mean to truly relate to another human being? What is that shared moment when we truly connect to one another? How do we know that we have spanned that interpersonal space to see and be seen?” (Gates, 2006: 237)

2.1. Literature Review

With the incidence of autism on the increase, the issue of care-giving is frequently recognised as being central to autistic children's ability to learn, adapt and survive in mainstream society. While there is a serious dearth in literature pertaining to care of individuals with autism, this chapter provides a synopsis of key literature available in the field of care provision for individuals with autism.

Historically, research in autism focused almost exclusively on the biomedical aspects of the condition and social research was largely from a psychological perspective or located within the health related sciences such as occupational and speech therapy. In these health related sciences, care-giving, as an essential component of the well-being of individuals with autism was limited to the role of ‘the specialist’ as care-giver. Watling et al (1999), for example, conducted a quantitative study which aimed at examining the practice patterns employed by occupational therapists when working with children with ASD. This study looked at types of intervention techniques that were used by therapists and the level of collaboration between professionals to provide a more holistic approach. Other more recent studies have turned their attention towards the perceptions, understandings and practices of health care professionals working with children with autism such as the writings of Brookman-Frazee et al (2011) and Lindsay (2011) but research on other care-givers remains sparse.

Anthropology, until recently, largely ignored the study of autism and what research there was focused on the examination of autism as a culture bound syndrome (CBS) (Grinker, 2007; Mezzich, 1996). Simmons (2001:1) defines culture bound syndromes as “those folk illnesses in which alterations of behaviour and experience figure prominently... they are local ways of explaining any wide assortment of misfortunes”. Accordingly, Maud (2007) in discussing autism as a culture bound syndrome makes reference to Reactive Attachment Disorder (RAD), a condition, also described by Grinker (2007) that is diagnosed in South Korea and has the same symptoms as that of autism. RAD, according to Rapaport and Ismond (1996) occurs in a child before that child reaches the age of five, and as Shreeve (2011) points out, is marked by disturbance in social relatedness. RAD includes developmental irregularities and has been described as “disturbed and developmentally inappropriate social relatedness” (Rapaport and Ismond, 1996: 97). Other characteristics of RAD include “failure to express age-appropriate signs of social responsiveness or indiscriminate sociability” (Rapaport and Ismond, 1996: 97). According to Shreeve (2011) there are two ways in which RAD may present itself; a child withdraws from interpersonal encounters (this is referred to as RAD inhibited-withdrawn type) or a child may present little or no reserve toward strangers and may come across as impulsive and non-selective in terms of their relationship patterns (this is referred to as RAD disinhibited-indiscriminate type).

Similarly, Boujarwah et al (2011) make reference to the Efe Pygmies of the Democratic Republic of Congo in their work to illustrate how culture can affect the way a social group understand a certain phenomenon and structure their lives around it. Maud (2007), also drawing on the Efe Pygmies, describes how the Efe believe that a child with autism is under attack from ancestral spirits and that the ‘cure’ for the condition is to send the child to a

village that is far away from his/ her home village so as to prevent contact with blood relatives. Grinker (2007) likewise refers to the case of a six-year-old South African boy who stopped talking and began making strange movements with his hands, leading the family to believe that evil spirits had possessed the young boy. The young boy, who presented with signs of classic autism, was construed by his community as being possessed and the behaviour he manifested was therefore interpreted through a cultural lens; allowing Grinker (2007) to highlight how autism has been interpreted as a culture bound syndrome in many social contexts.

Murray (2008), in *Representing Autism*, looks at how autism is “represented in the various cultural forms in which it features” (xvii) and therefore argues that autism should not be reduced to a simple medical, social or cultural account which aims to restrict what autism is rather than investigate what it can be. Aside from looking at the cultural, social and medical constructs surrounding the condition, Murray (2008) also delves into the fascination that the media has with autism, for example movies such as *The Rain Man* and *I Am Sam* which have presented a romanticised view of autism. In recent years, with more information on ASD being available to people, parents have better options in which to help their children and improve their quality of life. However, the fascination of Anthropologists with the link between autism and culture continues to filter through much of the literature. The present stance however has shifted from the ‘culture-bound’ nature of the condition to a focus specifically on people with autism, and consequently their care-givers, as forming a distinct social and cultural grouping. From this perspective, culture is regarded as fluid and as affecting the way in which one group of people interacts with and perceives another group (see for example Mesibov and Shea, 2011).

Autism as a developmental disability affects the way in which an individual acts in the world. Autism affects the way a person sees the world around them, the way in which that person understands and interprets the world they find themselves in and the way in which a person communicates with other people. It is in this regard that Mesibov and Shea (2011) argue that autism itself may function as a culture. Accordingly, Mesibov and Shea (2011) argue that individuals with autism share common characteristics and patterns of behaviour and can therefore be viewed as a group. While this group may inwardly function as a culture as they possess social commonalities, from the external perspective the position of the "other" is afforded to them because of the differences between neurotypical (NT) individuals and individuals with autism, and because of the way in which people with autism are viewed by NT individuals. This sense of 'us' against 'them' is echoed by Senator (2010) and online websites such as *Shut Up About Your Perfect Kid!*

Communication, Mesibov and Shea (2011) argue, is not easy and is often hampered by misunderstandings. Here, Mesibov and Shea (2011) describe the role of the care-giver (whether it be a parent, teacher or facilitator) to be that of a cross-cultural interpreter. In this sense the literature on autism as a CBS is useful to understanding the unique role of the care-giver. The research on autism as a culture-bound syndrome stresses that interpretation of an illness is significant to its management, treatment and care; that managing and treating autism as a culture-bound syndrome would need individuals tasked with understanding and treating the 'illness' of the individuals involved. This 'insider' status of the care-giver, borrowed from the literature on CBS, permeates much of the recent research on care-giving. As such, care-givers are described as individuals who understand both worlds and as a result are able to bridge the gap of understanding and communication. To do this effectively, Mesibov and

Shea (2011) assert, care-givers must be well-versed in the 'culture of autism', with the strengths and weaknesses associated with autism and with the individual in question.

Other authors (see Bogdashina, 2005 and Bernier and Gerdts, 2010) argue that autism is not strictly speaking 'a culture' and assert that families who have children with autism do not tend to live within the same community although they frequently do share a common identity. Such an understanding has given birth to the notion of an 'autism community' (Senator, 2005 and Tilton, 2004). This 'community', research indicates (see Mesibov and Shea, 2011) frequently experiences the effects of 'othering' due to the atypical behaviour of individuals with autism. This notion of the "other" is often transferred to individuals who are affected by autism; namely parents, siblings, family members and other non-kin care-providers by virtue of their relationship with the individual with autism. Autism, while previously conceptualised in purely biomedical terms is now considered in much of the literature to be strongly embedded within the social and cultural contexts of society.

According to Miller (2006), anthropology as a discipline which focuses on the social and cultural domains of society is well placed to study the social dynamics of autism and provide a holistic understanding of the care-giving experience. However, literature in the field of care provision for individuals with autism is surprisingly scant within the discipline. What literature there is reflects that while studies have shown the significance of the care-giving relationship (Darula, 2010; Travis and Sigman, 1998), and how the care-giver can help and improve the child's level of social interaction and academic functioning, the focus of such works has been on the child and not on the care-giver per se. Very little in-depth, qualitative

research has been conducted on the actual experiences of care-givers, how their lives are affected, their reasons for their choice of work, their commitment to the children they work with and the stresses they face. Instead, the limited current social science research which does exist on care-givers of children with autism focuses on the requirements that a person should have in terms of their personal and professional capacity (see Barg, 2003; Darula, 2010; and Downey, 2000).

In addition, much of the literature also serves as a guide for parents of children with autism in terms of diagnosis, potential treatments and the process of coping (refer Siff Exkorn, 2006; Tilton, 2004). In his book, *Asperger's Syndrome: A Guide for Parents and Professionals*, Attwood (2006), a clinical psychologist, provides a step-by-step guide in terms of the description and analysis of Asperger's Syndrome. He looks at typical and unusual characteristics that children display and what strategies parents and professionals may use to reduce them. His aim is to help parents and professionals alike identify Asperger's Syndrome and treat the outward manifestations of the condition.

Parents are the main form of care providers; they are the primary care-givers and as such while there are many texts available which are written as 'guide books for parents' there are also numerous texts available by parents (see Siff Exkorn, 2006; Grinker, 2007; Senator, 2010; Gardner, 2008 and Blastland, 2007) which provide insight into life with a child with autism. Siff Exkorn (2006), for example, focuses on the role of parents in care provision for the autistic child. As a mother of a child with autism, her '*Sourcebook*' is aimed at helping parents makes sense of what autism is, gives an overview of the diagnostic process and

provides information on possible treatment options and how to manage their lives with autism in it. Similarly, Senator (2010) a mother of a child with autism has written from the parent's perspective and has documented the challenges embedded within the role of care-giver to a child with autism. This is evident in her words, "From their first days of life, our children challenge us to rise to our fullest potential. In the end, they teach us acceptance of limitation, acceptance of what is" (Senator, 2010: 9). Likewise, in *Unstrange Minds*, Grinker (2007), who is an anthropologist and a parent of a girl with autism himself, provides a parent's account of the challenges of bringing up an autistic child. This is echoed fleetingly by Collins (cited in Ord, 2010) who states that even a normal activity such as eating out can be stressful and unpredictable for the family or non-kin care-giver.

The existing literature on autism, while providing a guideline for and from parents, and documenting lifestyle changes and challenges also provides a synopsis of the experiences and reactions of parents upon learning about their child's diagnosis. Senator (2010) argues that the biggest change for a parent comes when their child is diagnosed with ASD. Senator (2010) tells us that upon diagnosis she did not realise how much her and her family's life would be changed. She describes how every facet of their lives was affected from that moment; "how I parented, how I made plans, who I hung out with, how I felt about family, how I felt about my life" (Senator, 2010: 1). Dougherty, another mother who has written on her experiences of rearing a child with autism, likewise quips about her experiences with the diagnosis of her child "it was as if someone had slammed a cleaver through our lives", (2006: 36). The words of these authors (Senator, 2010 and Dougherty, 2006) both express the intensity and the heightened emotional stress that was experienced at the time of diagnosis. Dillon (1998) echoes these sentiments in acknowledging that autism places an added stress in

the parent's lives as they struggle to come to terms with their child's diagnosis. Dillon (1998) describes an intimate relationship and feelings of attachment which exist between parents and their child before the child is even born. It is common, he asserts, for parents to think about what their child will be like when it is born and who that child will grow into as it gets older. When a child is diagnosed with autism and when parents learn what autism is and what it means for their child, Dillon (1998) states that parents may go into a state of mourning, "for the child who will never be and for the present losses in the child with autism" (29). Dixon cements this notion by stating about his daughter, "indeed a child did die the day of her diagnosis" (2006: 192). Many parents, literature indicates, thus hold on to the image of the child they had pre-diagnosis, of their 'perfect' child who would grow into a 'normal' individual and who would be able to function like all other children. Fear, grief and sorrow appear to be a normal part of the diagnostic process and Senator (2010) argues that it may even be cathartic to parents and help with the acceptance of their child with autism. Dillon (1998) however argues that this mourning never really ends as parents are constantly made aware of their loss because of the constant presence of the disability, and Dixon points out that it is "not something you can turn off" (Dixon, 2006: 30). This opinion is also shared by O' Brian, (cited in Senator, 2010) in that her past research showed a high incidence of depression in parents, especially mothers of children with autism. Senator (2010) too explains how her depressive state affected her family and how it took her years to realise this. Her emotional state, she says, affected her son and his autism while she had initially thought it was his autism that affected her depression. Senator (2010), Grinker (2007) and Dixon (2006) all agree that time is the important factor in the healing process and that in time one is able to heal and move on.

While existing literature focuses in some detail on parental reactions to diagnosis, it simultaneously documents experiences of parents post diagnosis. Senator (2010) argues that after experiencing depression following diagnosis she decided to make a conscious effort to improve her mental state and while she knew that her depression would not leave her, she strived to make herself feel better. Senator (2010: 80) then goes on to explain how she consciously channels out the energy from her depression into “something good”. Parents of children with autism, Senator (2010) asserts, need to find a better quality of life and no doctor, argues Senator, can tell them how to do this. Due to the nature of autism; that its severity ranges in each child who is diagnosed, parents need to find what works for them, an opinion echoed by Grinker (2007) and Danta (2006).

Research indicates that autism takes over the life of those directly affected and parents need to work hard to make sure that they do not lose themselves in the process of caring for their children. Senator thus asserts that something as simple as looking after your appearance can make a big difference in how you feel about yourself and can improve your overall mood. In her research, Senator (2010) has spoken to parents who do a range of activities from blogging⁴, knitting, running, painting and writing poems. She states that these activities offer an outlet for the stress and pent up emotions that parents feel in their day-to-day lives while simultaneously acknowledging that achieving a state of happiness is not always easy as it is difficult to carve out a life outside of the child. Senator (2010) states that she herself, as a researcher and mother, sometimes backs out of get-togethers with friends because she is scared of something new and scared of having fun, “I feel selfish leaving, and the guilt suffuses me and threatens to spoil the fun”, (Senator, 2010: 97). Acceptance, Senator (2010)

⁴ Writing their thoughts on an online website.

thus argues, is the first step in getting children with autism the help they need, which is best done at an early age. Coming to terms with the diagnosis and accepting that the future of yours and your child's will not be as you had once envisioned. This, however, is not an easy process, as affirmed by both Grinker (2007) and Senator (2010). This acceptance is referred to as "achieving a sense of peace" by Senator (2010: 3) and she states that the process may take years depending on the parent and child involved. Parents experience a mixed range of emotions (in having to raise a child with autism) which, Senator (2010), Dougherty (2006), and Dixon (2006) argue, range from love and admiration to frustration and hate. While research therefore indicates that most parents in time accept the diagnosis and want to learn as much as possible about autism and where their child is placed on the spectrum in terms of ability, there are other parents who do not take the diagnosis as easily and refuse to believe that their child will have this 'disability' for the rest of their lives. Senator (2010) refers to this as the 'autism divide'.

Another common thread that runs through the existing literature on autism is the issue of routine. This characteristic displayed by children with autism, as various authors point out, can have a negative effect on the care-giving relationship. Children with autism are most comfortable when they are in a routine because they are doing something familiar and within their comfort zone. Doing something new, whether it is going for a meal at a restaurant or taking a vacation is not an easy task for families who have a child with autism. As Senator (2010) and Graff (2006) point out breaking away from routine and doing something new is difficult, "new is not better" (Graff, 2006: 50). Parents and families have to prepare thoroughly before a new activity is done or even for something as simple (that NT individuals often take for granted) as going to a restaurant.

An important tool available to parents and other non-kin care-givers is the use of social stories; a strategy which various researchers make reference to in the literature (see Senator, 2010; Ling and Cheng, 2010 and Howley and Arnold, 2005). In a social story the child is the main character and the social story is used to show the child potential scenarios, to understand the situation and to show and elicit from them expected actions and the consequences of their actions (see Senator, 2010; Ling and Cheng, 2010 and Howley and Arnold, 2005). Senator (2010) describes social stories as a step-by-step guided plan to an outing or event. Ling and Cheng (2010) describe social stories as a practical way in which to aid children who have special educational needs and who struggle with everyday social norms. Children with autism have difficulty interacting on a social level and as Howley and Arnold (2005) state, as humans we are social beings and social interaction is a significant part of our lives. Social stories help individuals with ASD to develop their social skills as well as their social understanding (Howley and Arnold, 2005). Senator (2010) has used the concept of social stories on numerous occasions and she argues that it is best to describe every possible scenario for a given event. This, she states, leaves both child and parent prepared for what is to come. This strategy, Senator (2010) maintains, also helps parents to understand the child's feelings about a certain event. Howley and Arnold (2005) and Senator (2010) stress that social stories should be read regularly in preparation for any change in routine, and can also be used in everyday tasks; for example learning to use the toilet.

A further theme which runs throughout the literature is the notion of social stigma. In the past, and to a lesser extent the present, there has been/is a lot of stigma associated with autism and related disorders. Miller (2006) tells us that in the early days of autism those who were diagnosed often faced being institutionalised as treatment that is available today, was unheard

of during the early years of autism. Autism was something that was not to be seen nor heard. Grinker (2007) relates a story from his research of a mother who wanted to hide the fact that she had a son who had autism. He describes her as a “well-educated, well-liked, stay-at-home mother ... trying to keep her son a secret” (Grinker, 2007: 67). This in itself tells us of the intense emotions that parents may go through when they have a child on the spectrum, and when that child is severely autistic this emotional state may be compounded by stigma imposed from outsiders. As Senator (2010), Grinker (2007) and Danta (2006) explain from their own experiences, people tend to blame the parent and the parent’s bad parenting for the child’s behaviour. Due to this outward imposition of stigma, Grinker (2007) states that some parents choose to keep their children away from the public and mainstream activities. On the other hand Grinker (2007) hypothesises whether the stigma is in turn internalised by the parent who, in response, becomes embarrassed by his/her child’s condition as he/she is aware of being regarded as responsible for anything that is ‘wrong’ with the child. This fits with the notion of ‘refrigerator mothers⁵’ and the idea that parents and mothers specifically, were responsible for their children developing autism. Both Grinker (2007) and Senator (2010) deal with the notion of parental blame and this is something that is often echoed by parents upon initial diagnosis. Parents, research indicates (Grinker, 2007; Senator, 2010), are often filled with self-doubt as to whether they could have done something differently during the early years of their child’s life that could potentially have prevented the child from becoming autistic. Grinker (2007) therefore describes autism as a two-fold illness, one encompassing the symptoms diagnosed and the other the stigma and exclusion that society adds to.

⁵ Refer to Chapter One

The stigma associated with autism has been closely intertwined with the condition since Kanner's initial study of autism. Grinker (2007) explains that Kanner initially believed that children were born with autism and they were already withdrawn from people and society from birth; that they had not withdrawn from their parents as a response to bad parenting. However, Kanner and Asperger had noted "subtle shades of autism" in the parents of their patient's and thus alluded to a biological connection (Grinker, 2010: 71). Psychoanalysts of the time took this to mean that individuals with autism had failed to form stable relationships with their parents, especially their mothers, and were thus socially impaired. Asperger used the term to indicate a genetic relation, but psychoanalyst, Bruno Bettelheim, took it to mean bad parenting (see Grinker, 2007). While debate continues about the biological nature of the condition⁶, recent evidence shows that there is a strong argument that autism has a genetic component, (Grinker, 2007; Zimmerman, 2008; Le Blanc, 2012). This does not, however, help parents to feel at ease with the cause of autism manifesting in their children as many parents take this to mean that they are the cause of the disability in their child, therefore compounding guilt. Grinker (2007) talks of a childhood experience regarding a mentally disabled boy whose parents eventually sent him to an institution (which was the norm in the 1970s). He describes the family as being "tainted by the disability" and as a child he could not understand why that family had ever let their son out in the public (Grinker, 2007: 77). In the past a child with a mental disability was something to be scared of, something to be ashamed and embarrassed of. Having a child of his own with a neurological disability in later life made him re-think his childhood perception of hiding children with disabilities.

⁶ See Chapter One

While there are a number of texts available from parents detailing their experiences with autism, and from researchers who have documented the role of parent as care-giver, I have found a noticeable gap in literature available from the educator or facilitator's point of view. After the child's parents, their teachers or facilitators spend the most time with children with autism, trying to teach them how to navigate their way through the social world. Care-giving therefore extends beyond the parent-child relationship and takes on many forms, which are constantly being expanded as the emphasis shifts towards social and educational inclusion rather than exclusion. Numerous authors (see Koudstaal, 2010; Miller, 2006; Grinker, 2007, Barg, 2003 and Darula, 2010) state that early intervention for children with autism is important and is the best possible route to go to ensure that the child learns the necessary skills for surviving in the 'outside world'. Since children who are diagnosed with autism are in need of early intervention, they begin 'school' earlier than most NT children. In cases where parents are not financially well-off one parent will often see to the child's education, but in cases where families can afford to do so, a private tutor is frequently hired to work with the child using specified interventions. Such interventions are designed for children with autism in order to identify problem areas in behaviour and education and begin to rectify the defined problem areas.

It is however with a sense of both dread and relief, states Senator (2010) that parents send their children off to school. Dread because parents know the type of behaviour their children may display, from tantrums to physical violence such as biting or scratching when they cannot explain themselves, and relief because they can send their child to a place with trained professionals and are able to take time away from the autism for a while each day. Thus, research suggests that schools with special needs programmes are important for the well-

being of not only the child but the parent as well. Grinker (2007) states that in the past there have not been many options for parents looking for special needs schools and this is echoed by Miller (2006) who provides us with a South African perspective. This is slowly changing as parents recognise the need for more schools and for a more inclusive curriculum.

Teachers and facilitators of children with autism however face a daily struggle, much like the parent, in terms of getting into the child's mind and successfully getting them to engage with the world around them; yet their experiences have not been documented to the same extent as the experiences of the parent. Miller's (2006) book is therefore something of a watershed work in the South African context as it provides an insider's perspective of the facilitator's role in the life of children with autism in Cape Town. Miller, while a student of anthropology, does not however frame the work around theoretical constructs and ethnography but simply provides a first-hand account of her experiences as a facilitator. In her book *Children on the Bridge*, Miller (2006) tells of the continuous struggle to first captivate the child's attention away from a current fixation and then, through time and planned tutorial sessions, teach the child ordinary social interactions that we often take for granted.

In her book Miller acknowledges that non-kin care-givers do not always have an easy passage to the child as some mothers especially do not like the idea of a stranger's presence. Senator (2010) and Graff (2006), as mothers themselves who worry about their child's well-being having first-hand experience of their child's difficulties, echo this sentiment. They know that their child is not able to function in the world adequately and they explain that they are scared of having an 'outsider' come into their world and tell them what to do with their child

(Senator, 2010). This, Miller (2006) stresses may inhibit the rehabilitation and learning process and thus strategies need to be developed to deal not only with the child but with the parent as well.

The ideal situation as Ariel and Naseef (2006) put forward is the collaboration between parents and care-giver (whether it is the educator, the facilitator or the therapist). They go on to state that parents and professionals each have information that the other does not have access to and that collaboration between the parties means a better outcome for the child. External care-givers, such as facilitators, teachers and therapists can offer an insight to the child that parents cannot have. According to Ariel and Naseef (2006), the fact that the external non-kin care-giver is (at first) emotionally detached from the child helps them form a different perspective of the child and, in this way, they are better able to acknowledge the problem areas and work from there.

According to Miller (2006) building a relationship of trust and communication with a child with autism requires patience with oneself and the child. She describes her experiences as sometimes exhausting and emotionally draining. Miller (2006), however, also speaks of the emotional reward of working with these special needs children as she stated that for every negative experience there is always something that the child may say or do at a later stage that will draw you into their world once again. The emotional well-being of an educator, she thus asserts, is important to the effective learning process of the child. In any situation, she maintains, a teacher needs to be emotionally stable in order to successfully teach and impart knowledge to the child. This is most especially so in the case of special education teachers.

The issue at hand though is that the job that special education teachers do is more demanding than that of mainstream teachers and therefore, while having a strong and stable emotional centre is important, it is also difficult to maintain. Lynn (2005) similarly states that it is important for teachers to be conscious of their emotional well-being and this means that not only do they have to be able to manage their emotions and those of the people around them, they also need to be conscious of their own emotional receptiveness.

Miller's (2006) book is pivotal to this research as it provides an insight into what care-givers go through during their time with a child. Her work also brings to light the notion that each child diagnosed with autism is different and has different emotional needs that must be met. De Nysschen, a teacher at a special needs school, reiterates this statement in saying that "each day presents a different set of challenges, for example social difficulties and odd or aggressive behaviour" and that "each learner brings his own potential, but also his own particular issues related to autism into the classroom, and how trying it is to deal with some of the learners" (2008: 107). This, Miller (2006) asserts, means that the non-kin care-giver is required to approach each child in a different manner and different skills are required to deal with each individual child.

Miller's (2006) work also reflects on the circumstances that bring a person into this profession and what makes them stay in it even when faced with extreme pressure from parents of children on the spectrum or from more experienced 'experts' (e.g. child psychologists, speech therapists and occupational therapists). Some of these may be because a person needed a job, as had happened with Miller (2006) or was offered a chance to work

with special needs children having worked with neurotypical children. Reasons why non-kin care-givers remain in this line of work include the relationship they build with the children they work with, the relationship they form with the parents and a love for what they do. According to Sicile-Kira (2003) there are a certain set of characteristics that educators of special needs children should have if they want to undertake the task of educating these children. This list of characteristics include; “a kind, warm and accepting nature, be firm, with a stable and calm personality, which must be maintained during a learner’s temper tantrum, negativism or any other undesirable behaviour” (de Nysschen, 2008: 75). Non-kin care-givers, de Nysschen adds, need to be able to think on their feet, to be adaptable and need high levels of energy to keep up with their charges. They also need to be willing to continuously learn about autism and keep up to date with the newest available information and intervention strategies. De Nysschen (2008) points out that most educators and facilitators in special needs schools are female and this ties in with the fact that historically nurturing roles fall within the domain of work considered to be ‘female work’. While the gendered nature of work is mentioned fleetingly by de Nysschen (2008), the gendered aspect of care-work has not been afforded much weight in the literature.

A theme which does run through the literature is that of stress within the non-kin care-giving role. Jennett et al (2003) note that educators and facilitators who are part of special needs schools may experience additional stressors as a result of the increase in their workload, managing individual learner’s needs, slower progress in lessons due to the disability and a more intense parent-educator relationship than a mainstream setting would require. In addition to this, de Nysschen (2008) points out that even though classes with children with autism are smaller than mainstream classes, non-kin care-givers of children with autism work

longer hours than their mainstream counterparts and they have a heavier workload as they tailor-make their lesson plans to suit the needs of the individual children in their class. One explanation, according to de Nysschen (2008) is that one child with autism is the equivalent of having six mainstream children and, as such, class sizes vary between six to eight learners at a time.

De Nysschen (2008) explains that each day with a class of children with autism is never the same. New challenges crop up and because learners vary in their severity of autism each situation cannot be handled in the same way. De Nysschen (2008: 107) thus points out that it is “very trying to deal with some of the learners”. What makes it especially difficult is the communication problems that non-kin care-givers are faced with. In a class with eight children, they are not all able to communicate on the same level and some lag behind and this inevitably slows down the learning process and could lead to the non-kin care-giver feeling frustrated with the process. Children are also not always able to communicate effectively verbally and this makes interaction very difficult as verbal communication is crucial to positive interaction (de Nysschen, 2008). This can lead to the teacher feeling frustrated as he/she is unaware if the child is able to understand and in turn teachers are oftentimes unable to properly understand the child and therefore meet his/ her needs. A common underlying theme which both Miller (2006) and de Nyscchen (2008) point out, and which stems from the additional stress, is that of mental and physical frustration and exhaustion. On the other hand, both these authors express joy and exhilaration when a child that they are teaching shows signs of improvement, of having understood and of having learnt something new.

Communication is one problem but odd and sometimes aggressive behaviour is also problematic, most especially so in the classroom setting where other children are involved. Non-kin care-givers, according to de Nysschen (2008), are responsible for the safety of children in their care and a violent outburst by one child is likely to affect others. De Nysschen (2008) states that working with a violent child is physically, mentally and emotionally draining, and also elevates the stress levels experienced by the non-kin care-giver. When a non-kin care-giver has a child in his/her care who is known for violent outbursts the non-kin care-giver has to be on guard for an episode at any time and this can leave one feeling on edge and anxious most of the time. Thus we find that the emotional well-being of the non-kin care-giver is at risk as a result of the constant bombardment of emotions experienced at any given time.

The literature thus points out that the role of the care-giver is a complex and ever changing one as the care-giver has many responsibilities to the children in their care. Due to the complexity of autism and the high level of care and intervention required, these care-givers are placed in high stress situations on a daily basis. However, while much literature has been written by parents and by experts for parents, there remains a limited pool of research from an analytical social science perspective which provides an in-depth analysis of the non-kin care-giving experience. In order to provide effective and long lasting intervention to children on the spectrum it is necessary to delve into the world of non-kin care-giver and obtain an in-depth understanding of their experiences; a key aim of the research undertaken for this thesis. The next section will detail the theoretical framework that will be used to analyse the data that was collected during the research process.

2.2. Theoretical Framework

Due to the fact that research focussing on the experiences of care-givers of children with autism is a relatively new area of research within the social sciences as a whole, and specifically within the discipline of anthropology, I opted for the use of grounded theory at the outset of this study. Grounded theory, first proposed by Glaser and Strauss in the 1960s, was considered to be the best approach at the outset of this particular study as it provides a framework for understanding and analysing the data as it emerges through the research process. In the case of Grounded Theory, the researcher thus generates theory from the data itself, without being confined by pre-existing models of analysis or, in other words, advocates ‘developing theories from research grounded in data rather than deducing testable hypotheses from existing theories’ (Strauss and Corbin, 1990: 4). The use of grounded theory thus permits researchers to look at their work in new ways, as by being simultaneously involved in data collection and analysis, Strauss and Corbin (1990) argue that researchers are able to control the research process and thus increase the analytical power of their work. Such a framework, which encourages the development of theory from research grounded in the information, is considered to be an excellent method of social analysis in the field of medical studies (Thomas and James, 2006) and it is indeed in the social studies of health that grounded theory was first conceptualised.

According to Strauss and Corbin (1990) human beings are not passive recipients of larger social forces; rather they are active agents in their lives. Human agency is thus important to acknowledge because the way in which people react to phenomena determines the direction which research takes, which in turn, impacts upon the development of the subsequent theoretical framework. Whilst society may teach its citizens to react in a certain way to

people with disabilities⁷, such as individuals with autism, the way in which people in close contact with children with autism (either through their working or living environment) act and react, is likely to be affected by a host of individual - as well as societal predictors - and one cannot therefore pre-suppose or hypothesise what the care-giving role entails. At the same time, while individuals are arguably active agents in their own right, one cannot negate the possibility that “society, reality and self are constructed through interaction” and that “interaction is inherently dynamic and interpretative” (Strauss and Corbin, 1990: 7). Symbolic interaction, a key aspect of grounded theory, is therefore a crucial component of this research as it acknowledges that people do not respond in an automated fashion to external stimuli, but rather, that thinking and reasoning shape interaction.

The use of Grounded Theory therefore enabled me to direct, manage, and streamline the data collection process and assisted in the construction of an original analysis of data (Strauss and Corbin, 1990). Grounded Theory has therefore been critical to this particular research endeavour as it allows for human agency and symbolic interactionism to be explored throughout the research process as the findings are analysed. The theoretical framework, which was not forced to fit into any specific theoretical mould, was then allowed to develop from the data collection and analysis process. Van Gennep’s (1960) ‘rites of passage’, coupled with Turner’s (1967) notion of liminality and Goffman’s (1969) concepts of symbolic interactionism and Spoilt Identity consequently emerged as important theoretical frameworks for this study.

⁷ This includes social disabilities.

In his work, *The Rites of Passage*, van Gennep (1960) looked at ceremonies which occur at important stages in an individual's life or at 'life crisis' events, such as death in the family, and he termed these *rites de passage*. Van Gennep (1960) was not interested in the actual actions involved in rituals and ceremonies; rather he was interested in their significance within the ceremony as well as in the relative order of things. Van Gennep (1960: 2) argued that "the life of an individual in any society is a series of passages from one age to another and from one occupation to another". Van Gennep (1960) argued that it is possible to differentiate between three main phases in any ceremony or indeed in life itself and these phases comprise: (1) separation, (2) transition and (3) incorporation.

Turner (1967), drawing on the work of van Gennep (1960), states that the phase of separation is marked by a symbolic action that signifies the detachment of the individual from a social structure, group or from cultural conditions. During the transition phase (or liminal phase) the individual finds him/ herself in a state of ambiguity as he/ she aims to navigate his/ her way through the new experiences to find a place within the social structure for him/ herself. The final stage, the phase of incorporation, Turner (1967: 235) asserts, is when the individual is once again in a stable state and has "rights and obligations of a clearly defined and structural type". As a result, the individual is expected, from then on, to behave according to a new set of cultural norms and ethical standards. According to van Gennep (1960) and Turner (1967) certain phases occur more prominently than others based on the particular situation yet the premise of the three phases can be ascribed to any major event or transition that occurs in an individual's life.

Van Gennep (1960) described the transition from one social position to the next as the 'opening of doors'. Within society there are several distinct social groupings and individuals

are able to move between these social groupings, either through a process of rituals or ceremonies; for example a wedding to mark a marriage, or through experiences. However, van Gennep (1960) argued that in order to pass between groups the individual must fulfil certain conditions that allow the individual to leave one group and be assimilated into the new group. In order to successfully pass into the new social group, the individual must exist for a period of time in an intermediate stage where he/ she will shed the old identity and markers associated with the group or former status and learn the roles ascribed to the new identity that he/ she will take on. Every change that occurs in an individual's life involves a series of actions and reactions which need to be regulated in order to prevent society from suffering any discomfort, van Gennep (1960) argues. Clearly defined stages of life; birth, social puberty⁸, occupation, marriage, parenthood and death, for example, mean that there are ceremonies which are used to help in the transition to each of these stages of life and allow the transition to be relatively easy. Turner (1967) terms these *critical moments of transition* and these are marked with observances so that the community members remember the events, for example, the celebration of birthdays and anniversaries. When becoming part of a new social group, the individual does not immediately become part of the group but must rather face a set of challenges that will allow for the individual to become part of the new group. Van Gennep (1960) termed these the rites of incorporation which occur through direct contact with the group.

The concept of rites of passage will be used to show how parents and non-kin care-givers of children with autism experience a rite of passage. The process begins with their journey into autism through diagnosis and working with children with autism respectively, which, in

⁸ Van Gennep argued that there was not always a biological link to puberty.

essence, separates parents and non-kin care-givers from mainstream society. These individuals during the transition phase begin to form a group through their common shared experiences of autism, and finally, in the stage of incorporation parents and non-kin care-givers are incorporated into the world of autism and arguably form an autism culture.

The emphasis that comes out of this is that individuals faced with a change from their previously ordinary lives are placed in a situation that is non-ordinary and must then journey to discover what will become the new ordinary for them. Graburn (1977) who also embraces the notion of a 'rite of passage' in his book *Tourism: The Sacred Journey* makes reference to the notion that in order to leave the ordinary, one must make a sacrifice which will serve to cut ties with the ordinary. This sacrifice can be seen in the choice of the non-kin care-giver to work with children with autism rather than with neurotypical children. Working with children with autism requires a different set of skills than those needed to work with neurotypical children and also involves leaving behind common understandings of how children behave and exist in the world. This 'sacralisation'⁹ then leads the individual to a non-ordinary state where the individual begins to have new experiences and assimilate these new experiences, accommodating them into their new concept of ordinary. Thus the process of 'desacralisation' occurs whereby the individual returns to an ordinary state, albeit a new sense of what is ordinary (Graburn, 1977). Graburn (1977) refers to meaningful events which he argued mark the passage of time and these meaningful events help one to gauge the length of the journey and show progress down the path. These events may become symbolic markers and can be used to determine success of the individual on the journey. Care-givers are able to share their journey because they share experiences and similar value systems.

⁹ Sacralisation is the process of leaving the ordinary.

To show how parents navigate their way into this space of autism two distinct theories, social cognitive theory and social identity theory, put forward by Bandura (2001) and Brewer (2001) respectively can be successfully applied to the study in addition to the work of van Genep (1960, Turner (1967), Goffman (1969) and Graburn (1977). Bandura's (2001) social cognitive theory is important for health communication. This theory looks at the cognitive, emotional and behavioural aspects for understanding behavioural change. It looks at a person's thought processes and previous behaviours and how these may influence behavioural change in a person in relation to the environment, people and their initial behaviour.

Social cognitive theory and social identity theory, when used in conjunction with each other, are able to provide meaningful insight into the way in which a person constructs identity as they enable us to see the individual's response to the social environment.

Brewer (2001: 115) argues that social identity theory "provides a link between the psychology of the individual, (the representation of the self), and the structure and process of social groups within which the self is embedded". Social identity theory looks at the socially constructed self; how one constructs individual identity in relation to those around them. Thus, according to Brewer (2001), one's social identity is constantly changing depending on the environment and the people around the individual and therefore may be constructed in a negative or positive way.

It is in this way that parents and non-kin care-givers of children with autism construct their social identity in response to the people who are around them and the availability of a support

group, for example, can make the difference between recognising oneself as a victim of autism or not. As such, strong mutual ties and group identity can yield positive results.

For Brewer (2001: 117), social identity represents “the internalisation of the rules, expectations, and the norms associated with specific social roles as aspects of the individual self”. The role of a parent, for example, has specific norms attributed to it; such as that of nurturer, provider, guide and teacher, and these roles are impacted upon when one is faced with autism.

As stated, Bandura’s (2001) social cognitive theory is concerned with the cognitive, emotional and behavioural aspects of understanding behavioural change. These internal processes can be linked to one’s individual self-concept and how an individual comes to see themselves and to see themselves as part of a group, in this case as part of the Autism Community. Social identity theory is the umbrella theory which is comprised of a number of different, but inter-related strands making up the composite whole. These strands include; person-based social identity, relational social identity, group-based social identity and collective social identity. For the purpose of this study person-based social identity, relational social identity and group-based social identity theories are important.

According to Brewer (2001) person-based social identity refers to the characterization of social identity that is located within the individual’s self-concept. This, according to Brewer (2001), refers to membership to specific social groups or categories and the shared socialisation experiences that membership implies. Brewer (2001) argues that the questions often asked are “What kind of person am I?” or “Who am I as” a (parent of a child with autism)? (Brewer, 2001: 118). For Brewer (2001), social identity is the acquisition of a sense

of self through ones socialisation and internalisation. In terms of this theory, people who are faced with raising a child that is different from other children can then base their self-concept on how they believe other parents see them.

According to Brewer (2001) relational social identity refers to an identity of the self as a certain kind of person. Here, argues Brewer (2001), a person defines him/ herself in relation to others. A parent of a child with autism therefore defines him/ herself in relations to parents of neurotypical children. For Brewer (2001) relational identities are co-dependent and the characteristics and behaviours that are expressed by an individual are dependent upon and are a response to the behaviour and expectancies of others in the relationship.

Group-based social identity theory, according to Brewer (2001), refers to one's perception of self in relation to being an integral and interchangeable part of a larger group or social unit. This theory, according to Brewer (2001), sees a move towards one's perception of self as an interchangeable example of some social category, (in this case a parent or non-kin care-giver of a child with autism), and away from one's perception of self as a unique person. Thus, identification occurs within the group as a whole, argues Brewer (2001). It is the experiences of having a child with autism, the understanding that there are a new set of rules that govern the way a parent interacts with their child that allows for entry to the Autism Community.

These theoretical frameworks will be used to analyse the data collected and will be explained further in Chapter 6 after the ethnography is detailed. Chapter Three serves to introduce the schools where fieldwork was conducted and the non-kin care-givers who were observed and interviewed during the research process.

CHAPTER THREE: AN OVERVIEW OF THE SCHOOLS

This chapter serves to introduce the two schools where I collected data through the use of participant observation. Here I will detail the backgrounds and structures of the schools, Durmstrang Institute for Remedial Studies and Beaxbatons Academy for Children with Autism.

3.1. Durmstrang Institute for Remedial Studies

“It is our mission to give our special children the confidence and hope for a better future through the specialised help they receive in a nurturing and caring environment”
(Durmstrang Mission Statement)

3.1.1. Durmstrang: The Beginning

The creation of Durmstrang Institute for Remedial Studies can be dated as far back as 1943 and was initially formed as a response to Cerebral Palsy. In 1952 a group of housewives began to raise money for a holiday home in Durban for Cerebral Palsied children. In 1955 a committee of twenty women and one man (who served as both Chairman and Treasurer of the committee) was formed under the name Durmstrang. The original concept was not that of a school but rather to allow the mothers of Cerebral Palsy children to be able to take a break from the demands involved in taking care of their children and also to allow the children to experience a holiday by the seaside.

The original premises, in 1959 accommodated twelve children and in addition to a holiday resort served as a diagnostic centre. Included in the services offered by the establishment were nursery school classes for the children, organised play sessions, speech therapy and an advice clinic for the mothers.

The establishment was funded solely by public donations and fundraising was a vital aspect of the running of Durmstrang. Fundraising for the organisation occurred through a sub-committee of the Durban Association for the Care of the Cripples. Over time the Natal Cripple Care Association was unable to maintain the costs of running the establishment due to the high running costs that were involved. The centre was then handed over to the care of the then Department of Education, Arts and Science and would follow the Special Schools Act. As a result of this decision the centre was then turned into a school and was governed by a different set of criteria than was previously the case. The diagnostic clinic and the holiday home that was part of the original centre, however, remained. By following the Special Schools Act admission to the centre was limited, for example, children who had an IQ below a certain level were not admitted to the school.

In 1964 the school officially began to operate as Durmstrang Institute for Remedial Studies. In those early days Durmstrang had a staff composition that included the principal, two educators, two nursery assistants, two physiotherapists (the school was still operating solely for Cerebral Palsied children), a speech and occupational therapist, a factotum¹⁰, a house

¹⁰ A 'general servant' is one who does many different and diverse jobs.

mother, a cook, a kitchen assistant, nine domestic workers, two labourers and a driver for the shuttle service the school offered the attending learners.

The number of learners enrolling at Durmstrang steadily increased and accommodation for the growing number of learners became problematic. As a result a larger school site was needed and the school moved to a larger and more open site north of Durban. This was not the final site as the school moved once more (within the same area) when changing infrastructure and accommodating an ever increasing number of learners became problematic. In 1979 construction of the new school buildings (at a cost of four million rand) was completed and this new school was designed to cater specifically for the requirements and needs of the Cerebral Palsied and learning disabled. Three hundred and twenty two learners were enrolled at the school when it re-opened in its new premises in 1979. There are currently around four hundred learners enrolled at Durmstrang and the current compliment of staff has grown considerably in relation to these numbers.

Due the fact that there was no other provision specifically for children with autism in KwaZulu-Natal, Durmstrang recognised the need to form a specialised Autistic Unit which consists of separate classes for children with autism so as to attend to their specific learning disabilities and therefore provide a more effective intervention strategy. There are currently seven classes within the autistic unit at Durmstrang.

3.1.2. Durmstrang Today

The school now caters for a fairly limited range of disabilities; these include Specific Learning Disabilities, (such as dyspraxia¹¹), autism, cerebral palsy and a few other rare disorders such as Prader-Willie Syndrome. Durmstrang believes that all children have the inherent ability to learn and to achieve in their lives and that these children should be given the chance to achieve their full potential while their unique qualities and characteristics are nurtured and encouraged. Durmstrang further believes that all children have the right to be respected, loved and to be appreciated.

The children attending Durmstrang range in age from three years old to seventeen years of age and they come from different backgrounds, races and religions. Admittance to the school is based on whether the disability the child has fits in with the range of disabilities which the school caters for. This is so that the children can be helped by the school system to the best effect. Durmstrang provides the learners with education that is, where possible, prescribed by the national curriculum. However, in most cases the school programme is modified to fit the individual child's needs and is then enforced with specialised support.

Durmstrang has an internal admissions committee and this committee oversees the applications of learners to the school. The admissions committee takes into consideration the learners recent school report (where the child has been referred to Durmstrang), a psychological assessment report, a motivation letter from the school that the learner is currently attending detailing why the child needs to be placed in a special needs facility and

¹¹ Dyspraxia is concerned with motor planning.

any other reports from relevant therapists that the child may have been to, for example occupational or speech therapists.

The professional team at Durmstrang is made up of educators, therapists (speech and occupational therapists), as well as remedial teachers. Education at Durmstrang is offered from the pre-primary school level to the Grade 7 level and those who have the academic capacity can complete Grade 7 and then move on into mainstream schools, or go to schools which cater for special needs and offer a matric qualification. The class size is significantly smaller than in mainstream schools so that educators can address the needs of each child individually. Class sizes vary from between 6 and 11 learners. The classrooms that I spent time in had either 6 or 7 learners. Depending on the nature of the disability of the learner, there are a few parents who employ private facilitators to assist their children at school. The school offers both academic programmes as well as life skills and craft programmes.

As noted, Durmstrang Remedial has a specialised Autistic Unit which caters only for children with autism. Durmstrang has seven separate classes for children with ASD and these classes have been grouped according to the age and level of progress of the children. During the research period I spent time observing the non-kin care-giver - child relationship in four of these classrooms. The children are taught as much academic work as they are capable of grasping as well as necessary life skills such as communication skills, self-awareness, decision making and emotional management. The focus of this research is on autism and care-giving and because Durmstrang has an Autistic Unit the school was ideal as a research site.

There are a total of seven educators in the Autism Unit at Durmstrang and each teacher is assisted by a facilitator. Three educators and two facilitators were interviewed from Durmstrang. All of the research participants interviewed are female. For the purpose of this research I will refer to the educators and facilitators alike as non-kin care-givers. These individuals have been at Durmstrang working with children with autism for varying periods of time; ranging from 2.5 years to 7 years. Two of the educators have been involved in teaching children with special needs for a longer period of time than they have been at Durmstrang and there was one educator, Pomona, who started her career with children with special needs, and especially children with autism, at Durmstrang.

3.1.3. The Non-Kin Care-givers at Durmstrang Institute for Remedial Studies

Of the five care-givers I interviewed from Durmstrang three had planned to work in the education field and, for various reasons, had ended up working with special needs children and then later with children with autism. The care-givers came to work at Durmstrang with varying degrees of experience in working with special needs children and particularly with children with autism.

Minerva, who works with children with varying levels of severity of ASD, has over thirty years of teaching experience, twenty eight of which were spent teaching in mainstream schools. Minerva says that “*when I was student in Cape Town, I always wanted to do special needs*” but due to circumstances¹² she was unable to do so. Minerva began working at

¹² Her mother did not want her to teach special needs children.

Durmstrang six years ago and although she had knowledge of autism from reading about it, this was her first time working with children with autism. During these six years Minerva says that she has “*come to love my job*”. Minerva has six children in her class, aged between six and eight years old; two of whom are girls and four are boys. Minerva has one facilitator to help her with her class. The facilitator helps Minerva with setting up the classroom for the different tasks, for example setting up the room for ‘arts and crafts’ or ‘table games¹³’. The facilitator also assists the children when they are doing certain tasks, for example when the children are painting the facilitator helps the children with the movements of the brush, or with other props, such as when using a potato to paint.

Minerva employs visual techniques in her teaching methods (for example flashcards¹⁴, and drawings with labels¹⁵), and believes in a hands-on approach to teaching. This was evident in the way in which she interacts with her children. Minerva sings with them, she dances with the children and she does one-on-one sessions with each child where she works side-by-side instructing the child at a pace that the child is comfortable with.

Pomona, another (educator) in the autistic unit at Durmstrang, has been working at Durmstrang for three years and has six boys in her class aged between five and seven years old. Four of her learners have been with her from the time she started working at Durmstrang, and the other two have been with her for one and two years respectively. Pomona has a

¹³ See Chapter 4.

¹⁴ Flash cards are a set of cards with words displayed on them.

¹⁵ Drawings of items, such as fruit, are labelled with the name.

facilitator working with her and her facilitator has been working at Durmstrang for two and a half years, having just become a permanent member of staff in 2011.

Pomona's teaching style is also very visual and this is common amongst the educators who work with children with autism. She, like the other educators, has a daily routine and this will be detailed later in the chapter.

During the interview phase Pomona expressed that growing up she did not always think that she would become a teacher let alone a remedial teacher. Unsure of what to study when she had completed Grade 12, Pomona says she "*thought I'll just study teaching and then see from there*". Pomona responded to an advertisement placed by Durmstrang in a local newspaper. She had little knowledge of autism aside from what she had picked up from newspaper articles and television. Pomona had thought that her lack of knowledge and experience would hinder her chances of successfully applying for the position at Durmstrang; however, she was told that a fresh mind that has not been introduced to negative information regarding autism is very helpful. Pomona then spent a week observing another educator's classroom environment and says that from that time she was "*pretty much hooked; fell in love with it*".

Sybil works with older children in the autism unit at Durmstrang. The learners in her class, at the time of research were all boys who are considered low functioning¹⁶ ASDs. Sybil has been at Durmstrang for five years and prior to this she had worked at a school in Durban that

¹⁶ Severely autistic

caters for children with multiple disabilities for eight years. Sybil stated that she has never seen herself working in any other area of education aside from special needs. The ages of the students in her class range from eight to seventeen years old. Sybil also has a facilitator to assist her with tasks in her classroom.

Isabel and Lucy are both facilitators at Durmstrang and have been at the school for five years and two years respectively. Isabel emphasised that she wanted to learn about early childhood development and had previously worked with a speech therapist at the school. Lucy was in need of a job and a friend recommended her to apply at Durmstrang and she has, since last year, been made a permanent member of staff. Isabel and Lucy's roles involve assisting educators with their day-to-day tasks and assisting the children during the day with their academic work, as well as assisting when children have a meltdown¹⁷ or tantrum.

Durmstrang Institute for Remedial Studies is a well-established special needs school in KwaZulu-Natal. Its current location lies outside of Durban and there is a fully functional shuttle service which ferries children to and from school. Durmstrang caters for children of school going age, and in the case of autism, the earlier the intervention is provided, the greater the chance of improvement for the child. This is where the next institution to be discussed plays a vital role.

¹⁷ This occurs when a child experiences some form of stressor or anxiety. For example being ill or if an unplanned change occurs during the day and the child is left feeling unsettled and lost. This may result in uncontrollable crying or violent outbursts such as biting and scratching.

Table 1: Information of Educators and Facilitators at Durmstrang Institute for Remedial Studies.

| Educator | Gender | Language | No of children in class | Teaching Experience in years | | |
|----------|--------|------------------|-------------------------|------------------------------|-------------------|-------|
| | | | | Mainstream | Special Education | Total |
| Minerva | Female | English | 7 | 28 | 5 | 33 |
| Pomona | Female | English | 6 | 0 | 2.5 | 2.5 |
| Sybil | Female | English | 8 | 0 | 13 | 13 |
| Lucy | Female | IsiZulu/ English | 6 | 0 | 2 | 2 |
| Isabel | Female | IsiZulu/ English | 8 | 0 | 5 | 5 |

3.2. Beaxbatons Academy for Children with Autism

Beaxbatons Academy for Children with Autism is a recently opened school in the Durban area. The school opened in April 2009 at the start of the second term of the school year. The major reasons for the creation of the school was due to a lack of resources and early intervention facilities for children with autism and their families in KwaZulu-Natal. As stated in Chapter One, early intervention programmes have been stressed in assisting children with autism because if autism is diagnosed early and treated accordingly then it is more than likely that the chances of the child improving, in terms of their level of functioning, is greater. In line with this, and due to the fact that there is a need for early intervention facilities for children with autism, Beaxbatons admits children younger than the school going age and as such the aim is to ready these children and equip them with the basic skills necessary for admission to schools such as Durmstrang. Beaxbatons aims to assist and

educate parents with knowledge and information about autism and the organisation does this by holding regular support groups¹⁸ and talks by professionals¹⁹ in the field of autism.

Beaxbatons seeks to provide quality intervention for children with autism up to 6 years of age and, in addition to this, provide support and resources to people with autism, their families and care-givers. Beaxbatons aims to create a nurturing environment of acceptance for the children and the school aims to create clear structures and goals for each child who is at the school. Beaxbatons works closely with the group Action in Autism, a non-profit organisation, and the provision of resources and support to family members and care-givers is one of the many functions of the organisation.

There are currently eight full-time staff members employed at the school. This is made up of the principal who doubles as an educator, one full-time educator²⁰, three facilitators, two assistants and one administration assistant. In addition to these permanent staff members, the school also has a speech therapist and an occupational therapist who work at the school once a week for four hours.

¹⁸ Support groups are available for parents and siblings of children with autism.

¹⁹ Professional refers to psychologists, therapists or specialist doctors.

²⁰ At the time of the interviews, there were two educators present and the principal assisted these educators when the need arose. One educator has since stepped down from her position however she is still involved with Beaxbatons and provides the current staff with training on a weekly basis.

Beaxbatons Academy for Children with Autism provides intervention for children with autism across the social, emotional, physical, cognitive and communication aspects of development. There are two classrooms that are in operation at Beaxbatons. The children in Fleur's class have some verbal communication skills (they are able to speak words and interact verbally), whilst the children in Romilda's class have either limited speech or are non-verbal. Beaxbatons utilises a variety of techniques and approaches to tailor individual programmes around individual children and their unique needs. Independent Education and Development Programmes are created through a collaborative effort with input coming from the parents of the children, the speech and occupational therapists, the educators and the facilitators. The approach to designing the programmes implemented at Beaxbatons is a team approach and is crucial in the implementation of Independent Education and Development Programmes. The idea behind this programme is based on the premise that each person involved in the education and care of the child has an important role to play and important information to offer and parents act as the 'child's advocate'. The programme is structured and child-centred and does not advocate one particular approach. Designing a programme that is tailor made to meet the requirements of each child's needs means that the propensity for improvement and advancement on the part of the child is greatly increased. Specialists such as occupational and speech therapists conduct classroom observations of the children and make recommendations for each child based on their observations. These therapists also work with the children for individual therapy for half an hour twice a month. The school regards this as a multidisciplinary approach that encourages role release and role transfer²¹ between groups of professionals and parents.

²¹ Assigning specific tasks and methods that are usually performed by one person on a child's team to other team members, in this case the parent.

3.2.1 The Non-kin Care-Givers at Beaxbatons Academy for Children with Autism

Beaxbatons Institute for Children with Autism is not as large as Durmstrang and has two classes for children with autism with seven children in each class. At the time that I was conducting participant observation the educators were Fleur, Romilda and Lavender. Lavender is the principal of the school and she also took on the role of an educator when necessary. Fleur and Romilda were the two specified educators but Fleur has since stopped teaching full-time and has taken up a role involving training the current staff at Beaxbatons. These educators each have varying degrees of experience and each bring something different and new to their classrooms. The educators come from different backgrounds and have different levels of experience. All of the staff at Beaxbatons are female except for the administration assistant.

Lavender has not always worked with children with autism, but the knowledge that she gained from reading up on and following autism spawned her initial interest in the condition and led her to obtain her diploma in remedial teaching. Lavender has, however, always had an interest in autism, *“since the early 1970’s, ever since I had met one of my mother’s friends who had two children on the spectrum and (I) started reading about it”*. Lavender recalls early writings on ASD with regards to ‘refrigerator mothers’ and the importance of the child bonding with the mother in order to lead a fulfilling and fully functional life. She kept up with the trends in research on autism and explains that her own son *“had a speech and communication disorder and it lead me to identify and understand what it was like for children who had no voice, who could not communicate. How terrible and scary the world was”*. Lavender spent twelve years teaching at a remedial school in Durban. The school that Lavender taught at did not have an autistic unit, however, Lavender explains that there were

children who were placed on the spectrum, though these were mainly children who were diagnosed with Asperger's Syndrome as opposed to classic autism. Lavender further states that she "*always worked quite well with kids with behavioural problems*" and her experience with her son, she maintains, has allowed her to understand the children she works with more easily and also helps her to identify with the parents as she says that she knows what it is like to have "*a child with socially inappropriate behaviour*".

Fleur has the most experience in working with children with autism of all the research participants interviewed²². Fleur studied drama and education whilst at university and had experience teaching children prior to working with children with autism. Fleur lived and worked in London after she qualified from university and says that she has also taught "*in a school where there were children with autism as well, for a short time*". Fleur had not planned to teach children with autism on a permanent basis but when she returned to South Africa she needed a job and took a position as a tutor to a child with ASD when the opportunity presented itself. Fleur had wanted to become a writer, something which she has achieved, in addition to working with children with ASD.

Romilda, the youngest research participant, would have been a physiotherapist had her "*passion for children*" not steered her in the direction of teaching. Romilda has seven children in her classroom and she has three facilitators to help her with her daily tasks and with the children because the children whom Romilda teaches have classic autism and, as a result, have either very low verbal skills or are non-verbal.

²² Including those at Durmstrang.

Romilda is still in the process of completing her teaching degree. Romilda stated that she has “*has always been the babysitter type*” and knew that she wanted to work with children but not necessarily with those with specials. Prior to working at Beaxbatons, Romilda worked with atypical²³ children (aged between two and six years of age) at an early learning centre in Johannesburg.

During my research period at Beaxbatons, I spent most of my time in the classroom with Romilda following her daily schedule. On my first visit to Beaxbatons, Romilda was away for the day because she had an exam to write and I was allowed to sit in on her class with the facilitators and help them with their tasks. On my following visit to the school I divided my time between Romilda’s classroom and Fleur’s but then decided that it was best for me to remain in one classroom as that would enable me to gain better rapport with the children. This was important because the children are low functioning and my presence was a distraction for them at first but by remaining in the same classroom each week the children became more comfortable with my presence and grew to be less distracted. During the time that was spent in Romilda’s classroom I was allowed to interact with the children and do some of the duties that a facilitator would do. This also allowed me to observe the non-kin care-givers more in-depth as I became familiar with them and they became more familiar and comfortable with me. I was able to observe the way in which Romilda and her facilitators interact with the children; the duties they carry out and how they work with the children while at the same time learn first-hand what working with children with autism is like.

²³ Not fitting a single diagnostic category.

Routine for children with autism is extremely important as has been mentioned in the previous chapters. Each school follows its own set of daily routines that are applied in different ways to assist the children who attend the schools in learning and improving their abilities. The next part of this chapter will detail the daily routine as carried out by non-kin care-givers at Durmstrang and Beaxbatons respectively.

Table 2: Information of Educators at Beaxbatons Academy for Children with Autism.

| Educator | Gender | Language | No of children in class | Teaching Experience in years | | |
|----------|--------|----------|-------------------------|------------------------------|-------------------|-------|
| | | | | Mainstream | Special Education | Total |
| Lavender | Female | English | 0 | 0 | 13 | 13 |
| Fleur | Female | English | 7 | 0 | 15 | 15 |
| Romilda | Female | English | 7 | 1 | 2 | 3 |

3.3. Daily Routine

3.3.1. Daily Routine at Durmstrang

Every school system has a structured time table and the same goes for Durmstrang. The school day typically begins at 8:00 am and finishes at 12:00 pm. Some children stay after the school day is over until their parents arrive to take them home and other children make use of the transport service that the school offers. The difference in the structure of teaching is that the type of subjects that are taught at the school are not taught in the same way as they are in schools for neurotypical children. As noted, the children with autism at Durmstrang do not

follow a nationally prescribed curriculum but rather educators create their own curriculum that is specific to the needs of the children they teach. Furthermore, as stated in previous chapters, children with autism are rigid and prefer routine over spontaneity. This means that daily tasks need to be structured and adhered to at all times and each classroom therefore has a structured timetable of what to expect for the day. Children with autism are more visually responsive and the daily schedule thus has pictures of tasks and activities which set out what will be happening for the day.

Sybil says about the daily routine: *“everything has to be structured so before they come in the morning you need to know what you're going to be doing for the day. You can't on the day decide this is what you're going to do. Everything has to be structured, your classroom has to be structured which makes your day easier when the children know what they're doing. We also follow a timetable, we follow routine.”*

The educators try their best to stay on schedule as this makes the day move easily and it is in this sense that my research participants stated that their days are very much the same. However, what they cannot account for are the reactions of the children on each and every day. Sometimes a child may have a bad day or a child may be sick and this will impact on the way in which the child behaves in the classroom situation. Accordingly, Sybil thus stated that *“sometimes it changes, sometimes you have power cuts, sometimes another child plays up but basically what you plan may not work out completely and you may not get to each child individually but each child gets to do what they are meant to do for that day”*.

3.3.1.2. Minerva's Daily Routine

To illustrate the type of layout that is the routine of a day in one of these classes, I will describe how Minerva has her day planned out and how the children are aware of what will be happening for the day. Minerva has one facilitator with her in the classroom and the helper aids with the children and with the classroom tasks. She has a class schedule²⁴ which outlines the tasks for the day as well as individual schedules²⁵ for each child which allows each individual child to know what it is that they are meant to be doing during the course of the day. The class schedule does not change too much during the week with only certain aspects changing each day; for example depending on whether the children will have music classes or a baking class. The school day begins at 8:00 am and ends at around 12:30 pm however some children do stay for after care. A typical day begins with 'play on the mat'; which begins at 7:30 am and is done while Minerva waits for the children to get to school. This keeps the children occupied until the official class is ready to begin. One type of game that I observed Minerva having her class play was a type of 'shop game'; where she would have a small table laid out with different types of fruits and vegetables and each child would have a little shopping basket and a shopping list and they would pretend that they are in a shop and are buying fruit and vegetables. While this was done as a game, this is in fact a very important life skill which aims at teaching the children specific skills which will enable them to function somewhat independently in their later life.

²⁴ Appendix 1

²⁵ Appendix 2

The next item on the schedule is 'circle time'; and this starts at 8:00 am. During this period the teacher sits in a ring with the children and does daily interaction exercises for example singing a song saying 'hello' to each member of the class who is present on that day. Other activities that make up 'circle time' include naming the day of the week and doing the weather. For these exercises one child is used as the 'helper' for the week and he or she will come forward and name the day of the week and check the weather (this is done by the child looking out of the window and seeing whether the sun is out, or if it is raining for example). 'Circle time' includes the children learning about a particular letter of the alphabet every week and depending on what letter the children are learning about, Minerva has a small table with objects which begin with that particular letter of the alphabet and the children will learn about these objects and learn to name them. During 'circle time' Minerva also plays an alphabet song which the class sings along to.

After 'circle time' the children then go on to 'table games' or 'arts and crafts' at 8:30 am. During 'table games' the children do various puzzles (which encourages creative thinking) and Minerva then takes each child for individual instruction where the child works with her out of the work books which she has prepared, individually, for them. The children then have 'toilet time' followed by 'tea time' after which they go off to the playground at 10:30 am and enjoy the jungle gym, sand pit and swings²⁶. After the playground the children come back to the class, have 'toilet time' and then attend further lessons, and these, again, differ depending on the day, for example, they may have 'music time', 'story time' and then eat lunch. Lunch is generally followed by 'brushing teeth', 'sleep time' and then the children either leave to go home or wait in after care provided by the school until a parent arrives to take them home.

²⁶ Appendix 3

As mentioned previously, each child has his/ her own schedule which is incorporated into the general schedule but allows for individualised activity and therapy such as when a child has to go for speech or occupational therapy. These schedules are made visual through laminated pictures depicting the activity the child will be doing and these pictures are then stuck with Velcro onto a strip of Velcro on a wall. Thus, while the main schedule has specific times allocated to each activity, so too will the individual schedules. At the time that the child has an appointment with a therapist, then instead of ‘table games’ for example being on the schedule the picture depicting therapy will be in its place or before the ‘table games’ picture. This is done so as to avoid confusion for the child as the children follow their individual schedules more closely. The child will go to their own schedule and see what it is that they should be doing and then pull the picture off and put it into an envelope below their schedule once they are finished with the activity. During ‘table games’ the children have a similar visual schedule on their tables which outlines whether they will be doing puzzles or drawings in that time. The reason for this is so that each child is doing a separate activity at any given time at the table and this ensures that the children do not conflict with each other. Thus, while one child is painting, another will be doing a puzzle and another will be doing a drawing or colouring. The educators try their best to keep in line with the daily schedule and maintain the routine which structures the class and children's activities as doing so optimises the learning potential for autistic children.

3.3.2. Daily Routine at Beaxbatons

The educators have stressed throughout not only the interview process but also while conducting participant observation that routine is very important for children with autism.

Romilda and Fleur both have a daily schedule²⁷ which plans out the day and the children each have photographs of themselves with their names on the photographs which they place under the task they are doing. As part of my research I spent my time in Romilda's classroom. Romilda's day starts at about 7:30 am and runs through to about 12:00 pm. When the first child comes in, the first thing that is done is to 'brush' the child. This entails using a soft brush to brush the child on each arm, each leg and on the back ten times. The brushing technique which entails slow and even strokes on the child, Romilda explains, serves to calm the children down.

Once all the children arrive, usually by 8:30 am (although the school day officially starts at 8:00 am it is not always easy for parents to get their children ready for school so early in the morning and waking them up, parents have stated, can be a difficult task) and each child has been brushed, Romilda then has a 'circle time' with the children where the children sing songs and go through the days of the week. The day then continues with the children doing various tasks, some of which are doing puzzles, playing with play dough, and using building blocks. There is also a set time for the children to go to the toilet, although if they need to use the toilet at any time they know that they just need to indicate to the educator or helper with them. This is very similar to Durmstrang and the routine that is set out by the educators. One of the key differences is in the tasks that the children are given to do as the children at Durmstrang are higher functioning in terms of verbal and motor skills in comparison to the children at Beaxbatons. The educators at Beaxbatons make use of a schedule as well; however, they use one schedule for the whole class as opposed to class schedule and individual schedule used at Durmstrang.

²⁷ Appendix 4

The children also have time outside referred to as ‘bikes and balls’ where the children play on push-bikes, kick balls and there is a hammock-sling²⁸ which the children love to play in because they are able to get into the hammock-sling and be completely enveloped by the soft and stretchy material which holds the child very snugly. Each day, as long as the weather allows (no rain or it is not too cold) the children spend about 15 minutes outside playing on the bikes, throwing the balls around or playing in the hammock. This is unstructured play and the children choose whichever item they like and play with it and this also serves as exercise for the children. The children then go back into the classroom and attend further lessons until 10:00 am when the children then go outside for snack-time before going back into the classroom for the next round of activities. Romilda also sets time aside for one-on-one consults with each child where she works on specific tasks such as motor co-ordination.

This chapter has served as an introduction to the institutions in order to outline the mission and purpose of these schools in providing care and education to children with autism. In addition to this it is important to understand the background of the non-kin care-givers who are directly involved in caring for, nurturing and educating children with autism in order to better understand the work that they do. Building on the information presented within this chapter, the following chapter will detail the experiences of non-kin care-givers in relation to working with children with autism.

²⁸ See pictures in Appendix 5

CHAPTER FOUR: THE EXPERIENCES OF EDUCATORS AND FACILITATORS AS NON-KIN CARE-GIVERS TO CHILDREN WITH AUTISM

This chapter will discuss the experiences of the non-kin care-givers interviewed and the interviews will be coupled with participant observation carried out at the schools in order to provide a holistic analysis of the non-kin care-giving experience. A number of themes have emerged from the research process and these will be discussed within the chapter. These themes include: (i) characteristics required to work with children with autism, (ii) the stress and challenges associated with working with children with autism, (iii) the highlights of working with children with autism, (iv) the personal impact of working with children with autism, (v) support systems, (vi) the non-kin care-giver and parent relationship and (vii) motivating factors to continue working with children with autism.

4.1. Characteristics Required to Work with Children with Autism

Throughout the interviews with the non-kin care-givers, it became apparent that teaching children with any form of special need is very different from teaching children with no disability (whether physical or mental).

Due to various circumstances, all of the non-kin care-givers have come to teach children with special needs whether they had planned to or not. Five non-kin care-givers expressed that they specifically chose to work with special needs children and the remaining three started working with special needs children as a result of circumstances. What became very clear through the interviews was that these educators stated that there were certain personality

traits that one needed in order to work with children with autism. These characteristics were also easily identifiable throughout the research process when I spent time at the schools, observing the non-kin care-giver relationship between the educator and the learner and these characteristics closely mirror the characteristics outlined by de Nysschen (2008). According to de Nysschen (2008:75) an educator should have “a kind, warm and accepting nature, be firm, with a stable and calm personality, which must be maintained during a learner’s temper tantrum”. Similarly some of the characteristics that my research participants specified included; patience, calmness, flexibility, an ability to see things from the child's perspective, be the type of person who is prepared and who can maintain a schedule (because children with autism prefer routine), have a sense of humour and be the type of person who is not easily stressed out.

4.1.1. The Educators and Facilitators at Durmstrang

During my time at Durmstrang, I witnessed each of the educators involved in the research process display the characteristics outlined in 4.1. The educators who were part of the research process vary considerably in age (ranging from as young as their early twenties to their late fifties) and each individual brings something different to her classroom. When I first met Sybil, who teaches lower functioning children at Durmstrang, I found that she had a warm and mothering type of approach with her students. She displayed patience with learners who do not have much speech and her gentleness came through in her interactions with her children.

Non-kin care-givers take their roles very seriously and often, both during and out of interview sessions, educators referred to the children they teach in very personal ways, for example as "*my boys*". The non-kin care-givers who were interviewed viewed the children as their own as they felt that because they spent so much of time with these children they formed a strong bond with them, "*because you're with them all the time you become attached*".

Minerva has a similar approach to Sybil in her teaching. She is light hearted in her teaching approach and she is high spirited in terms of the way in which she interacts²⁹ with her children. Minerva, having taught at a mainstream school, explained that all aspects of teaching are very different and that while teaching in general is not an easy job, teaching children with autism is more of a challenge. Minerva also displays a warm, motherly type of affection towards her children and would often refer to the children in her class as "*these are my kids*". When a child would get upset about something, perhaps if something did not go according to the class schedule and the daily routine was put off course, Minerva would take the crying child into her arms in a firm hug and hold the child, soothing him/ her until he/ she calmed down.

Pomona ran an interactive classroom with her younger children as well. When faced with a child who was being aggressive, Pomona would display firmness in her approach to dealing with the aggressiveness and then would patiently try to find out what it was that was troubling the child. There have been instances when one child did not like the attention that

²⁹ One of the activities that Minerva does with her children regularly is dancing. This assists with motor co-ordination.

another was getting from the non-kin care-giver and would lash out as a result. Pomona says that it is important to stay calm and try to find out what is troubling the child and to find a way to sort the problem out. She said that sometimes it can be the “*smallest thing that will set a child off*” and “*because he has difficulty in expressing himself it can manifest in a form of aggression and taking yourself too seriously around these children will not help matters at all either*”. On one particular day one of the learners in Pomona’s class was having a bad day. He was upset and restless and would not listen to Pomona or her facilitator and neither could understand what the problem was. They found out a few days later that he had the flu and in the days leading up to his sickness he had felt irritable because he could not tell anyone that he was feeling sick.

During my research period at Durmstrang I would spend the morning with Minerva, observing her morning routine as this was usually the busiest part of her day, and she would often encourage me to join in on their singing and activities for the morning. On one occasion Minerva let me in on her one-on-one time with her children and allowed to me to try and work with a child and to see if I could manage it. This gave me an opportunity to gain insight into what these women do on a daily basis. Initially I was very anxious about doing this, but after spending time trying to do a puzzle with one of the learners I was able to glimpse, even if only on a small scale, the type of patience and care that one needs in order to work with children with autism. I have often taken it for granted that if I was to instruct a child to do something that the child would understand most of what I was saying and would then be able to easily carry out the task. But in this situation, with this child, I, being a naturally impatient person, had to force myself to slow down, take a step back, and let the child lead. I had to bring out the patient side in me and I had to seek a way in which to help the child with his

puzzle by giving him the simplest set of instructions I could think of. I had to realise that if he wasn't understanding me it wasn't my fault and nor was it his, rather I had to remain calm and stay firm in getting him to concentrate and complete the puzzle when he wanted to run off and play rather than do his work. This little exercise taught me that to work with children with autism one needs to be the type of person who is foremost patient and calm, who is not easily stressed out and who has the ability to get down to the child's level in order to get the child to understand the task or instruction. These are the qualities that these women have and this calm and easy-going nature ensures that the children are seen to as best as the non-kin care-givers possibly can.

4.1.2. The Educators of Beaxbatons

Like the educators at Durmstrang, some of the characteristics that my research participants at Beaxbatons felt were important for a non-kin care-giver of a child with autism include, in the words of Romilda, someone who is “*calm, patient, positive and true*” which reflects an overlap with the literature (see Miller, 2006; de Nysschen, 2008). Romilda explains that there are sometimes situations in the work context which an educator is faced with that may be frustrating because a child does not want to do what he/ she is asked to do or is having a bad day. The child may, Romilda continues, become aggressive but when you work with children like this then you need to be patient and be able to maintain a calm exterior at all times. An example of this can be seen when a child, Neville, returned to school after a few weeks away. Neville refused to enter the classroom and when the non-kin care-givers tried to get him to go into the classroom he bit, scratched and kicked the non-kin care-givers because he did not want to be in the classroom. In this situation the non-kin care-givers needed to be patient and

often the response to a child who is having a physical breakdown is to firmly hold the child in a bear hug until he/ she calms down. Romilda says *“you have to have so much patience, you have to remove your frustrations and leave it outside your classroom”*.

Fleur regards being tolerant and understanding as very important and says that one needs to have the *“ability to step out of yourself and step into the child’s headspace... what we take for granted, the children need for it to be broken down into very small steps”*. Fleur believes that it is important to be able to try to view things from the child’s point of view as this can be helpful in aiding the child to carry out daily tasks. Fleur also asserts that when working with a child with autism one should not go to the extreme of doing everything for the child when he/ she is having difficulty with certain tasks, rather *“support him on this number of levels but he’s going to meet me halfway, trying with me”*. For example when doing a task such as threading a shoe lace, rather than doing it for the child, non-kin care-givers would hold the child’s hands and guide them through the first few attempts and then let the child continue on his/ her own afterward.

Essentially, Fleur maintains that non-kin care-givers are there to equip children with autism with the life skills that will enable them to live their lives as completely as possible, and so, in this manner, educators need to be firm with the children they teach and make sure that these children are able to learn to function as much as possible on their own. When teaching the children, the educators and facilitators ensure that their learners pay attention and attempt the tasks laid out to them and if a child does not want to pay attention then the non-kin care-giver steps in to make sure that the child is focused. One child, Justin, has a habit of running

around the room. Lavender had decided that she would sit in on the class and during a puzzle exercise Justin took off and would not let any of the non-kin care-givers take him to the table to work. Lavender recognised that this is how he tries to get out of doing work and she chased him around the room until she managed to stop him. Lavender then took him to the table, sat him down on her lap, held him around his chest and said that if she couldn't get him to do the actual puzzle she would start by getting him to sit still for a while.

As stated in the previous chapter one of the activities that is done as soon as the children start their day at Beaxbatons is the 'brushing' activity which aims to create a sense of calmness in a child as well as making the child aware of bodily boundaries. The brushing technique may sound very simple and easy to do; however, I was tasked with brushing a child on one of the mornings and found that it was not as easy as it looked. I began by rolling Blaise's sleeve up so that I could begin to brush his arm, and every time I rolled his sleeve up and ran the brush down, Blaise would use his other hand to pull the sleeve of his shirt down again. This was the same for when I brushed his other arm and so a task that should have taken me less than five minutes took me longer because I had to try and keep Blaise's sleeve up with one hand and hold his arm at the same time and then run the brush down his arm. Brushing his legs was easier because I was able to balance each foot on my own legs and brush him quite easily. Brushing Blaise's back was a more difficult because I had to try and keep him leaning forward so that I could run the brush down his back. This became a game of peek-a-boo as I would pull Blaise forward and then he would giggle and then pop his head back to look at me and giggle some more. While brushing Blaise was a relatively easy task, by comparison, I realised that this is not an easy task to do with a child who is having a bad morning because if

a child is unresponsive then brushing can be difficult as it is hard to keep the child sitting still.

Beaxbatons has two hammocks in the courtyard in between the classrooms and the children especially like the hammocks. Lavender showed me how a few of the children enjoy being wrapped tightly within the hammock and spun around. I would often spend time at the hammock helping the children in and out of the sling and then twisting the hammock around them forming a tight cocoon and then unwinding it. After doing this a few times it became a tedious task, however, the children loved being spun around in the hammock, or simply using the hammock as a swing, and I had to remain patient and oblige them. When I was drawn into the activities of the teachers, even if only for a short period of time, I became acutely aware of the patience required to work with children who require routine but who, at the same time, are unpredictable in their behaviour.

4.2. Stress and Challenges Associated with Working with Children with Autism

De Nysschen (2008) argues that the education environment is a stressful profession, and this is regardless of whether an educator is in mainstream teaching or in special needs teaching. She further argues that educators need to be "aware of their emotional well-being, they need to be sensitive to their own emotions, and be able to manage their own emotions as well as others" (2008: 66). A dominant reason why teaching is deemed to be a stressful profession is that educators are dealing with young individuals and are tasked with providing learners with not only academic information but also with life skills. When teaching children with autism educators have the added task of trying to get through to the individual child who is placed

within a group of children with autism (each with their own level of functioning and individual issues) and to teach the children the most basic skills that others often take for granted. This can be a very taxing and stressful task and educators need to have a way to cope with the situation that they find themselves in, as alluded to by my research participants.

4.2.1. The Auditory Challenge

Fleur says that on an *“auditory level there are lots of sounds and it is quite different from working one-on-one with a child at home”*. It is sometimes hard for her to deal with the noise but she says that having others to help her with the children makes a difference. When she goes home Fleur says that she enjoys the quietness of her home. Fleur explains that when a child has his/ her first intervention³⁰ away from his/ her parents and the safety of the home, this can be very trying for the child and *“sometimes you have this constant screaming”*. Fleur recalls a child who *“screamed for three weeks before she settled down... scream and cry and fight and I would have to sit with her until she calmed down”*. Fleur recognises that this is something that a child may go through because it is a big change to suddenly have to go to a new place and be away from home and familiarity. She explains that after the initial shock, once the children get used to the routine of coming to school, *“they are a joy”*. The easiest way to cope, says Fleur, is to *“relax about it”*. By doing the same tasks in the same order repeatedly, children begin to get into a routine and after a while they settle down and become used to the daily activities. Sometimes Fleur sits with the child just to offer a sense of

³⁰ Intervention refers to learning skills away from the home environment and in a classroom setting. These can be academic skills such as writing and basic mathematics.

reassurance and she also says that “*if I have to take the child off for a walk it’s okay, if it’s a beautiful day then walking with the child is just as good as staying inside*”.

4.2.2. The Challenge of Dealing with Aggression and Not Taking the Child’s Reaction Personally

There have also been instances when a child has physically hurt the non-kin care-giver when throwing a tantrum. On one of my visits to Durmstrang, I was with Pomona who showed me a dark purple bruise on her hand and she explained that one of the children had had a particularly rough day as he was not feeling well³¹ and that he had bitten her while she was trying to hold him and calm him down. As de Nysschen (2008) points out, educators need to be able to manage their emotions well and remember that when a child acts out that this is not a personal attack on the educator but rather a symptom of something else upsetting the child which the educator needs to decipher. Pomona explained to me this notion of not taking the child's reaction to you personally, and she stated that she often tried to find the humour in particularly frustrating situations in order to cope with the situation at hand. Humour was Pomona's way of dealing with any stressful situation that presented itself to her; “*just laughing. If you don't laugh about it then you're just going to get depressed*”. On one occasion when walking to the playground, Pomona was walking with Oliver and he suddenly hit her on her hand. Before she could do anything or ask him why he had hit her, Oliver stopped walking and proceeded to reprimand himself in the third person, even shaking his finger in front of him with a very serious expression on his face. Pomona looked over at me, shrugged and laughed.

³¹ The child was coming down with the flu.

Sybil further mentioned that aggressive behaviours are a challenging part of the job and noted that since she teaches older boys this can be quite problematic. In this respect, Sybil stated that the use of a reinforcement system can help in improving the negative behaviours of a child or even with fixations that a child may have. Sybil says "*we monitor them and we use, for example, a star chart or reinforcement. Like at the moment Paul is going through difficulties and he's got a rugby shirt, that's his thing now, rugby is on his mind now. He has obsessive behaviours. So we will say to him, if you do this for Monday, Tuesday and Wednesday, no teasing the children, then on Friday he gets to wear the rugby T-shirt*". Pomona, like Sybil, makes use of a reward system and during her 'circle time' she rewards her class with sweets if they answer a question correctly. She also uses stickers which her learners wear proudly on their hands or forehead. During one session Jack did not listen to Pomona and her facilitator Wendy when he was asked to remain seated and as a result Pomona did not let him have a sticker. He was upset at first but he then tried his best to behave afterwards.

4.2.3. The Challenge of Dealing with Routine

The repetitiveness of the daily routine is another factor that non-kin care-givers found to be a challenge. Each day consists of the same tasks at the same time of the day but non-kin care-givers have explained that this is their job and they have to do it properly. Routine is very important to the children and there is no room to decide on the spur of the moment to do a new activity that has not been planned. When something happens that results in a deviation from the schedule, it can lead to a child becoming upset. This was something that I observed, on a few occasions, during my time in Minerva's class. For instance, on one particular day

Rose, a six year old with high functioning autism, was delayed at therapy and when she got back to the class she was expecting to do a particular activity but had missed it as a result of going to therapy and was extremely upset as a result. This was an occasion where I observed the type of motherly affection that I mentioned previously. Minerva gathered the little girl up into her arms and cradled her, rocking the child back and forth in order to calm her down and get her to relax. Minerva remained calm throughout the entire time and sat with the little girl until she had calmed down and was able to continue with the day.

The importance of the routine of tasks for the children is also apparent when Romilda says “*one of my kids has a problem with change and he needs that visual schedule to know what’s next... missing something out is huge unless you prepare them*”. With this child Romilda explains that she has to take him to the schedule each time to show him what is to be done next to reassure him and if something is going to change for the day, for example if it is the day that the speech and occupational therapists are coming to the school, then Romilda has to remind him by taking him to the schedule during the day and showing him that there will be a change in the schedule for that day.

Although each day is planned out with specific tasks, Romilda echoes the sentiments of Pomona and Minerva and explains that the day does not always go exactly as planned because “*some days it’s so calm and so positive... all the children are cooperating... and then you get days where you can’t even keep them in the classroom*”. Minerva, having previously worked in a mainstream setting, initially found it difficult to adjust to the repetitiveness of the routine but has found that through the activities that she does with her

class, for example painting exercises, the non-kin care-givers are able to have creative freedom. While the general tasks outlined for each day may be repetitive, non-kin care-givers have stated that it is the children who make the day interesting because of the things they do. During 'table games' in Minerva's class Rose was given a matching puzzle to complete but instead of matching up the pieces Rose decided that she would sort them into cupcakes, cakes, biscuits and sweets and when it was time to put the puzzle away she said to me that she was baking cookies and they had to go in the oven (the box). So what would have been an ordinary, daily task was turned into something more interesting.

4.2.4. The Challenge of Deciphering what is Upsetting the Child: Communication and Sensory Issues

Emotionally the job can thus be very stressful and sometimes children are unresponsive or they are too active³² and non-kin care-givers need to be constantly alert to changes in the child's attitude and behaviour in order to understand what is going on with the child and what the child is trying to say or do. There are often times when an educator will be faced with a child who is having a particularly bad day and they have to find out what it is that is troubling the child. This is not always an easy task for these educators who are working with children who do not have the language capacity to explain the way they feel and what is bothering them. This can make a person frustrated and requires a lot of patience. Pomona describes an incident with a learner who was on the school bus and had left a toy in the classroom and he was very upset, she says "*you've got to work that out, you've got to figure it out, that's the fun part (laughs), and sometimes you can't figure out what happened, and it could be a funny smell or it could be because my hair is different, but you have to figure it out because these*

³² Children with ASD are often diagnosed with ADHD as well

kids aren't throwing tantrums because they can, they do it because for them, something is not right".

Children with autism have difficulty communicating (both verbally and physically) and with language and this means that communication between educators and learners is not always easy and can present a challenge to educators during the course of the class. Each learner, as de Nysschen (2008) states, brings his/ her own set of autism related issues to the classroom and educators need to find a way in which to deal with and manage these differences. During an incident on the playground at Durmstrang, one boy became aggressive with the other children and Pomona called him over to her to ask him what was wrong and why he was behaving badly. This learner had only recently begun to speak in full sentences and in his excitement his words would not come out clearly but were rushed and mixed up. Neither of us could understand what he was saying after repeatedly asking him. Pomona could not let him go back to the group so she instructed him to sit with her until the end of play time.

Isabel, likewise, relates that communication can sometimes be problematic, especially with children who are low functioning and have trouble expressing themselves verbally. Like Pomona stated earlier, the challenge then, Isabel says, is trying to work out what it is that the child wants or is trying to say to you; *"you have to start out small, pointing at objects, maybe like a toy and if that doesn't work then maybe you can use pictures, but you have to keep going until you find out what it is that the child is trying to tell you"*. This is something that non-kin care-givers face often, especially when the child has low verbal skills. In one particular incident, Rose had been late to 'table games' as she had been at her workstation

and the class had moved on to pottery. She began to cry uncontrollably and would not tell Minerva or her facilitator, Angela, what was wrong. The non-kin care-givers tried asking her (Rose has good verbal communication skills) but she continued to cry. They then tried to ask her if she was hurt, by pointing to parts of her body, and still there was no response. Minerva then took her to the schedule to show her that it was time for pottery and Rose then pointed to the 'table games' picture indicating that she had not done 'table games'.

Romilda, much like Sybil who also teaches low-functioning children with autism, states that it is difficult to get nonverbal children to communicate. Even though Romilda feels that this is a constant struggle, she believes that there is always a way to communicate with a child but one needs to be aware and willing to "*persevere*". This is very much what Pomona expressed in terms of trying to understand the child and finding different ways to understand what it is that the child is saying. As the children she teaches are mostly nonverbal, Romilda tries to use an alternative form of communication such as hand signals or pictures. While this is not an easy task, this is better than the children not being able to communicate at all. Sometimes when a child is nonverbal and is struggling to communicate something, the child may become frustrated and then throw a tantrum. For example, Peter, who normally has a calm disposition, was coming down with a cold and he became very unsettled and unresponsive and would cry continuously. Romilda says that while the child may not be able to speak, "*they understand everything you are saying to them*" and sometimes "*it is best to just wait it out because they need to get something out of their system*". What is important though is to get to know the child and Romilda believes that if you pay attention to the child and know the way in which the child behaves, their individual likes and dislikes, then you may be able to learn what triggers a tantrum and how to calm a child down.

There was also a particular case during play time when Charlie was fighting with another boy, Ted, and when Charlie was asked why he was misbehaving the non-kin care-giver on duty had to decipher what was wrong. Charlie is not very clear when he speaks and Lucy, the non-kin care-giver on duty on that day, had to work out what he was trying to tell her. This took some time as she had to ask him to slow down and talk and then point out to her who or what was troubling him. Lucy then had to explain to Charlie that he must not fight by telling him that he would go into 'time out' if he continued to misbehave.

In addition to language difficulties posing a challenge to educators, Sybil explained that sensory difficulties experienced by learners can be difficult to deal with. This is evident in her words "*one day they won't like the tap open, or they don't like the colour that you are using, or they don't like the door being opened*" and this, Sybil stated, poses a dilemma as educators cannot always foresee what may cause a child to become uncomfortable. Similarly, Pomona related a story about one child who had a fixation with feet, toes to be particular, and did not like it when an educator painted her toenails. He would not speak to that educator and when Pomona asked him what was wrong, he eventually said that her toenails should not be painted. Pomona says that it is often simple things that affect the children rather than something complex as one would expect. For Romilda, due to the fact that most of the children she works with are nonverbal, one of the biggest challenges that she faces relates to knowing what it is that a child wants and at times she "*feels stuck. I have so many different strategies and I've tried them all but nothing seems to work*".

When working with the children, it is not always easy to get them to learn new skills and sometimes it is difficult for a child to grasp a new concept. This may result in the child having a tantrum and Fleur says that sometimes, *“the easiest way to cope is to just relax about it and realise that if somebody doesn't learn something today it is okay. They might learn it tomorrow or next week or next month or next year. They will only learn it when they are ready and there is nothing, if a child doesn't want to do something and you persist with all your might, there is nothing that you can do to change that child except through asking yourself why is it so difficult for that child to sit always, why is it difficult for her to focus on that task, to try and work out ways to help get the child”*. Remaining calm in the face of a tantrum is vital both for the educator and the child and having the patience to try and understand what it is that is upsetting the child is important to finding a solution to the issue at hand.

The challenges which educators described were thus mainly centred upon auditory issues, routine and sensory related issues, communication skills and social behaviour. Working with children with autism has been described as mentally and emotionally exhausting and as Pomona states: *“I go home and I just flop on my couch. I'm finished. And I'm only 24”*. This is understandable because having spent time in a number of classrooms throughout the research process; I observed that although the class numbers are smaller than in mainstream schools, this does not in any way translate into an easier workload for the educators. Whilst classes are grouped according to ability, this does not mean that each child functions in the same way as the next child. Educators need to get to know each child, individually, and find out what works with each child and what does not. This takes time and educators are in a process of constantly learning about the children they teach. Despite the challenges of working with

children with autism, educators were quick to note that their work simultaneously consists of numerous highlights.

4.3. Highlights of Working with Children with ASD

Whilst the task of working with children with autism can be stressful and exhausting, this is not a complete reflection of what working with children with autism is like as there are also many highlights within this line of work. These benefits are not physical benefits, but tend to be emotional and psychological in nature.

First and foremost these women are educators and their primary task is to impart knowledge and skills to the children they teach. However, due to the nature of autism, these educators find that the occupants of the classes they have do not change every year as they would in a school with neurotypical learners. At Durmstrang, the children may stay with one teacher for a number of years (for example Pomona has had four of her learners with her for three years), and depending on their level of ability they will move into a different class at a later stage. This means that these educators are able to form a stronger and more personal bond with the children they teach. As stated previously, educators have often referred to the children they teach as "*my kids*" or "*my boys*". This in itself shows a deep emotional connection between educators and learners. Fleur feels that one of the best parts of working with children with autism is the bond that she forms with the child. Working with the children and learning about each and every child, Fleur describes as "*the best and most fun part*" of her career.

Being accepted by the child is something Fleur holds as very important as she says *“they are free, and if you get a hug, that love and affection, it is an honest and true thing”*.

The relationship that the educators have with their learners comes across as very fulfilling. Miller’s (2006) work, from her experience in working with children with autism, expresses a similar sentiment in that it is hard for a person not to become emotionally involved with children with autism. Miller (2006) describes many such relationships that she has had with children and their families over the years and describes her relationship with one child she worked with as being her “greatest lesson in love” (Miller, 2006: 59). Miller (2006) has also stated in her book that she has maintained contact with some families even after her time with them had come to an end.

Research participants stated that a child responding to them was a very important aspect of them knowing that they were in fact reaching the child. This creates a sense of personal satisfaction when a child responds positively to intervention, whether it is academic learning or social skills. When a child learns a new word or a socially appropriate behaviour this leaves the educator with a positive feeling. Research participants stated that this was important to them, as Sybil says, *“when they’ve got a skill and you know they can carry it forward... it may be small but you see it and that is the joy of it all – for example like he can actually go into the water now, he actually can write his name now”*. At this point, Sybil recalls some past memory of a learner and I see her face light up as she talks about children learning new skills and the fact that she has had an impact on that.

When one reads about children with autism, Romilda says that the idea that is given is that these children “*cannot learn anything, they cannot do anything...*” but when you work with them and you get to know each child it becomes evident that in reality such children are often a “*joy to work with*” as Fleur explains. Reading about working with children with autism can sometimes paint a picture of a job that has many negatives attached to it, however, the educators interviewed have expressed that their job, while it entails hard work and is very exhausting both physically and mentally, has definite and distinctive highlights.

During the research process I became familiar with the children as well and I found that with some children it was easy to see when they made progress, for example, in their speech. There was one particular child whom I met at the start of my research who did not speak and the sounds he made were not clear. Dudley attended his speech therapy regularly and each week that I went back to Durmstrang I found that his speech was slowly improving. When I first met Dudley at the start of the school year he was unable to say his own name. This changed after a few weeks and he was able to pronounce his name very well and would shout his name when his teacher asked him a question. By the end of the research process Dudley had learnt a number of words and was able to communicate better. He became more interactive in the classroom, tried to talk more and would also try to sing along to the songs that Minerva played each morning. Each time he was able to say a new word during class Minerva would ‘high five’³³ him or give him a hug to show him that she was happy with his attempts and to encourage Dudley to speak more. It was fascinating to watch Minerva during this time as she would often clap her hands to applaud him when he would say something and

³³ A ‘high five’ is the action whereby one person slaps their open and upraised palm against that of another person as a sign of success.

the look of excitement and pride on her face was evident when hearing this particular little boy speak.

I had a similar experience in Pomona's classroom with a boy who would not speak a lot and noticed upon further visits that his speech and language acquisition was improving. Pomona would get excited whenever he spoke, even when it was out of turn, and would encourage him to tell her whatever it was. *"I just let him talk because he doesn't do it very often, I just let him go on until he is finished"* she said to me once, with a smile on her face.

The highlights of working with children with autism does not have to be big but rather they are what most people would take for granted in their neurotypical children, such as when they learn new words and new skills. These educators have to work at teaching these children social skills and when the child learns the new skill and is able to apply it successfully then this leaves the educator with a sense of achievement and satisfaction.

One of the key aspects that all my research participants agree on is the happiness that they feel when a child learns something that they, the educators, have been trying to teach the child for a long time. For Romilda it's the simple things that make her day, *"when a child looks up at you and smiles... they say hello to you... it's those simple things because we know they have such problems with social interaction and communication"*. Romilda relates an instance of a child who she was toilet training and who was just beginning to verbalise who, one morning, turned to her and said "wee". At first Romilda says that she did not realise that

he was speaking to her but when she did realise that he was saying a word rather than making sounds she says that she was shocked, *“I had tears in my eyes because that was such a big thing for me”*.

4.4. The Personal Impact of Working with Children with Autism

The non-kin care-givers who were interviewed stated that their personal lives have in some way been affected by working with children with autism, but that since this is their livelihood, which some have stated is more of a calling, a vocation, they have found ways in which to manage the stress that this work brings to their lives.

4.4.1. The Impact on the Social Life of Non-kin Care-Givers

Miller (2006) describes how her life changed when she began working with children with autism. In her book Miller describes her early days of working with children with autism and points out her “lack of social life” (Miller, 2006: 67). She discusses how there is less time to spend with family and friends because working with children with autism is emotionally and physically draining. Miller (2006) explains that it is often the case that family do not understand the choice to work with children with autism and they do not understand what this type of job entails or how it affects a person. In this way, family is unable to offer the type of support that is needed by non-kin care-givers. Miller (2006) asserts that family and friends do not understand why non-kin care-givers are tired or unable to go out for social occasions during the week, for example, and relationships may break down as a result. Research

participants have expressed that a person can learn a lot about themselves through this line of work.

Participants expressed that they preferred to stay at home and relax and Pomona stated that she would keep to a sleep schedule during the week because she knew that she had to wake up fresh for school the next day and if she did not get enough sleep the night before then she would not be physically prepared for the day that lay ahead; "*I need to be in bed by 10:00pm otherwise I'm going to struggle the next day*".

Pomona then compared this to when she was at university and says that "*even though studying was hard work, I would still make a plan to go out...*" while these days she says that "*I don't see much of my other friends any more...*". She further says that even visiting her parents during the course of the school term is not an easy thing to do as her parents live a few hours out of Durban and "*it is just too far to drive home on a Friday after school. It's just too much for me to drive on my own because I'm just exhausted. So a Friday night at home is just for me to relax, it's awesome.*"

Fleur has been working with children with autism for fifteen years and says that her life has definitely been affected by working with children with autism. Educators do not have a lot of time to themselves but as Fleur says "*I want a social life at some stage*". Lavender echoes this when she tells me that although she finds that she has more free time available to her

since starting to work at Beaxbatons³⁴, when she was at her previous job which spanned approximately twelve years, her children would often say to her that “*I was married to my job*” because she spent so much of her time focusing on her work.

Fleur says that when she takes time off or when it is the school holidays she is able to recover and recuperate and in this time she finds that she has more time for her family and friends and has the energy to stay up late and go out visiting or for fun; “*I have taken a little bit of time off ... more energy for family and friends again which is just wonderful... I'm keen to go out and I enjoy seeing people*”. This is in stark contrast to what Fleur experiences during term time when she finds that she is exhausted every day and wants to be alone which “*has a profound effect on what I do after school, my relationship with my husband's family. I don't nurture relationships as I would like to because I am just too tired*”.

This impact of exhaustion has been echoed by other educators as well; Minerva states that she is “*exhausted when I get home. It is a very hard career, mainstream is quite different because you give a task and that's it... but here it's one-on-one, it's preparing all the time... it's hard work so I would say being tired and instead of going to bed at 10:00 or 11:00 at night you're in bed by 8 o'clock (laughs) ... I do find that I am exhausted when I get home*”.

³⁴ Lavender is the principal and does not have a specific classroom assigned to her. Rather, Lavender is able to move between classrooms as and when she is needed.

In addition to exhaustion, Sybil, who teaches a class of learners who have low functioning communication and social skills, says that she sometimes finds that when she converses with people out of the school environment she uses very simplistic language to get her point across and she says that *“you use limited language in the class and when you are speaking to adults you still maintain that simplistic language and sometimes you repeat and this is where you find that family members get - they always say that this is not your class”*. Sybil said that she has to consciously remind herself that she is interacting with neurotypical individuals when she is away from school and has to adjust herself to the outside world.

For educators, there is a deliberate compulsion to try and separate work from home. This type of work, educators stated, takes an emotional toll on them and simply leaving work related issues at work is not something that can be easily done. Educators stated that even when they go home they are constantly thinking of ways in which to engage with the children they teach and thinking of tasks for their children to do. Minerva once told me that whenever she was out shopping she would keep an eye out for educational toys, games, musical compact discs (CDs) and books that she could use in her class to help her children.

Thus, in some way, working with children with autism does impact on the educator’s personal life. The main form of impact is exhaustion and the way in which non-kin care-givers interact with people. However non-kin care-givers expressed that they are able to deal with these issues and that the frequent school breaks allows for them to relax and recuperate for the term to follow.

Romilda reflects that she was “*extremely emotional*” when she first started working at Beaxbatons. One of the main positive aspects that has come out of her position as Beaxbatons is that Romilda is now able to appreciate life more and not take it for granted because her work with children with autism has taught her that there are those who have problems that are beyond their control. In this way autism has had a profound effect on Romilda’s personal life in the sense that it has been a life changing experience for her. Romilda states when she talks about the parents of the children she teaches; “*I choose to be here, I choose to teach children with autism, they (parents) didn’t choose their children to be like this and that’s the difference*”. Romilda says that working with children with autism has made her a stronger person emotionally and she says that while she is a sensitive person by nature, she has become more sensitive and perceptive to other’s feelings and she “*thinks much more of other people than I do of myself*”.

Working with children with autism is an occupation that affects a person both physically and mentally and affects all aspects of their lives. Educators have shown that they prioritise working with children with autism in their lives, whether it be spending time planning out the routine for the next day, looking for new educational toys or simply making sure that they get a good night’s sleep so that they can be fresh for their class the next day.

4.5. Support Systems

4.5.1. Support from Co-Workers

The most important support system mentioned by educators and facilitators at both of the schools is the support network that exists between the educators and facilitators that work there. These non-kin care-givers form a tight knit group of working individuals and they form a primary support system for each other. A close knit support system at work allows the non-kin care-givers the ability to interact with people who understand what the other goes through on a daily basis and they are able to share information, offer advice based on experience; as well as offering each other emotional support. I remember one particular afternoon at Durmstrang when a few teachers were gathered in the playground during play time to watch the children, they spent the time talking to each other about what their children had been getting up to and providing positive reinforcement and encouragement to each other. On one occasion when most of the educators from the Autism Unit at Durmstrang were together in the playground, they were discussing their day and stressful situations that they had had to deal with. One educator complained that she had a lot of tension in her shoulders and Minerva then went up to her and gave her a shoulder and neck massage while they were watching the children. It was evident that this is a tightly knit group of professionals who have a close bond and who provide each other with support on a professional and academic level as well as on a private and emotional level. Non-kin care-givers are always willing to help each other deal with tough situations, for example Pomona says that if a child in Phase

5³⁵ is misbehaving then the teacher will send him/ her to the Phase 1 class to stay there for a while with the little children to have a 'time-out' and the older boys do not like this.

Romilda was new to working with special needs children and autism when she first started work at Beaxbatons and she found that Lavender and Fleur were a great help to her in terms of listening to her, offering her advice and helping her deal with difficult situations such as when a child was having a bad day and would not listen to her or remain in one place and do a task. Romilda describes Lavender as her "*bigger support being so experienced and much more educated... she has always been there for me... kept me going because there have been a lot of times when I've had my own meltdowns... she (Lavender) was always there to pick me up and listen when I needed to talk*". If Romilda is having a difficult time with a child she knows that she can call Lavender to assist her and she knows that because Lavender has more experience and more confidence in her approach she will be able to deal with whatever issue the child is having.

Miller (2006) describes her own experiences when she began working with a girl while she was in Cape Town. Miller spent six hours a day with Amelia at her school and she describes various incidents which occurred at the school, when Miller was still learning her way around autism. An incident, Miller describes, was when Amelia became difficult and pinched and screamed when she could not get an apple that she wanted. Miller was able to get Amelia in a firm grip but she was having difficulty confining her and one teacher called a more

³⁵ There are 5 Phases at Durmstrang differentiating between the different levels of advancement for children with autism. Phase 1 is for the younger children who have just started school and have very limited academic ability. Phase 5 is the last phase and has older children, in their early teens, who are academically 'advanced'.

experienced facilitator to assist with the child. The other facilitators did not judge but rather offered her the support and understanding that Miller needed. The educators agreed that having a support system of this kind is very important to helping each other deal with stressful situations and with problem solving.

4.5.2. Organisational Support

While there is mutual support between educators, the educators similarly feel that they have the full support of the organisations in which they work. At Durmstrang, Minerva says that the Autism Unit gets together at least once a week and “*we share ideas and everybody is supportive of one another*”. Minerva explains that this is very helpful to the teachers and facilitators and especially to those who are new to working with special needs children. The school has a resource library to assist staff and non-kin care-givers are always informed and kept up to date on different courses that are available that are related to autism. Pomona and Minerva have both stated that the Head of the Department of the Autism Unit has been very helpful to them over the years with problems related to the children they work with and with difficult situations they are faced with. Pomona states that the deputy principal at Durmstrang has also been extremely helpful and supportive to her on both a professional and personal level and has helped her a great deal in terms of emotional support.

4.5.3. Support from Family (or Lack Thereof)

Support systems at work have been stated to be the primary support system that non-kin care-givers have. Families of non-kin care-givers do not always play a big role as a support system and some non-kin care-givers have stated that they expected their families to “*be there*” for them (emotionally) when they needed to talk about a particularly rough day, for example, but that is not always the reality. Fleur says that “*unless you know autism, you cannot possibly know what somebody goes through and empathise with and support them*”. Fleur says that after fifteen years of working with children with autism her parents “*don’t know what I do, they don’t know what I go through, they don’t know why I do it and they just cannot understand that. For a long time you can build up resentment that people don’t support you or you don’t feel supported, but I learnt that the best thing is to stop expecting it from them and if you really need support turn to people who know autism and who are in the field*”.

Fleur states that those whom she works with offer her the support she needs and those who work with children with autism and parents of children with autism understand what her job entails. Romilda, however, says that she has a great support system at home in the form of her parents and they have been there for her throughout her journey into working with children and they help “*keep me together*”.

4.6. Non-kin Care-Giver and Parent Relationship

Research participants were also asked about the working relationship which they had with their learner's parents and all stated that they had a good working relationship with the parents of their learners. Pomona did attest to having one or two instances where she and a parent had disagreed regarding the learner's schooling but she said that this was resolved *"because at the end of the day we both want what's best for the child. That's the important thing and we have to always remember that"*. Sybil reiterated this by stating *"whatever you do in the class has to be carried over in the home to carry things forward. So we have a good relationship, which you have to maintain"*. Non-kin care-givers did state that they do not have particular strategies that they use when working with parents, but rather that the school promotes regular meetings between parents and educators where educators and parents are able to discuss the child's progress and any issues that need to be worked on. Parents are encouraged to meet with educators whenever they find that there is a problem that needs to be addressed. The emphasis is thus clearly on transparency within the teacher-parent relationship and Minerva even let a parent sit in on her class for a day just so that the parent could observe her child in the classroom environment to see if she could learn from watching the classroom interaction.

Research participants acknowledged that it is important to them when a parent is happy with their work and the progress that their child is making. Gratitude from parents is also a motivating factor for non-kin care-givers. Fleur stated that when she first began working with children with autism she used to be very anxious and *"very scared of the parents. Was I doing a good enough job or not?"* With experience comes confidence and this helps the parent-non-

kin care-giver relationship as parents need to be reassured that the people they entrust their children with are helping their child as best as they can.

Both Durmstrang and Beaxbatons allow parents to sit in on classes and watch their children interact. This transparency allows for the parent to know and understand what the educator does with their child and this helps to improve the teacher-parent relationship. Arrangements for this can be made with the school and Fleur and Minerva have both had parents sit in on their classes. Fleur actively encourages parents to observe their child in a setting away from home as this allows the parent to take a step back and watch their child with someone else. A parent who had attended Fleur's class said to Fleur that she had "*never seen her child listen to anybody like that before*". Fleur says that she tries to pass on the techniques she uses to parents to help them in the home. This is very much like the incident at Durmstrang where a parent had come to spend the day with her daughter who attends Minerva's class. Bella, an eight year old low functioning child is normally very quiet but she knew that her mother was in the classroom and there was a visible change in her attitude and behaviour. On that day Bella attempted to answer questions when Minerva asked her something, she performed the actions to the dance of the song that was used for the day and was interactive and well behaved. Bella's mother was surprised at her daughter's response to Minerva and at her behaviour. At one point Rita exclaimed "*she's not like this at home. She doesn't listen, she doesn't pay attention. How do you do it?*"

The schools both have activities that bring parents and non-kin care-givers into regular contact with each other. There are formal parent-teacher meetings where educators and parents are able to discuss the child's progress and any issues that need to be worked on. Beaxbatons has a close working relationship with the autism awareness group Action in Autism which many parents are also a part of. Fleur offers training sessions for parents and there is also a weekly support group meeting for mothers held at Beaxbatons. Once a month the school holds a support group for parents and siblings of children with autism and there is often a guest speaker to discuss specific problems that parents have expressed interest in.

Durmstrang has a parent information evening or morning at the beginning of each school year where educators explain to the parents what the programme consists of and what the school and educators expect of them as parents. At the end of the term when report cards are sent home there are parent consultations that can be arranged to discuss the child's progress. Both schools also use a notebook communication system whereby the child has a notebook that the teacher writes in providing feedback to the parent and the parent can then make requests or ask for information. Durmstrang regularly holds talks for parents and they have specific days where parents are encouraged to join their children in taking part in activities. One example of this is the annual walk that is held at Durmstrang. Parents are invited to join their children and the non-kin care-givers in a walk around the school. All the children take part, including those in wheelchairs and some parents bring bicycles and cycle around the school with their children while others walk at a leisurely pace with their children and the non-kin care-givers. Afterward they all proceed to an activity area on the school's grounds where the school has hired a series of jumping castles and set up sport arenas for the children and their parents to enjoy. Another occasion at Durmstrang was when the school library had received new books

and the librarian decided to have a dress-up costume contest where learners and non-kin care-givers dressed up as their favourite fictional characters. These types of light-hearted gatherings are an important way to bring parents and non-kin care-givers together and help to facilitate the relationship in a relaxing and fun atmosphere rather than in the formal classroom.

4.7. Motivating Factors to Continue Working with Children with ASD

From the above themes it has been found that working with children with autism affects one emotionally and physically and also impacts on the personal lives of those involved in working with the children. Non-kin care-givers, however, continue to work in this field and this theme aims to look at why they choose to do so.

Teaching, as a profession, is about more than earning a salary, as these non-kin care-givers have pointed out. If "*it's not about the money because there is no money in it*" then what is it that motivates these women to continue working in this area? Sybil stated that she could not see herself doing anything else apart from teaching special needs children and that "*I don't need to find a reason not to go to work. I just enjoy it and when you enjoy it then you want to keep doing it*". There seems to be an intrinsic factor at play with educators wanting to continue working in this field.

As Pomona says "*even though it's a lot of work to see a little bit of improvement you've got to have a heart for it... that is where my motivation is, having a heart for these children, it*

would have to be an intrinsic motivation...". During the research process what was evident was the emotional connection that these educators have with the children they teach and that is a major factor in them continuing to work with children with autism. Pomona added that there are times when you feel that "*you become their mother (at school)*" and since she is leaving to go overseas Pomona has said that she has told the parents (as well as the new teacher) to keep in touch with her and let her know how the children are doing.

Another important aspect that keeps the educators motivated to work with children with autism is when a child shows some form of progress. Sometimes it can take months before something that has been taught manifests and the child shows the ability to perform a certain task or show a certain skill for example in the life skills area, picking up a new word or an improvement in reading. Minerva says that "*It's wonderful to see that there is progress happening... slow progress but when progress is made then it's wonderful*". This comes back to the notion that educators are making an active difference in the lives of these children and helping them to improve and learn important life skills that will enable them to function in the world when they are old enough. This also means that they are of an enormous help to the child's parents and educators have expressed that when parents are happy this impacts on the way they feel about their job and makes them realise that they are making a difference in someone else's life. This is evident in Lavender's words "*the input that we get from the parents to say that parents can see an improvement is wonderful*".

Fleur, who says that working with the children "*is a joy*", also mentions that the parents play an important role in why she continues to work with children with autism. When parents

listen to the educator's advice and act on it, it makes the educator feel valued and Fleur states that the gratitude of parents makes a very big difference to the educators. The appreciation and recognition of the work put in and the improvement of their child that educators get from parents is important and is a motivating factor because the educator knows that the work they do is being valued.

Whilst working with children with autism is not always easy, there are definite motivations for these women to continue in their line of work. As mentioned earlier the motivation to continue working with children with autism is often times intrinsic. The fact that there is a possibility that one can make a difference, regardless of how small, in the life of another is important. When an educator makes a break through with a child who could not speak and can now say a few words, it is something that my research participants have stated plays a huge role in their decision to continue on this path and that they gain a sense of personal satisfaction and achievement from working with children with autism.

Romilda says that seeing the difference in the child is what keeps her motivated, because this means that she is getting through to the child on some level and that any improvement is important not only for the parents of the child but also for the child themselves. The feeling of *“making a positive change in their lives motivates me... to help them communicate and to understand how they see the world”*.

There is another aspect to the motivation of working with children with autism. Due to the increasing body of research that is emerging about autism and that children are being diagnosed with ASD in increasing numbers, Fleur states that it is important to make sure that the knowledge that individuals have built up over years is not lost. Fleur has fifteen years of experience of working with children with autism and knows that the knowledge she has regarding autism is very important and valuable; *“I have a keen knowledge of children and how to understand them and that kind of responsibility has kept me going”*. Fleur believes that those who have extensive knowledge of autism and how to work with children with autism should try and impart that knowledge to others and use their expertise to help families. By remaining in the field, she is able to help train others. Fleur states that *“I really want to impart my knowledge to the people who work with me so that there is a broader network of people who understand about the children”*. This is important to note because as Fleur recounts, when she first moved to Durban, she had not planned to continue to work with children with autism, but because there was a need for her skills and knowledge base, she ended up working with children with autism once again.

This chapter has built on the background information of the schools and has provided a detailed understanding of what non-kin care-givers of children with autism experience in terms of daily interactions, their motivation for working with children with autism and the experiences they have in terms of challenges and highlights of working with children with autism. The following chapter turns its focus towards parents as care-givers of children with autism.

CHAPTER FIVE: THE EXPERIENCES OF PARENTS OF CHILDREN WITH AUTISM

“When my son Nat was diagnosed with autism at the age of three, I had no idea how much autism was going to force me to change: how I parented, how I made plans, who I hung out with, how I felt about family, how I felt about my life” – (Senator, 2010: 1)

This chapter explores the journey that parents of children with autism have embarked on through their child’s diagnosis with Autism Spectrum Disorder (ASD). In doing so, it further aims to provide a holistic understanding of their experiences and how raising a child with autism has affected them personally and socially.

This phase of the study which involved research conducted with eight parents of children with autism focused directly on a number of key issues including diagnosis, guilt and depression, the effect of autism in parental and family relationships, support structures and dealing with personal experiences. These issues highlight a number of pertinent challenges regarding parental experiences with regards to care provision for their child with autism, their relationship with their child, their relationship with those around them (family and friends) and their understanding of their concept of self. The following discussion does not go into extensive detail in terms of all the research participants interviewed. Rather, I have chosen to provide detailed information from participants who stand out significantly in their experiences in relation to the various themes. It is important to note however that these key informants are representative of the parents interviewed for this. While they will be the main point of discussion, reference will be made to other participants as well.

Table 3: Parental Information

| Name | Gender | Marital Status | Number of children | Number of children on the spectrum | Age of children with autism | Age of diagnosis |
|-------------|---------------|-----------------------|---------------------------|---|------------------------------------|-------------------------|
| Hermione | Female | Married | 2 | 1 | 9 | 24 months |
| Kendra | Female | Married | 2 | 1 | 13 | 26 months |
| Dora | Female | Married | 1 | 1 | 9 | 32 months |
| Remus | Male | Married | 1 | 1 | 9 | 32 months |
| James | Male | Married | 1 | 1 | 6 | 3 years |
| Molly | Female | Married | 4 | 1 | 21 | 14 months |
| Bathilda | Female | Divorced | 1 | 1 | 6 | 38 months |
| Hannah | Female | Married | 2 | 2 | 13 | 36 months 18 months |

5.1. Diagnosis

5.1.1. Pre-Diagnosis

A common trend that was found amongst research participants was that their children were diagnosed with ASD at around the age of 36 months. This is reflective of research as Koudstaal (2010) points out that most children are not diagnosed until they are around 36 months of age. It is around this age that children display more prominent signs and symptoms of ASD and parents begin to worry that something is ‘wrong’ with their child. The pre-diagnosis stage of the child’s life may vary though and can be as confusing and traumatic for the parents as after the official diagnosis (Senator, 2010).

From the eight parents³⁶ who were interviewed, seven parents had had their children diagnosed on the spectrum between the ages of 24 months and 38 months. The remaining parent's child was diagnosed very early, at around 14 months of age. From the parents who were interviewed, six parents had sons who were diagnosed on the spectrum and two parents (the only couple that was interviewed) had a daughter. This ratio of male to female fits with research which states that there are more males diagnosed with ASD than there are females.

Six of the parents stated that when their children were born they had not seen any signs to alert them that there could be an irregularity in the development of their child.

Hannah has two boys diagnosed on the spectrum. With her first son, Bill, whom she describes as being "*high functioning*", Hannah was not immediately aware that he had a disability. She says that he was a "*calm child, very relaxed when he was a baby. You hear horror stories of screaming babies but Bill wasn't loud at all*". Bill started talking at about 16 months of age and seemed to progress well. Hannah did not think anything was different, however she mentions that Bill did not have very good eye contact and was not very interactive as a growing child. When Bill was around 24 months his speech began to change, he spoke fewer words than before and did not learn new words that they tried to teach him. Hannah took Bill to the doctor who checked his hearing and told her that nothing was wrong with his hearing but that he was just unresponsive. The doctor referred the couple to a child psychologist who, after conducting a set of assessments³⁷, told the couple that she suspected that Bill is on the

³⁶ Two were part of the same couple.

³⁷ One such test used in diagnosing autism is the Griffith's Test.

spectrum, but that the autism was not severe and that if they got him the right type of help that he would be *“functioning almost normally”*. Hannah says that they were *“lucky that we noticed that he wasn’t behaving right. If we had left it any longer, who knows how bad Bill would have been”*.

Hermione states that her son Hugo was *“the most delightful, perfect child you could ever imagine, never made any noises... quiet, quiet, quiet, slept throughout the night”*, but a year later this changed drastically and she says *“the angel became a monster who literally screamed from the time he woke up to the time he went to bed”*. Hermione’s son, Hugo, who at the age of 9 months accompanied his mother and brother Percy to the doctor and the doctor was surprised to see him *“lying screaming and kicking about on the floor”*.

Hermione’s doctor suggested that she take Hugo for an assessment and at 14 months of age he was taken to have a hearing test. Although Hugo could hear well he had an inability to understand language. The next step was to check his progress in terms of development and he was found to be behind his age group. After a visit to an occupational therapist, Hermione was told that she should look into Asperger’s Syndrome and become familiar with the disorder. Hermione and her husband then took Hugo to a paediatric neurologist who then diagnosed Hugo as having PDD-NOS.

Kendra, a mother of two, whose son, Albus, was diagnosed with ASD when he was 26 months old had a similar experience. When he was a baby, Kendra stated that Albus was *“quiet, too quiet, sometimes. I could leave him sitting in his cot for hours and he would be*

perfectly happy; almost as though he were in his own world. I see now, that that in itself should have been a warning sign to me". As he grew older though, Kendra says that Albus did not form words properly and would grunt instead and then scream when he was not understood, *"He became so difficult. He would hide in a corner and rock back and forth and any attempt to coax him out would be met by the most horrendous banshee cry and flailing arms. I think my family and I had a permanent headache for about two years from all the frantic screaming"*.

A common expression amongst the interviewed parents was the tension which they experienced prior to having their child diagnosed. Parents stated that they felt exhausted from the irregular behaviour that their children displayed. One parent specifically stated that she was fearful of the unknown and what was wrong with her child and was scared to get him diagnosed. Some parents stated that their children had gone from being 'normal' children to someone completely different. They were often faced with screaming children who would be difficult to wake up and difficult to put to sleep. Add to this the fact that they did not know what was wrong with the child as well as the confusion, frustration and angst which they felt and their concern escalated.

Dora and Remus's daughter, Ginevra, was unresponsive to her care-givers and this prompted them to take Ginevra to an ear specialist as they thought that perhaps she had an ear problem that was affecting her hearing. As Dora says *"she never hugged us on her own, you know, we would have to hug her if we wanted a hug and she didn't always look at us in the eye when we tried to speak to her, but otherwise she was okay"*. She would also be unpredictable and

would run out of the room if the door was left open. Remus explained the fear that he felt and he would call the crèche numerous times during a single day just to put his mind at ease as he was terrified that his daughter would run out through an open door, out of the house and onto the road or that someone would grab her.

James also had his child in a crèche and at the age of 26 months Horace had started to become very aggressive. Horace had no speech at the time and was unable to communicate effectively. One day when he went to fetch his son from the crèche, the care-giver told him that his son had thrown a tantrum and become aggressive during a play session and had thrown toy wooden blocks at another child. Luckily the other child's parents did not get upset and brushed the incident off as 'children playing'. James became very anxious from that day and expressed feelings of dread every time his phone rang at work, wondering if it was the crèche calling him about another incident. James and his wife had taken their son to the doctor to make sure that he was okay, because when he would get sick, he would be very irritable. The doctor assured them that there was nothing wrong with their son physically. Another incident did however occur which resulted in James being asked to take the child out of the crèche permanently as he had bitten another child, again during play. The care-giver in charge had told James that they could not have a child who was so disruptive, incommunicable and aggressive with the other children as this was simply too dangerous.

James and his wife were both working and they thus had to ask their domestic worker to look after their son during the day, while they were at work. This, James explains, was an even more stressful situation, as their domestic worker, though a mother herself was not equipped

to deal with an aggressive child. James describes how every day felt “*like a ticking time-bomb*”. The domestic worker would call in tears because she could not control Horace and complete her work simultaneously. Horace was becoming worse and it was only when his doctor suggested that he and his wife take their son to a neurological paediatrician for testing that they started making progress in terms of finding out what was wrong with Horace.

Bathilda, a recently divorced mother of a 6 year old boy with ASD, Teddy, related how she and her then husband had noticed that something was ‘*wrong*’ with Teddy when he began to lose his speech at around the age of 2 years. He also became very fussy about the types of food he would eat and would only eat foods of a smooth consistency. She and her ex-husband had taken Teddy to his paediatrician on numerous occasions because they thought that he may be ill. At one stage they took him to his doctor to check for an ear infection as he was becoming unresponsive to them. The paediatrician reassured them that Teddy was in good health and that he could see nothing wrong with him. Bathilda angrily exclaims that “*if he didn’t know what was wrong with my child he should have just told us and referred us to someone who could help. But no, he kept saying that everything was fine. We trusted him. We could have gotten our son help sooner if the doctor had been more helpful*”.

Bathilda was furious with her son’s paediatrician for not giving her better advice and for not knowing better himself. Teddy was diagnosed, at age 4, as having PDD-NOS. Bathilda says that she is grateful that Teddy was not more severe because he was diagnosed quite late and intervention may not have been as successful as it has been. She further thinks that all paediatricians should have a basic understanding of ASD as they are the first doctor parents

take their child to; she says “*who thinks to take their little child to a psychologist?*” This sentiment is re-enforced by Le Blanc (2010) who states that while diagnosing ASD is not within the realm of the paediatrician, he does see the importance of creating awareness amongst paediatricians so that children are able to be diagnosed earlier and so that both the parent and child are able to get the assistance they need early.

In the case of Ginevra, Dora and Remus’s daughter, consults with a paediatrician were not considered to be helpful. Paediatricians look for physical signs of illness, they are not trained to diagnose or be specifically aware of symptoms of autism and that is why Grinker (2007) argues that in the United States paediatricians are the number one target for autism awareness. It is Grinker’s (2007) belief that paediatricians can assist in early diagnosis if they are trained to recognise the signs of ASD. As stated earlier,³⁸ research in the biological arena seeks to find the cause of autism. However, whilst ASD may be a neurological condition, it affects parts of the brain which deal with social aspects of life such as speech. Due to the nature of this disorder, it is important that a holistic approach be used in dealing with ASD individuals because all aspects of the individual’s life are affected rather than the disorder occurring in isolation. The social sciences and anthropology in particular, can provide a more holistic understanding of ASD than the biomedical models that are often used for treating illness and disease.

The pre-diagnosis period was thus clearly a stressful, frustrating and confusing experience for parents which is frequently compounded by feelings of both physical and mental exhaustion.

³⁸ See Chapter 1

However, the pre-diagnosis period is only the beginning stage and these emotions permeate into every aspect of the parent's life.

5.1.2. Diagnosis

Diagnosing a child with autism is a complicated process and often requires more than one specialist and a range of tests which need to be carried out to determine whether the child in question is, in fact, on the autism spectrum. Research participants stated that the first test which they were recommended to take their children for was hearing related since lack of communication (verbal and responsive) is one of the signs of autism. The hearing test is done in order to check whether the child's non-responsive state or sudden outbursts at inappropriate times is a result of a hearing problem or not. Other specialists which parents may be recommended to see include child psychologists, speech and occupational therapists and neurological paediatricians.

All the parents in the study were employed at the time that their child was born and diagnosed. Parents explained how frustrating and exhausting it was to have a child who they could not communicate effectively with or have some form of control over. One father stated that his job required him to be at work at 6:00 am to begin his twelve hour shift at the factory where he was a quality controller (QC). Remus said that he would be so exhausted and stressed from the night before that he found it difficult to focus and function at work. He says that he would often even catch up on sleep during his hour long lunch break. Remus also worried about leaving his child with his parents during the day as they are elderly and their child, Ginevra, was quite a handful. Remus says "*she was very energetic and at any*

opportunity would run off. She has since been diagnosed with ADHD³⁹ with the autism. Because Ginevra could not talk, she would scream non-stop and my parents are old. It was hard to know what she wanted when she was screaming. They didn't need that, but we didn't have anywhere else to put her". Both he and his wife, Dora, worked during the day. His wife is a nurse and she also worked long and often late shifts at the hospital and she could not leave work as they both needed their jobs to run their household.

Most parents stated that they would be tired when they went to work but there was also an expression of relief that they were away from home and in a quiet environment. This is not to say that they did not worry about their child, there was a constant worry by parents whilst they were at work regarding what their child was doing and how he/ she was behaving with the care-giver at home or at crèche⁴⁰. Five of the eight parents had their children in a crèche while they were at work.

From the parents who were interviewed, five had prior knowledge of autism in terms of knowing of its existence from movies and what they had read in newspapers about savants. They did not, however, have any in-depth knowledge on the subject, did not know how it would affect their child or themselves and did not know that there was a spectrum. The other three parents had no knowledge of ASD and expressed a sense of confusion and anxiety over the diagnosis.

³⁹ Attention Deficit Hyperactivity Disorder.

⁴⁰ Crèche is a day care or nursery school.

James said: “we had taken Horace for a scan of his brain (an MRI)⁴¹ because the doctor wanted to make sure that he did not have any abnormalities. It was terribly scary because Horace was so little and we didn’t know what was wrong with him. He had to be sedated as well because he refused to sit still and would thrash around wildly. When the doctor later told us he suspects that Horace has autism we were dumbfounded. We didn’t know what this was and what this would mean for Horace”.

The fear of the unknown was, as some parents put it, “*very stressful*” and they began to try and learn as much as they could about autism spectrum disorders. There was a need from parents to understand what was going on with their child and more importantly, to learn if they could help their child and improve their child’s development.

Because Hannah already had a son on the spectrum and she and her husband had begun to educate themselves as much as they could about ASD, when her second son was born they were excited and did not for a moment think that they would have another son on the spectrum. Hannah expresses how “*heart sore*” she was when Bill was diagnosed. Because she and her husband had read widely on autism, when Bill began to show signals of autism she says “*I just knew in my heart that Bill was autistic. I was so disappointed and heartbroken, that my beautiful boy would not be what I had hoped and prayed for him to be. I was also extremely scared, what was I going to do now that I had two boys on the spectrum?*”

⁴¹ Magnetic Resonance Imaging Scan used to detect abnormalities in the body, in this case to detect if their son had any abnormality in the brain.

Parental responses to their children's diagnosis were mixed. Parents related feelings of shock, fear, disappointment and relief at finally knowing what was going on with their children. Hermione was relieved at the diagnosis of autism as she states that they feared that Hugo may have been brain damaged, "*and for me, terminal things are much worse, so it almost came as a relief to think of it as a mental thing*". Kendra expressed a similar sentiment. She was relieved that she finally knew what was going on with her son and could get him the help that he needed.

Two of the mothers stated that they had to leave their jobs when their children were diagnosed because they needed to provide care for their children and were too worried to leave the child with anyone else. Parents who continued to work did so for various reasons, amongst them that both parents needed to work in order to run the household and afford the care that their child needed; in terms of being able to afford fees for special needs schooling and therapies for example.

5.2. 'Judging Parents': Blame and Guilt

"You were in the judgement seat, and he was your judge, your prosecutor, your everything. He was going to send you to mother hell because you made this kid autistic" (Grinker, 2007: 68).

In the past, much emphasis has been placed on the role of the mother and the relationship of the mother and child. Ginker (2007) states that throughout history there have existed negative stereotypes of 'mother'. In American history, Grinker (2007) points out, the mother is portrayed as a professional or working woman who does not see her children, as people who

merely act out the role of 'mother' in public, and as mothers who are over-protective. Mothers, Grinker (2007) argues, have been harassed for being either too affectionate to their children or too cold towards them. In the 1890's, Grinker (2007) states that Emmet Holt, insisted that mothers refrain from showing too much affection toward their children and went as far as to discourage breast-feeding. In the 1920s, mothers were told to apply 'scientific methods' to raising their children. During the 1940s, however, Grinker states that psychoanalysis began to move away from this thinking and emphasised "affection, emotional contact and nurturing to good child-rearing" (Grinker, 2007:87). John Bruer, according to Grinker (2007) stated that the first 3 years of the child's life are significant and that children raised in warm, rich and stimulating environments would have more synapses in their brain than those children raised in harsher conditions. Bruno Bettelheim, in the 1950s, argued that mothers were naturally cold and distant to their children and were more interested in their careers and this is what caused the child to withdraw and become unresponsive to those around them (Grinker, 2007). These 'cold' and 'distant' mothers were viewed as withholding affection from their children and this was constructed as resulting in the child becoming withdrawn, having speech difficulties, becoming isolated from others and becoming locked in state of rigid repetitiveness (Grinker, 2007).

Grinker (2007) makes reference to a South Korean study that argued that young children diagnosed with autism had experienced a breakdown in the attachment to their mothers and that mother and child had become disengaged from each other. The researchers observed the mother's interaction with their children but did not consider the artificial setting which they had placed the mothers and children in. The researchers described the mothers as lacking in social skills, as being insensitive to their child's prompting and as expressing little emotion to

the child. Grinker (2007) argues that what the researchers were seeing was actually the mother's reaction to their child's autism. Researchers, Grinker (2007) argued, would not see the mother's attitude as a result of their child's disability but rather as causing it.

While mothers of children with autism were blamed and were the target of research and interventions in the past, it is in fact both parents who feel responsible for their child's health and well-being. However, Kanner argued that children are, in fact, born with autism though it frequently only manifested later in life.

In terms of the notion of the 'refrigerator mother' and 'cold parents produce cold children' (Grinker, 2007), none of the parents who were interviewed said that they experienced blame (in terms of their relationship with their children) from their children's specialists or therapists. Parents have acknowledged that they were questioned about their interaction with their child and what the interaction was like but did not generally get the feeling that they were being blamed for their child's autism.

While it seems that, for the most part, professionals are not blaming parents for the situation of their children, my research compliments other material available (see Siff Exkorn, 2006 and Senator, 2010) and shows that there is considerable stigma from people outside of the immediate family and in the social environment, such as from work colleagues, unsuspecting teachers, distant relatives and people met on outings.

Children with autism can be unpredictable and when they are in social situations which they do not understand or are uncomfortable with, and especially when they are unable to express the way they feel about it, there may be instances when they act out for example by throwing a tantrum. Kendra refers to these moments as *“cringe moments. You just know the screaming is going to start and you have to prepare yourself for the worst”*.

If we look at one of the earliest forms of social spheres that a child is exposed to other than the family such as the crèche environment, James explains how he felt judged by the pre-school teacher because Horace began throwing tantrums when other children would want to play with him or his toys, *“the care-givers seemed to think that my wife and I were over-indulgent with Horace; that we would give him what he wanted, since he was an only child and this was why he would behave like this in the crèche”*. This perception got worse as Horace showed more and more signs of autism. James said *“they would watch me when I came to fetch Horace from crèche in the afternoons, watch me out of the corners of their eyes. While I would struggle with him, struggle to get him into the car, you know, because he would just scream or want to run off, they (the care-givers) would just shake their head, almost as though they were thinking that I could not control my own child”*. James said that he got the feeling that the care-givers thought that he was a bad parent or that he did not know what he was doing. He stated that as a father, it is more uncomfortable because *“in my community, as a man, you are meant to be in control of your family and it makes you feel like you are inadequate as a man and as a parent”*. Rather, it is because children are on the autism spectrum that they behave in ways (which are a natural result of the condition) that are inappropriate and lead unknowing others to pass judgement on and question the parenting abilities of the parents.

From the parents who were interviewed, even those with children who are regarded as ‘high functioning’, there was a consensus that going out into public spaces was something that was difficult and had to be planned. Kendra’s son doesn’t like bright lights and going to a shopping mall with him is difficult as she says that he constantly tries to pull away and struggle with her. Hannah has an easier time with her youngest son, even though his autism is more severe in comparison to his brother, and he walks with her holding her hand, whereas her older son, being very inquisitive, wants to go off and question people.

Parents have expressed that people who do not know them personally, or who do not know that their child has autism, are judgemental. There have been occasions where parents have been accused of poor parenting, of indulging their children too much and of being unable to control their child. It is only when a parent makes it known that their child has a disability that the other person’s attitude changes. Bathilda explains how when she was out with her son at a family occasion, *“Teddy was refusing to eat something, he didn’t like the way it tasted, and I was trying to get him to eat and he was close to an outburst and I remember people staring at us as Teddy refused and refused till he was blue in the face to eat this thing. I heard someone say “ridiculous how she’s begging him” and I almost burst into tears”*.

It emerged from the interview process that parents felt that they were being judged by others, by other parents, by teachers (who, at the time, did not know that the child has autism) and by the general public when they were out. Mothers do tend to bear the brunt of this though, as mothers are still viewed as the primary care-giver. In circumstances where it is unknown to

others that the child has autism, it was found that blame for the child's behaviour was ascribed to the parent and 'lax' parenting controls.

This has, in turn, left a few of the parents questioning their ability to rear their child properly. This was predominantly found in those parents who have only one child, as they are not able to compare their parenting skills with a child other than the one who has autism. Parents who have more than one child and who have both a child on the spectrum and a neurotypical child stated that they did not consider there to be anything wrong with the way in which they treated their child/ren or with the way in which they brought them up. Having a second neurotypical child made the parents feel at ease with themselves because they knew that they could not be blamed for their child's disorder.

One aspect that did however emerge during the research process from those parents who have only one child as opposed to those who have a child on the spectrum and neurotypical children was linked to guilt in relation to their child's diagnosis and feelings of self-doubt regarding the ability to parent. This is in line with thoughts of guilt expressed by Grinker (2007) and Senator (2010) who as parents of children with ASD had questioned themselves regarding their child's disorder and whether or not they, the parent, was to blame. Grinker (2007) points out a particular situation when he and his wife had first taken their daughter, Isabel, to be diagnosed. The psychologist had focused on and questioned Grinker's wife about how she behaved with their daughter, neglecting to question Grinker himself. Grinker's wife is an academic and the psychologist stated, albeit subtly, that it was her having a career and being away from their daughter that had caused the autism in Isabel. This, Grinker (2007)

argues, leads to a parent feeling doubtful about their ability to care for their own child. Although parents are less likely to be blamed by professionals for their child's condition upon diagnosis today than was the case with their counterparts of the past there have been some parents who have mentioned that they did, at some point, believe that they may have been responsible for their child's autism. James had wondered whether autism was genetic and if he or his wife had passed the trait onto their son. Dora says "*I thought that I did not stimulate her (Ginevra) enough when she was a baby. I thought that if I had talked to her more then she would have learned to speak. If I had gotten more educational or developmental toys for her to play with, it would have made a difference*".

Autism was something that parents in this study were unfamiliar with until their child was diagnosed and most parents expressed that it was hard for them to know what to do and what type of treatment would be best for their child. From the information that they had read up on, both from books and the internet, parents knew that early intervention was crucial to their child's development but they were unsure as to how to go about getting the help that they needed. There are only a handful of schools in the KwaZulu-Natal area that cater for children with autism, and the majority of these schools do not cater for those who have lower developmental skills and who are placed at the lower end of the spectrum with severe development issues. Schools want to be able to provide skills to children that will equip them to function adequately and independently in the outside world. The reality is that not all children diagnosed as being on the spectrum are able to learn very fast and function at an appropriate level. This causes parents a lot of stress and angst as they want their children to live as 'normal' a life as they can and be able to help themselves.

One of the greatest parental fears that has come out through the interview process is that parents question what will happen to their child when they are dead. Molly, whose son turned 21 this year, says that up until now *“everything has been okay”*. Her son George has been living with her and her husband and when George (who was home schooled) finished school, they decided to move to a quieter area in the Natal Midlands. George is their oldest child and they have three younger sons. Molly, however, worries considerably about what will happen to George when she and her husband are no longer able to provide for their family. Molly says that she does not want to burden her younger sons with having to care for their brother as it is not their responsibility. Molly says *“George isn’t a handful, he’s pretty easy going, but you have to be there with him all the time and he does have his episodes. Sometimes he has these seizures as well. It scares me to think that one day we may not be around for him, to help and protect him. My other boys are great, they’ve put up with a lot, but my husband and I can’t really expect them to spend the rest of their lives looking after George. They will want to have their own families and their own lives away from all of this. We can’t deny them that, but at the same time, who will look after George when we die?”*

Kendra’s son, Albus, is turning thirteen but he is not in high school, functions at the level of a six year old and has very little speech. Her daughter, Arianna, has just completed her second year at university in another province. Kendra says that they are fortunate enough to be able to afford to send Arianna to a university away from home as she and her husband wanted Arianna to experience life away from home and from living in an autism household. According to Kendra *“Arianna has been great all these years. She has been the model older sibling, but we know that it has taken a toll on her. Sending her away for school (university)*

was difficult but we knew that it had to be done for her, because she needed to be free of the responsibility for a while and to focus on herself and her life.

Parents frequently also experience a sense of guilt over their other children, and try to keep a balance and give their children the same amount of attention, but they admit that this is difficult to do and does not happen as often as they would like. Hannah, who has both her sons on the spectrum, states that she is aware that she gives Bill more attention than she does Fred and this is because Bill's autism is more severe than Fred's; *"I've got two autistic boys... I can't balance my time between them because Bill needs me more. Even when I am helping Fred with his homework, I'll have Bill with me. Fred gets upset sometimes because he wants time with me but there isn't much I can do"*. Molly has said that she has spent more time with George, trying to teach him new things or help him understand what is happening around him; *"It's hard. I've got three other boys but I've never been able to give them all the same attention that I give George. We take their 'normalcy' for granted knowing that they can deal with things on their own"*. Senator (2010) has two NT sons younger than Nate (her son with autism). In her book she describes the time when Nate moved into his new home⁴² and she and the rest of her family took a vacation. It was their first vacation without Nate and Senator (2010) describes how easy it was for the family to make spontaneous decisions and how her other sons enjoyed this. One of her sons was particularly withdrawn and was able to become more involved in the family than he used to.

⁴² An adult home for people with autism which teaches them life skills and how to be independent.

Not only do parents experience guilt over their children and the different ways in which they sometimes treat them, parents also experience a sense of guilt in their relationships. James stated that his wife had to leave work in order to stay at home with their son Horace and care for him. He was earning a better salary than she was and so they decided that it would be best that she leave her job. James says that he feels guilty that his wife has had to give up her job and spend her day caring for their son; *“I get to go to work and ‘relax’ and get away from it all, but Lily has to deal with autism all the time. Work is an escape for me and even though I try to help out as much as I can when I am home, I am a bit glad that I get to go to work every day”*. He notices how exhausted she is when he gets home and he tries to compensate for this when he is home and on weekends by helping out with their son, but Horace, because he is used to his mother, only wants her to do things for him. This also leaves James feeling frustrated, hurt and left out. James says *“It hurts when your kid doesn’t want your help, when you’re right there and he is screaming for someone else. Or when I do something the wrong way and he gets upset because I am not used to his normal routine. Sometimes I wonder if I know my own child”*.

Hannah also became a ‘stay at home mom’ when her second son Bill was diagnosed with ASD. She did not want to put her boys into the care of others and felt that he was her responsibility. Hannah spent time at the library and in books stores and later used the internet to obtain as much information on autism as she could find so as to learn early intervention practices. Hannah said that although it was not easy to give up her job she knew that she had to do it. James said that his wife felt similarly but it was not something that she could avoid. Both these women did not want to leave their children in the care of a stranger and felt more

comfortable looking after their child themselves, even though it brought an added stress into their life.

However, both of Hannah's sons are now school going. Hannah found it easier to care for Bill when Fred was at school and she says *"I feel bad for feeling this way, but I was relieved when Bill was admitted to a school. His autism is quite severe but we found a school that was willing to take him in and he has progressed quite a lot since"*. Hannah says that she can now find time to relax during the day and is considering looking around for a part-time job as soon as Bill is settled in his school properly. She did admit that she felt guilty at the immense relief that she felt when she found out that Bill would be going to school; *"I have more time now and can do things that I couldn't before, like sit and watch the TV without interruption. It's the small things that make the most difference. I can even sleep more if I want"*.

Thus we find that parents experience guilt, frustration and exhaustion in a multitude of ways. Senator (2010) points out; parents of children with autism have an amplified sense of these emotions due to the nature of their child's diagnosis. Each parent has to find ways in which to cope with the range of emotions which they feel and these coping strategies will be tackled in the next section.

5.3. Autism Parents and Support

Autism parents find that they are separated from neurotypical parents; they are different in terms of their experience as parents. Individuals are unknowingly judging and being judged from the moment they begin their interaction with each other. Goffman (1969: 12) argues that if a person is categorised as negative or as having negative traits then they are “reduced in our minds from a whole and usual person to a tainted, discounted one”. Autism parents are faced with having to bring up their children in a society that is not altogether accepting or understanding. Children and parents are labelled from the moment of diagnosis and carry this label with them for life. These aspects affect the way in which an individual constructs his/her identity, as identity is not constructed in isolation, but rather through interaction with others/ peers.

Autism parents, as they refer to themselves, experience a range of emotions that ultimately affect the way in which they view themselves in terms of being a parent and in terms of their own sense of self.

Parents have related incidents when they were out with their families for dinner or shopping and something would happen, causing their child with autism to become scared or throw a tantrum and the resulting stares and disapproving looks that would be passed their way. The way in which incidents such as these were internalised by the parents varied. Whilst social interaction does affect the way in which one identifies oneself and constructs one’s identity, there is also the input that the individual him/ herself has, the choice to acknowledge the public and agree with what they seem to think about the parent and the child or to disregard

the public's category of 'normal' and create one's own sense of 'normalcy' and force the public to fit in.

There has come through in the research two extremes in this regard. Parents who felt hurt and embarrassed by others stigmatising them because of the way their child reacted in public and those who refused to be viewed as any less of a parent by others due to their circumstances. Thus while some parents accepted the criticism and internalised it, blaming themselves for the problem, others took a firmer stance and chose to ignore the comments and stares of others, brushing it off as ignorance.

James stated that when his son, Horace, was in crèche and the care-givers and other parents would stare at him when Horace threw a tantrum because he had to leave the toys and go home, he felt judged. In the words of James, "*What do you do when your child is kicking and screaming at you? I would just grab him up and hold him tightly for a while and then struggle to get him into the car seat, which was no easy feat. The looks on the faces of the other parents was unsettling. I felt judged, even though they knew nothing about me, they judged me as though they did*". James admitted that he would want to leave the place as fast as he could so as not to have to put up with the disapproving stares. Shame is a part of stigma, and Goffman (1969) states that when others view you as being inadequate (as a parent) then you begin to question yourself and your abilities to raise your child. When Bathilda's son was diagnosed she did not want to isolate Teddy and would sometimes take him to the park so that he could see how other children played with each other. Although this was not easy as Teddy did not play well with other children as he found it difficult to share and would walk

up to a child and simply take a toy out their hand, Bathilda persevered. She did not feel welcome by the other parents, the looks they would give her would sometimes make her think that she was the reason her son behaved the way he did, that she was not parenting him properly by teaching Teddy proper social etiquette. Bathilda says *“when you feel judged negatively by your peers (other parents) then you feel like a failure”*.

Hermione related a story about her son, Hugo, going with her into a shop when he was five years old and snatching up clothing from a rail and throwing onto the floor. Hermione stated that one of the shop assistants turned to her and exclaimed *“You’ve got the naughtiest child I’ve ever met”*. Hermione says she promptly responded with *“Don’t judge a person if you don’t know anything about them”* and left the store. Hermione takes a rather strong point of view and her thoughts are that *“if you’re not dealing with it, you don’t have any right to stand and stare or complain or whatever”*.

Although parents of children with autism have to constantly deal with other individuals judging them when they are in public, Kendra says that *“other people and parents, when you’re on an outing, do not know your child has autism. Most people are not that aware of autism in the first place, so when they look at you and your child they simply think that you are not doing a good job at parenting. They’re just ignorant and in need of an education. There have been times when I went up to people and explained my son’s behaviour and their whole attitude changed”*.

Autism awareness is on the increase in KwaZulu-Natal and there are a number of non-profit organisations that are involved in increasing awareness of the condition amongst the general public. These non-profit organisations bring together parents who are facing similar trials in their lives and autism parents, as I have found during the research process, prefer to stick together. This is where the group identity becomes important and can turn a social stigma from a negative to a positive. This can be seen, for example, in support groups that are run for parents of children with autism. One such group is the Action in Autism support group which runs once every month. During the meetings, guest speakers are brought in to provide expert knowledge on particular issues dealing with autism and parents are able to get together and talk about issues that are troubling them. There are also occasions where families are able to get together and have social outings like braais and they do not have to worry about other parents judging them, rather, they are surrounded by individuals who understand what the other is going through and can offer a sense of strength and support. Non-kin care-givers also offer a sense of support for parents and are sympathetic others in terms of understanding and having similar experiences to the parents of the children they work with. Non-kin care-givers are also part of a stigmatised group in terms of the work they do as they are set apart from mainstream educators. This brings us, once again, to the concept of the 'culture of autism'. The notion that there is an 'us' versus 'them' approach underlying interaction between those who belong to the autism community and those who do not, and this comes from both mutual understanding and experiences of parents and non-kin care-givers. Those who find themselves to be part of this autism culture tend to think, feel and behave similarly in response to certain situations. This allows like-minded individuals to form a support for each other whereby they are able to identify, through their own experience, and thus assist when one member of the community is in need.

Those parents who had their children in special needs schools made the effort to make friends with other parents because they knew that they would be understood and that they would be accepted by other autism parents. By sharing a social space with other like-minded individuals autism parents are able to gauge a sense of 'normalcy' and not feel as though they are outcasts, from even their own extended families. Parents have expressed that their families (both immediate and extended family members) do not always understand what it is like to have a child with autism. The more severe the autism is the harder it is for parents. Dora explained that there was a time when some members of her family were weary of inviting her to family get-togethers because they were scared of how her daughter would behave, *"when you are not invited for your own nephew or niece's party because of your child it makes you feel unwanted and that no matter what, they (the family) will never understand what it is like and that we are always trying our best, that Ginevra is trying too"*. Having other autism parents as friends means that they can share their problems and get help from the other parents as people in the same situation are able to better understand what each other are going through. In this respect, James said that he felt more confident when he went out on family outings with other autism parents and their children because he felt as though he and his wife were not alone, *"you are not the only one whose child is doing something that other people would think 'odd'. You don't feel alone and cut off from the rest of the people around you. When we are out with other autism parents my wife and I are able to relax more because there are people who understand us, who understand our child"*. In the other parents, James and his wife thus found people they could rely on and trust and who would be there for them if an incident with Horace occurred.

5.4. The Role of the Activist

The group identity thus helps to reinforce a positive sense of self in parents, and helps them to become more confident in their role as parents. From the group identity emerges the role of the activist parent. Autism parents in Durban are very active in terms of campaigning for the rights of children with autism and in terms of raising awareness. There are many groups made up of parents in the greater Durban area and during autism awareness month (April) or World Autism Day (2nd April) parents actively campaign and create awareness. During my research process I attended the Autism Walk which took place on the Durban beachfront. Parents arrived with their entire family, had their hair sprayed different colours and their faces painted and took to a stretch along the Durban Beachfront with their placards marching to create awareness of autism in South Africa. The atmosphere at the event was electric as parents marched with their children in tow, proud of their autism status, whereas in the past, children with autism would have been kept away from the outside world, institutionalised, or parents would deny the existence of the child.

Autism parents have become more active in their children's lives, taking it upon themselves to learn about the disorder rather than leaving it solely to professionals. They choose not to hide their children from the outside world and are moving more and more into the activist role than ever before. They want their children to be part of mainstream society and are willing to fight for it.

5.5. Teachers as a Lifeline

All the parents who were interviewed had children who were of school going age. This meant that teachers played a significant part in their child's life. Parents were asked during the course of the interview what form of care they had for their children, whether they employed external care-givers to teach their children or if they sent their child to school. Seven of the parents including the couple who was interviewed have children who are placed in a school for children with special needs and the remaining parent has a child in a mainstream setting with a facilitator.

When questioned about the importance of the role of the teacher, the general consensus was that their child's teacher was one of the most important people to their child. Parents stated that they wanted their children to lead functional lives where they would be able to function on their own, and key to this, was the role of the teacher. Parents often view teachers as a lifeline because the teacher is often one of the few people who truly understand what type of a life an autism parent leads. Dora once said of her daughter's teacher *"I can barely manage with one and yet she manages with six. I don't know how she does it!"*

Parents recognised the need to have a good, stable working relationship with their child's teacher so that what the teacher would do in school would be carried over into home life so that the child would constantly be practising what they were learning. Parents expressed a strong sense of trust in the teachers, but stated that this did not occur immediately. Trust between parent and teacher was built up over time and was based upon a mutual need to see the child succeed.

The important thing to note in this is that these teachers are those who are trained for special needs education. They know their job and the type of children whom they are educating. Problems do arise when, as in the case of Hermione's son Hugo who is in a mainstream school environment, the teacher is unaware of the complete extent of the child's disability.

In most cases parents acknowledge the importance of the educators and parents have, for the most part, a positive relationship with their child's teacher. Having a positive relationship with the educator had a significant impact on the parent in terms of being at ease when they were at work and their child was at school.

This chapter has outlined the journey of the parents into the world of autism. In Chapter Six I turn my attention towards analysing the data in Chapters Four and Five around suitable theoretical frameworks (outlined in Chapter Two) to show the journey experienced by parents and non-kin care-givers of children with autism and to expose the creation of an Autism Community and culture of autism.

CHAPTER SIX: A SYMBOLIC JOURNEY INTO THE CULTURE OF AUTISM

Parents and non-kin care-givers alike embark on a symbolic journey with autism but they do so in different ways and for different reasons. This chapter aims to analyse the research findings that have been presented in Chapters Four and Five in line with van Gennep's (1960) *Rites de passage* and Turner's (1967) use of the term *liminality* derived from van Gennep's (1960) work. Symbolic interaction and Goffman's (1969) *Spoilt Identity* will also be used to analyse the experiences of care-givers as will be the theories of social cognitive theory and social identity theory by Bandura (2001) and Brewer (2001) respectively. This transition, experienced by parents and non-kin care-givers alike, has given rise to the culture of autism and this will be illustrated in this chapter.

6.2. Parent's Journey into Autism

Parents⁴³, my research reveals, have undertaken a journey from the moment they notice that something is different about their child. This journey moves from events prior to diagnosis; continues through the diagnosis period and into every step of their lives as parents learn to live and cope with their child and with autism. Drawing on van Gennep's (1960) *Rites de Passage*, the initial phase of separation occurs during the pre-diagnosis phase of autism, where the parents acknowledge that there is something 'different' about their child in relation to other neurotypical children. This is where their journey begins. Many children with autism initially develop like neurotypical children and begin to show signs that something is different around the ages of 24 to 36 months of age⁴⁴. Parents are frequently faced with a

⁴³ Parents, at the time of research had passed through the separation phase and the liminal phase into the phase of incorporation.

⁴⁴ As mentioned in Chapter Five

visible change in their child's behaviour and development. Parents expressed that they experienced confusion, tension and fear of the unknown at the pre-diagnosis stage of the journey. Hermione says that she always suspected that there was something different about Hugo but that the differences became more apparent as he entered the toddler phase. In her words *"my sister's son is the same age as Hugo and when I saw what Brett (her sister's son) was doing in comparison to Hugo the differences were huge. While Brett would be doing wooden puzzles, Hugo would be putting the pieces in his mouth and shaking his head around while making a roaring sound. He also didn't develop language skills and an understanding of language. Knowing that there was something different about him but not knowing what it was separates you from other mothers and their children. While they are discussing how many millilitres their children drink or what foods they like, you are constantly thinking, you are lucky that is all you have to worry about"*.

Kendra who has a daughter older than her son Albus says that she recognised that Albus behaved very differently from how his sister did when she compares their behaviour at a similar age. She says *"Arianna was a very engaging child. She would respond to her name being called and did not mind being in large crowds if I took her shopping with me. Albus was the complete opposite. If I had to go to the shops then I had to leave him with my mom otherwise he would scream when we got into a shopping centre and wouldn't stop until we got home again. And people would stare and make comments about me not being able to control my child"*. Having a child who looks 'normal' but behaves differently from other children immediately places parents of children with autism in a different social space from parents of neurotypical children and children with other (physical) disabilities. Parents of children with autism are thus separated from other parents, not physically, but rather in a symbolic manner.

When a child is diagnosed as being on the autism spectrum this marks a definite separation from mainstream society for parents. Parents know on a more formal and concrete level that their child is in fact ‘different’ from other children. In addition to this there is now a label attached to the child that markedly separates the child and the parent from other individuals. This separation means that parents must now learn a new set of rules by which to interact, not only with their child but also with wider society, as the way in which society views children with autism, and by extension the parent, impacts on how parents interact with others, for example, family members and friends. Hermione stated *“I found at school (at the time Hugo was at a short term remedial school) that parents were overly interested in what was ‘wrong’ with each other’s children and those who had obvious physical disabilities, such as hearing problems which required hearing aids or cochlear implants were definitely less stigmatised. Those who were considered to have a ‘mental’ or ‘social’ problem were looked at in another way altogether. I find that negative attitudes from other parents or the general public who perceive your child to be plain ‘rude’ or as ‘having no manners’ because he ‘speaks out of turn’ is literally like a red rag to a bull. You become a soldier for your child and although this is common for a lot parents anyway, the feeling is more overt when you feel your child is being judged just for being the way he is”*.

Once the child is diagnosed, parents then begin to learn about autism and through their experiences of their child they are able to learn how to understand and manage their child’s disability. This is not an easy or quick process. Autism has been described as a development disability (see Grinker, 2007; Miller, 2006; Senator, 2010 and Koudstaal, 2010) and as such it is diagnosed at an age where the child is in early development and at this stage parents are still learning how severe their child’s diagnosis is.

Turner (1967) focuses on the liminal period and he argues that society is a “structure of positions” and he regards the liminal phase as an “inter structural situation” (Turner, 1967: 234). During the liminal period the individual no longer identifies with the social structure or group that they were once a part of, but neither does the individual identify with any other social structure or group because the individual is in a state of transition, searching or trying to incorporate himself/ herself into a new social structure. Turner (1967) likens this to a social death and rebirth for parents. At this stage they are separated from mainstream society by virtue of their child’s autism but have not been incorporated into the autism community which Mesibov and Shea (2011) allude to in their writings on the autism culture. The problem with existing in this phase is that the individual has no status or place within society as he/ she is still working to achieve a place in a new social structure or group.

When parents move into the transition or liminal phase they are faced with new situations and are constantly learning how to negotiate and adapt to these situations. This leads to the incorporation of new understandings and a new set of norms by which parents live. Seemingly simple decision-making processes become more complex and time consuming. If a family wants to go on an outing, for example to a restaurant for a meal then they need to plan in advance. When Molly’s family would want to go out for a meal they would need to go to a place that George knew and liked and they would have to prepare him for the outing a few days in advance. Molly says “*there is no such thing as going out on the spur of the moment. It has to be planned. I used to do little picture stories for George and I would tell him where we were going to go and when. And then we would talk about what he was going to eat. It was always planned. Always*”.

Parents must thus learn to negotiate their way around public outings, how to deal with a child ‘tantrumming’ in the middle of a shopping centre, how to deal with inappropriate social behaviour and most importantly how to deal with people who do not know or understand autism. None of this can be taught in a text book. Parents have to learn how to manage their child by learning about their child’s individual characteristics and as such deal with the situations that they find themselves in accordingly. This can essentially be done only through first-hand experience. Kendra reiterates this notion in her words “*You either sink or swim*”. Reading about other parent’s experiences and the way in which they deal with their child’s autism may however help to validate the parent’s reactions and feelings and show them that they are not alone in their experiences.

All of this is part of the parent learning about and moving into a distinct new social grouping that they then learn to identify themselves with; i.e. the autism parent. However, it needs to be noted that while parents begin to identify themselves as autism parents, they are always learning new things about their child each time the parent and child is faced with a new situation.

An integral part to separation and later transition is when one is cut off from society at large. When van Gennep (1960) introduced his rites of passage he was studying cultures and how individuals travel from one state to the next. In these cases the transition would be from childhood to adulthood and this change would often be marked by a physical change in appearance. This transition is evident in the case of a group of pubescent boys who separate from the larger group and isolate themselves physically in order to undergo initiation rites and when they return after successfully completing the initiation rites are seen as adults. Here the change is physical and is marked by physical characteristics and ceremony. In terms of

autism and parents (and to an extent paid (non-kin) care-givers) the separation is not marked by a physical change but rather a mental change; a change in how others perceive the parents, how the parents perceive themselves and their child and how the parents perceive autism. The separation then occurs initially on a cognitive level and parents and their children become (symbolically) isolated from other (neurotypical) parents and their children.

This isolation of parent and child can be linked to Goffman's (1969) notion of spoiled identity. Goffman (1969) looks at stigma and social identity in relation to medical conditions, both physical and cognitive disabilities. Stigma, Goffman (1969:11) argues, originally referred to physical signs on the body that serve to 'expose something unusual and bad about the moral status' of the person, for example a criminal or traitor. Goffman (1969:11) describes the person (who would have a sign physically cut or burnt onto their body) as being "blemished, ritually polluted, to be avoided, especially in public places". Stigma can still be applied in the same sense today but does not necessarily need the physical alterations of the body to mark social stigma and shame.

Society places people into categories of what is deemed ordinary and natural (Goffman, 1969). Society chooses how people are grouped according to personal and public attributes that are felt to be "ordinary and natural for members of those categories" (Goffman, 1969: 11). Within society individuals seek to be part of a group and if they do not share common characteristics and attitudes with the larger group then they often fall outside of the group dynamic. If we take a look at the structure of the family, which varies from culture to culture, we find that there are rules and norms that are associated with how people perceive families should be structured and how they believe families should function. Accordingly, people hold

unconscious thoughts regarding what a family is supposed to be and how children and parents are supposed to behave and react to one another.

Goffman (1969) states that when people come into contact with each other they watch for signs that the new individual may fall into the same social grouping as they do. Some of the traits which help individuals categorise each other can be personal attributes such as honesty as well as structural attributes such as a person's occupation, and as such, their social status. Structural attributes allow us to create an image of the individual in our minds and the family structure is also used in the creation of this image of a person. Appearance is important in categorising an individual. At a first glance, a family which includes a child with autism may come across as 'ordinary' and 'normal' by societal standards. We incorporate 'normal' attributes of a parent and child into our unconscious and create "normative expectations into righteously presented demands" (Goffman, 1969: 12). This means that we expect 'normal' behaviour from both parent and child. We expect the child to behave a certain way and the parent to interact with their child in a certain way. Goffman (1969) argues that we are unaware that we have placed these demands on the individuals in question until a situation arises where we question if these demands have been fulfilled. This occurs when we notice a difference in the behaviour of the child and in the parent's response to their child. An example of this could be if a seemingly 'normal' child begins to flap his/ her arms uncontrollably and the parent responds by trying to control the child's movements. If we look at the example of Bathilda⁴⁵ who describes taking her son Teddy on social outings we can see how this is evident. Bathilda has, on occasion, taken her son to the park so that he could interact with neurotypical children and Bathilda hoped that he would learn socially

⁴⁵ The incident was previously discussed in Chapter Five.

appropriate behaviour in this way. She stated that when she first got to the park she did not receive any special attention from other parents. She and Teddy were greeted with friendly “hellos” and smiles. However, once Teddy went among the other children in the sandpit and he began to grab toys out of the hands of the children, the other parents’ reactions to her changed, and she heard comments that her son was a bully and that she was not able to control him. Since her initial visit to the park, Bathilda says that parents would greet her stiffly, would not want to be around her and would try to keep their children away from the area that Teddy was playing in.

In this way we see that the parent and child are “reduced in our minds from a whole and usual person to a tainted, discounted one” (Goffman, 1969: 12). Parents are viewed as failures, unable to cope with the demands of raising a child and personal blame is put at the door of the parent and most especially the mother who may be thought to focus too much on a career rather than staying home and bonding with the child (Grinker, 2007). The autism then becomes stigmatised, an “undesired differentness from what we had anticipated” (Goffman, 1969: 15). Goffman (1969) argues that an understanding is then constructed; i.e. bad parenting, to explain the inadequacy of the parent and child and this allows for the effective separation of the autism parent and child from mainstream society.

From this, the notion of ‘shame’ comes to the forefront where the parent sees him/ herself as falling short of how he/ she should be as a parent. Shame, then, comes from the individual’s perception of his/ her attributes, in this case the ability to parent. Goffman (1969) argues that this then leads to ‘acceptance’ whereby the parent anticipates particular responses from others in society to his/ her child. The response to shame, argues Goffman (1969), is to change what causes the shame. However, autism cannot be ‘cured’ and in this sense change cannot occur

in that the autism will not go away. Parents must then learn to manage their child's autism and this generally entails intervention on a social and developmental level. A child with autism may be sent to a special needs school that caters for his/ her specific needs and the non-kin care-givers at the school will then attempt to improve the child's social and developmental skills. Parents need to acknowledge and accept that autism is life-long and they will have to learn to adapt and live with autism for the rest of their lives.

The phase of incorporation is the final phase of van Gennep's (1960) rites of passage and entails the incorporation of new understandings and a new set of norms by which parents identify and begin to live by. This includes the acceptance by the parent of both their and their child's situation. Bathilda says that she initially found it hard to accept that her son Teddy is never going to grow up to have a 'normal' life. She says *"You have plans for your children, for their future, of who you think they are going to become. But then this happens and those plans change. I'm grateful that Teddy's autism is not as severe as some of the other children I've seen. I've learnt a lot in this time about myself and my child and about what we are both capable of. There have been a lot of adjustments that have been made and each day is a set routine. Teddy only eats certain types of food and my family has had to adjust to that and accommodate his specific tastes."*

Molly says that for her and her family, they had to find out what was 'normal' for them and work with that rather than worry about what others thought of them. Molly says that adapting to life with a child on the spectrum is not easy, especially when you have other children who are not on the spectrum, *"you have to find a balance between them all. Obviously George gets more attention from my husband and me but he needs more attention than our other boys. That was hard for them growing up but they learnt and eventually understood that it was*

necessary rather than us favouring him. You get used to the chaos that comes with having four boys and a child on the spectrum. You learn ways to deal with it and manage them. Life is now always planned and prepared as much as possible and there are back up plans for any plan that may go wrong.”

Goffman (1969: 31) discusses the concept of sympathetic others “who are ready to adopt his standpoint in the world and to share with him the feeling that he is human and essentially normal in spite of his own self-doubts”. Goffman (1969) describes two types of sympathetic others. The first type of sympathetic others are those who have their own experience with this particular stigma (autism) and can “provide the individual with instruction in the tricks of the trade and with a circle of lament to which he can withdraw for moral support and feel at ease, accepted as a person who is really like any other person” (Goffman, 1969: 32). This is achieved through the creation of support groups for parents of children with autism. By the time parents reach the phase of incorporation parents have learnt to overcome feelings of shame and inadequacy and this comes as a result of interaction with other autism parents whereby parents validate each other’s feelings and concerns regarding their children and their experiences with autism.

The second type of sympathetic other, Goffman (1969) refers to as the ‘wise’. These are people who are categorised by society as ‘normal’, however it is their “special situation” (Goffman, 1969: 41) in relation to the stigmatised (the autism parent and their child) that has given them insight into the life of the stigmatised and as a result they are sympathetic to the cause. Within the context of this research these sympathetic others are the non-kin care-givers (educators and facilitators) who choose to work with children with autism rather than to work in a mainstream setting. Through their direct work with children with autism, non-kin care-

givers have an insight into the life of parents and share understandings about autism and autism related issues. These non-kin care-givers are accepted by parents into their community and become honorary members of the community. Goffman (1969:41) described these ‘wise persons’ as those “before whom the individual with a fault need feel no shame nor exert self-control, knowing that in spite of his failing he will be seen as an ordinary other”. These ‘wise persons’, the non-kin care-givers, also have to “pass through a heart-changing personal experience” (Goffman, 1969: 41). Non-kin care-givers themselves must therefore go on a journey of self-discovery before they can be accepted by autism parents as part of their community.

6.3. The Journey into Autism: Non-kin Care-Givers

In terms of non-kin care-givers it can be seen that there are care-givers at varying stages of transition. In reference to their positioning, they are in the process of developing perspectives and capacities that will serve to enhance their care-giving experience (Cook-Sather and Alter, 2011). Non-kin care-givers who enter the field of autism find that they need to reposition themselves ‘in between’ in relation to their classrooms, staff members, learners and their parents (Cook-Sather and Alter, 2011). They thus learn to negotiate relationships and responsibilities within the role they are about to enter completely.

Non-kin care-givers of children with autism make a conscious decision to work with children with autism rather than work with children in a mainstream setting. These non-kin care-givers experience a separation from mainstream society and begin their journey into autism as a result. As stated in Chapter Three non-kin care-givers have had different reasons for choosing to work with children with autism. Romilda said that the main thing to remember is that “*I choose to be here, I choose to teach children with autism*”. It is important to note however

that they do not experience the separation in the same way as the parents. As part of the separation non-kin care-givers experience a change in their social and physical environments, as pointed out by Bandura (2001), and this change for non-kin care-givers is the move to a special needs school and being surrounded by people who work with special needs children. Romilda describes her feelings as being “*extremely emotional*” when she first began to work at Beaxbatons and she further states that she has become “*more aware of children around her and more sensitive to what I say and how I act*”. Sybil has stated that when she is in a social setting with family members she has to remember that she is with neurotypical people and she says “*I find with language it’s limited because you use limited language in the class and then when you are speaking to adults you still maintain that simplistic language and you repeat your words and family members don’t understand this... they say this is not your class. You have to remember to separate work from home*”. Fleur stated specifically that during the school term she does not socialise much with family and friends because she is always exhausted from teaching during the week. Fleur describes herself as being “*tired at the end of the day that I don’t want see anybody... I don’t nurture friendships and relationships as I would like too because I’m just too tired. I don’t feel like going out at nights, once I get home I don’t want to get in the car and visit somebody. I just want to be alone*”.

Non-kin care-givers become separated from mainstream society as a result of the pressure of their jobs, and prefer, during the school term, to remain away from mainstream society. A reversal does occur when the school term ends as Fleur states that “*in the holidays and times when I haven’t worked with the kids I feel that reverses very quickly. I’m keen to go out and I enjoy seeing people and I love it*”.

Whilst there is a change in the social and physical sphere for non-kin care-givers, there is also a change that must occur in terms of knowledge and understanding about autism. Non-kin care-givers explained that they have taken courses that deal specifically with autism since they began to work with children with autism and continue to do so when the opportunity arises. Increasing one's knowledge about autism and how to work with children with autism requires a change in understanding autism and a change in mind-set.

Van Gennep's (1960) separation then occurs in both a physical sense and a cognitive sense in that educators begin to think about themselves in relation to other educators differently. While the work that they do may have the same meaning in terms of preparing learners with skills to assist them in the future, there is a vast difference in the type of skills that are taught by educators of children with autism as opposed to their mainstream counterparts.

Once non-kin care-givers have made the choice to work with children with autism and have separated themselves from mainstream society by joining a special needs school they are placed in the classroom environment where they now have to negotiate this new space that they find themselves in and adapt to the changes. This is regarded as the liminal or transitional phase of the non-kin care-givers journey. The non-kin care-giver is faced with putting the skills that they have learnt in an academic setting into practice as well as learning tacit skills that will enable them to manage their children. Romilda says that the workshops she has attended *“helped me to an extent. I knew what kinds of things to expect and how I should behave in the situation. But sometimes it's difficult when you have to act in the instant like if a child is having a meltdown it just comes like that, working in the moment. When I experienced my first tantrum and meltdown with one of the kids I think I was completely shocked because from what I've learnt in workshops and from books didn't help me or*

prepare me. They tell you that you need to be calm and lower your voice and use fewer words but in actual fact the reality is very different and you only know this when you experience it”.

The transitional phase is not an easy one as non-kin care-givers are placed in a stressful environment and are tasked with teaching skills to children who have difficulty with speech and with understanding what it is they are meant to do. Non-kin care-givers need to find ways in which to deal with and manage the situations they find themselves faced with, for example, a screaming child or a child who is being aggressive to another child. The support of other non-kin care-givers with similar experiences is vital in this regard as non-kin care-givers are able to share experiences with each other as well as the various ways in which they counter situations. Pomona said that *“you discuss different ways of dealing with something with other care-givers and then you find the one that works for you and you use it. It is not something that they teach you out of a book; it is something you learn as you go along”*. Experienced non-kin care-givers serve as mentors to those who are new to working with children with autism and assist with advice and emotional support as well because they have already passed through this liminal phase.

The phase of incorporation is when the non-kin care-giver has successfully navigated her way through the new social space of the autism classroom and has accepted her place in the social structure of working with children with autism. The non-kin care-giver then sees herself as a care-giver of children with autism and has the label of autism attached to her working identity. These rights of incorporation are found in the experiences that these individuals have, the way in which they handle the situations they are faced with and the way in which they develop a group identity separate from their former individual identities.

6.4. Incorporation into the Autism Community

Social cognitive theory and social identity theory put forward by Bandura (2001) and Brewer (2001) respectively, as mentioned in Chapter Two, has been used to illustrate how care-givers navigate their way into this ‘autism space’.

The core hypothesis and statement of social cognitive theory deals directly with those who are affected by health issues, however, this theory can be applied to those who are, by extension, affected by health related issues, in this case a parent who has a child with autism. In order to evaluate behavioural changes, Bandura (2001) argues that three factors need to be looked at; namely the environment, people and their initial behaviour.

For Bandura (2001), the environment refers to external factors that can and do affect a person’s attitude and behaviour. There are two types of environment described by Bandura (2001); the social environment and the physical environment. According to Bandura (2001) a person’s social environment is made up of personal family members, close friends and even work colleagues. The social environment for parents of children with autism relates to the individuals that parents now find themselves interacting with. Prior to diagnosis the people whom parents of children with autism may have been friendly with and associated with often differ from those whom they associate with after diagnosis; this is because those who do not know autism do not understand it or parents of neurotypical children may be worried about their child associating with and learning behaviours displayed by a child with autism. Autism parents therefore find it difficult to associate with neurotypical parents. This comes from the separation of the parent from mainstream society and their transitioning into a new social space that is occupied mainly by autism related issues.

Bandura (2001) asserts that the physical environment refers to a person's actual surroundings; for example in terms of where they are and the situation they are in. The situation that people find themselves in affects their behaviour. Parents of children with autism find that their physical environment changes in that their child is no longer going to a mainstream school and needs to be placed in a special needs school. This, as Hermione notes, can be very difficult for parents. As Hermione states *"I had it planned in my head where I wanted my children to go to school but that all changed with Hugo. He needed extra attention that he was not getting in a mainstream environment so we, upon expert recommendation and our own gut feel, moved him to a short term remedial school. I didn't really like the school as it was new at the time and there were a lot of teething problems but with children who are not considered to be 'mainstream' the choices are limited. Over the years the search for an 'appropriate' school has been endless but as options are limited we often have to accept what we think is the best option at the time even if we know it is not the ideal"*.

The places that parents take their children to change as well as it is not always easy to take a child with ASD out to a shopping mall or park. As Hermione further re-iterates, *"when Hugo was small shopping was a nightmare. We'd drive into the parking lot and the screaming would start. I'd literally have to do the shopping with a child screaming like a banshee. One day the manager of Pick n Pay came up to me and suggested that I just write a list and that they'd do the shopping for me instead!"* This is not to say that parents stay at home or keep their children at home as was done in the past (see Grinker, 2007). Rather, with a change in the social environment parents are able to change the physical environment and how they interact within the physical environment. For example, instead of going to a park alone, many families may get together and go to a park together so that they do not stand out from other families and are able to support each other if the need arises. The changes in the social and

physical environment, therefore, lead to changes in the thought processes of individuals and by extension results in changes in their behaviours and attitudes to autism.

According to Bandura (2001) the three factors; the environment, people and behaviour constantly influence one another. They do not exist independently; rather they are mutually dependent on each other. Interacting with other autism parents creates a sense of normalcy and this influences how parents perceive themselves as parents and how they act in the world around them.

In addition to this, social identity theory, according to Brewer (2001), looks at how one constructs individual identity in relation to those around them and this can be constructed in either a positive or negative way depending on the environment and the people around the individual in question. Surrounding oneself with like-minded people or people who have had similar experiences can lead to a more positive construction of identity in the individual.

When Bathilda found a school for her son Teddy to attend she also found like-minded individuals who were faced with similar issues to deal with as herself. Bathilda says *“it is a relief to know that there are people out there who have the same concerns that I have and who are faced with similar if not the same problems that I find myself struggling with every day. When I talk to other parents I don’t feel as though I need to censor myself, I can be honest. We share stories about our children and we are able to laugh at situations that, at the time, were far from funny. I’ve learnt things from other parents who have children with autism that you can’t learn from a book and I’ve tried to help out where I can as well. It feels good not to be alone and on the outside like I used to feel”*.

For a non-kin care-giver to be accepted into the Autism Community it is not as easy because while they may work with children with autism, they are also able to have a life away from autism. It is not only shared experiences and understanding of ASD that grants a non-kin care-giver access to the Autism Community but also to a relationship of trust that is built up with those who are already part of the community, in this case the parents. Non-kin care-givers first need to build up a relationship of trust with parents through the work that they do with the child and it is through this trust that non-kin care-givers are accepted into the Autism Community. Non-kin care-givers may be members of the Autism Community prior to the parents becoming members as some non-kin care-givers have been working with children with autism for many years while parents become members when their child is diagnosed.

Therefore group identities are forged from common ties to a shared category membership, the common factor in this sense is ASD, and in the case of this research how parents and non-kin care-givers of children with autism have had similar experiences and have thus come together through the use of support groups and the work environment to forge an identity based on the group. This can be seen in parent support groups that meet regularly such as *Action in Autism*, to online groups such as *Shut Up About Your Perfect Kid* and support groups that non-kin care-givers form within the organisations they work for. These support groups and common spaces allow members to express themselves in a space where what would be considered 'abnormal' or 'strange' by mainstream society is seen as the 'norm' by the Autism Community.

These theories focus on the importance of the social environment in the construction of identity. Human beings are social beings and these theories enable us to see how a person is affected by both the physical and social environment. Parents of children with autism find

that they cannot always be part of mainstream society due to the stigma and ‘differentness’ associated with autism and, as in the example of Bathilda and her trips with her son to the park, when there is a breakdown in the social environment this has an effect on parents. People who do not know autism are unable to understand the effects that working and living with a child with autism has on a person and care-givers find that they will gravitate towards others who understand what they are going through. Group identities are constructed in relation to those around us and the social environment of care-givers changes to include those who are involved with autism in different ways. The use of social cognitive theory and the different facets of social identity theory show us that identities are fluid and are subject to change when the social and physical environment changes. These theories thus enable us to understand how new group identities are constructed in relation to new experiences and how people move from one group to another based on these shared experiences and understandings.

This separation of parents and non-kin care-givers from mainstream society results in the creation of a new community and a new culture, the autism community, and by extension a culture of autism. Parents and non-kin care-givers identify themselves in relation to their ‘other’ neurotypical/ mainstream counterparts. Bathilda says *“I am an autism parent. My experience of my child and of parenting is different to other parents. If I have a problem I can’t call my mom for advice I would have better luck calling someone who has a child with autism”*. This is the case because mainstream society may find the autism culture to be “incomprehensible or very unusual” (Mesibov and Shea, 2011). As parents and non-kin care-givers are accepted into the community and become part of the autism community, they adopt a shared set of beliefs and values and this is passed on to new members through interaction. Autism affects the way parents and non-kin care-givers interact with the children and it

involves characteristics and predictable patterns of behaviour that lead to predictable responses from parents and non-kin care-givers (Mesibov and Shea, 2011). In this way routine may become ritualised in the sense of adhering to specific routines such as a morning routine; waking up, going to the bathroom, brushing your teeth, having a wash and then eating breakfast.

Non-kin care-givers, given their unique position within the autism community, may act as cultural interpreters because the role they play may serve as an intermediary between the child and parent (Mesibov and Shea, 2011). In this sense, the non-kin care-giver is more objective when interacting with the child and is able to better observe the child as they do not have the same emotional investment in the child than the parent does. This allows the non-kin care-giver to relay information to the parent regarding the characteristics and behaviour of the child and this may aid the parent in being better able to understand and work with their child in the future. Although the non-kin care-giver is an ‘insider’, they fall between two worlds; that of the autism community because of the direct link through their work with children with autism, and the ‘other’ mainstream community. As a non-kin care-giver, one needs to put aside old understandings and beliefs and adopt a new set of understandings and beliefs and work with those. Non-kin care-givers are cultural interpreters and in this way they may be able to bring together these separate worlds and assist in creating a better and more positive understanding in mainstream society of autism (Mesibov and Shea, 2011).

This chapter has shown how parents and non-kin care-givers embark on a symbolic journey with autism. This journey has led to a separation of parents and non-kin care-givers from mainstream society, thus allowing these groups to form a collective community based on their varying involvement with ASD which in turn gives rise to a culture of autism. The

following chapter will provide the conclusion to this study and offer recommendations for further study in the field.

CHAPTER SEVEN: CONCLUSION

Autism Spectrum Disorders are life-long and affect not only the individual diagnosed with the condition but also those who are connected to him/ her through different types of relationships. Parents, as care-givers, are the most affected but there are other non-kin care-givers, such as educators and facilitators, who through their work are also affected by Autism Spectrum Disorders. This qualitative study has focused on examining the journey into autism of those individuals who are involved in providing care, both paid and non-paid, for children who are on the spectrum.

As Grinker (2007) has pointed out the diagnosis of Autism Spectrum Disorders, PDD and PDD-NOS has increased in recent years. As has been discussed in previous chapters there are various reasons for this, however, the concern of this research has been to show how the diagnosis and subsequent changes in life affects those who are closest to the individual with autism. In the early years of research into autism it was believed that the mother of the child had caused the occurrence of the developmental disorder in the child through the lack of bonding in the early years of childhood. As research has progressed in this area it has been confirmed that there is no correlation between mother-child bonding and Autism Spectrum Disorders. However the specific cause of autism and other related disorders has yet to be found. There is much scientific research available on Autism, Asperger's Syndrome, PDD and PDD-NOS, and there are many personal accounts of autism and its effects on the family by parents of children with autism. There is, however, a noticeable gap in the literature regarding non-kin care-givers, most specifically educators and facilitators of children with autism, and how these individuals are affected by their close relationship with these children.

This study has been made up of two parts. The first looks at the experiences of non-kin care-givers and their relationships with the children whom they work with. These non-kin care-givers include educators and facilitators who work at two schools in the KwaZulu-Natal area that cater for children with autism. The second part of the study includes parents as non-paid care-givers of children with autism. The aim has been to gain an insight into the world of a care-giver of a child with autism and to attempt to understand how the life of the care-giver is affected through their interaction with the child.

For parents of children with autism there is a shift in how they perceive themselves as parents in a largely neurotypical world. For educators and facilitators who work with children with autism, while the change in their perception of self is not as profound, they do experience a shift in how they identify themselves through the work that they do. Through their work experiences these non-kin care-givers are able to identify with and empathise with parents and offer support and understanding that parents need because one can only truly understand autism if one has been affected by it in some way.

The main themes that have emerged during the course of the study relate to a shift in attitudes and understandings of autism and how this affects a person. For parents it begins with the period prior to diagnosis where parents suspect that something is ‘different’ about their child and consequently learn to navigate through the unknown. The central themes for parents included diagnosis, feelings of guilt over their child’s diagnosis, the effects that living with a child with autism has on relationships both within and external to the family structure, the

challenges that parents face in bringing up their children in a predominantly neurotypical environment and the support structures parents use.

Non-kin care-givers, who for the purpose of this study have included educators and facilitators, choose to work with children with autism and are fully aware that the job requires much more from them emotionally and physically than mainstream teaching. Central themes that have emerged when looking at non-kin care-givers include the stress and challenges associated with working with children with autism, highlights of working with children with autism, the personal impact of working with children with autism, the relationship between the non-kin care-giver and parents and the motivating factors which probe non-kin care-givers to continue working with children with autism in the long term.

A key aspect that has come through the research process is that care-givers have embarked on a journey that began with pre-diagnosis/diagnosis or choosing to work with children with autism. This journey, described by van Gennep (1960) as the '*Rites de Passage*', is made up of three phases, namely; separation, transition and incorporation. This journey sees the participant, through his/ her involvement with Autism Spectrum Disorders, being separated from mainstream society and having to negotiate a new space within the autism framework. In doing so, the care-giver is forced to learn to understand autism and come to terms with autism. The individual then incorporates these new understandings and experiences into a new way of life; a new set of norms by which to live. It is through these common understandings and shared perceptions and experiences that we find that an Autism Community is formed.

With the creation of an Autism Community, Goffman's (1969) notion of the Spoilt Identity and the resultant stigma which is attached to the care-giver by virtue of his/ her relationship with a child on the spectrum has been applied. The stigma experienced by parents is more profound than that experienced by educators and facilitators as parents are cut off from mainstream society by their peers for having a child that is different, whilst educators and facilitators are less stigmatised because they can choose to stop working with children with autism and re-enter mainstream teaching for example. Educators and facilitators are seen as the 'sympathetic other', a term used by Goffman (1969) to describe those individuals who are not stigmatised but who can identify with the stigmatised individual through their experiences and involvement with ASD, and in this way become honorary members of the stigmatised community. This has created an 'us vs. them' mentality in mainstream society and as such Mesibov and Shea (2011) have argued that a culture of autism exists. This research has aimed to show how this is possible through the creation of an Autism Community.

This qualitative study of two schools, one which has a dedicated Autism Unit and another newer school which was created specifically for children with autism, did not aim to compare the care available in each school but rather to observe and note the experiences of the non-kin care-givers who are directly involved with autism and who are as a result, affected by it. One of the aims of this study has been not only to highlight the experiences of these individuals and their work with children with autism but to provide a platform for these non-kin care-givers to have their voice brought forward and to tell their story. Special needs schools provide learners with the necessary life skills to function in the world. These children may not be able to lead completely independent lives but with early intervention and regular instruction they will be able to perform basic necessary tasks for themselves.

More research is needed in terms of understanding non-kin care-giver perceptions, understandings and experiences of working with children with autism. Studies such as this can aid in understanding the motivation of an individual to work with children with autism. This form of work is stressful both physically and emotionally and further study can find ways in which to improve the experiences of non-kin care-givers and in so doing improve the experiences of those living with Autism Spectrum Disorders. A valuable body of knowledge can be created if more research is conducted in this area widening the social aspect of autism and its effects.

Research that looks at family members, such as grandparents or siblings of children with autism is another area of research that has largely been overlooked. This type of research would be beneficial in exploring the impact that autism has on the family on a wider scale and on the experiences and perception of family members and would thus create a broader base of knowledge in terms of the social aspects of autism.

The culture of autism is a relatively new concept as has been discussed in Chapter Six. This concept has the potential to be expanded upon with more insight provided as to what the culture of autism is and how it is experienced by those people who form part of the Autism Community. Research into the culture of autism can show what function it serves to the Autism Community, what shared beliefs and understandings members hold as well as ways of doing things that members have. Further in-depth research is required to fully understand how this culture of autism has been created and how it exists within the broader socio-cultural framework of mainstream society.

The themes highlighted suggest that Autism, Asperger's Syndrome, PDD and PDD-NOS are not merely biological disorders but also have social aspects to them that should not be overlooked. It is clear then that when studying illness and disease in any form it is important not to overlook those who are closely involved with the condition in question and that the psychological and social aspects of living and working with a child with autism are important to take into consideration as such factors impact upon the care-giver-child relationship. Anthropology provides a holistic perspective and looks beyond the biological effects of the disorder by taking into consideration the psychological, the social and the cultural. Anthropology, as discipline, therefore has much to offer to the study of autism.

Appendix 1

Minerva's Day Schedule:



Appendix 2

Individual Learner's Daily Schedules:



Appendix 3

Playground at Durmstrang Institute for Remedial Studies:



Appendix 4

Romilda's Class Schedule:



Fleur's Class Schedule:



Appendix 5

Hammocks at Beaxbatons Academy for Children with Autism:



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